# JMIR Infodemiology

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## Contents





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## Corrigenda and Addenda





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Editorial

# Advancing Infodemiology in a Digital Intensive Era

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**KEYWORDS**

infoveillance; infodemiology; infodemic; social listening; COVID-19; Twitter; machine learning; surveillance; infoveillance; public health; infodemic management; fake news; conspiracy; health communication; medical informatics; digital health; scholarly publishing; misinformation; digital epidemiology; medical informatics; journalogy

## *Infodemiology: Then and Now*

### Origins of Infodemiology

The concept of *infodemiology* was introduced in 2002 by Gunther Eysenbach [1], the editor and founder of the *Journal of Medical Internet Research* (*JMIR*), to identify, characterize, and measure misinformation, in analogy to epidemiology, the science of determinants and distribution of disease:

> *A new research discipline and methodology has emerged—the study of the determinants and distribution of health information and misinformation—which may be useful in guiding health professionals and patients to quality health information on the Internet.* [1]

Having done research on how to quantify and prevent outbreaks of misinformation [2,3], Eysenbach [4] was acutely aware that "quality of health information" and "misinformation" were elusive concepts with little or no consensus on how to define, let alone combat low quality and misinformation. For these reasons, the original definition of "infodemiology" purposefully avoided the term "misinformation."

> *Information epidemiology, or infodemiology, identifies areas where there is a knowledge translation gap between best evidence (what some experts know) and practice (what most people do or believe), as well as markers for "high-quality" information.* [1]

In subsequent studies, Eysenbach [5,6] and the early work of others [7,8] found further use cases for studying information patterns and information retrieval patterns, including the detection of emerging outbreaks by studying the search and click behavior of populations [5]—ideas that were later adopted and implemented on a larger scale by Google Flu Trends [9].

The concept and area of study continued to evolve and advance, and by 2009, the now most frequently cited definition for infodemiology emerged in an article also by Eysenbach [10] in *JMIR*:

> *the science of distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy.* [10]

More than a decade since infodemiology entered the scientific consciousness, JMIR Publications has been committed to spearheading, advancing, and shaping this emerging field. The JMIR family of journals have strived to publish leading-edge studies that complement and push the methodological and disciplinary boundaries of health informatics research. Reflecting those efforts, a recent scoping review by Mavragani [11] found that more than 83% of studies focused on infodemiology and infoveillance have been published by JMIR Publications, with interest and number of publications increasing



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every year. Hence, recognizing a need for a formal scientific space to further catalyze advancement of this interdisciplinary community, in mid-2021, we launched JMIR Infodemiology.

### The Urgency of Now

Nearly 20 years after the concept was first introduced and with an increasing breadth and depth of research [11], infodemiology was further recognized as a critical field of study and formal practice in conjunction with the current COVID-19 pandemic. In March 2020, the World Health Organization (WHO) declared an "infodemic" and now defines it as when there is "too much information including false or misleading information in digital and physical environments during a disease outbreak" [4,12], and in June 2020, the WHO held its first WHO Infodemiology Conference [13], following a preparatory online crowdsourcing process to develop a policy framework to fight infodemics, which was published in *JMIR* [4,14].

The WHO would use this occasion to define infodemiology as the "science of managing infodemics" in the context of the COVID-19 infodemic itself, which aligns with the WHO's important work and capacity building in advancing the field of infodemic management. These efforts include supporting the generation of tools to respond to misinformation, building community resilience to misinformation, fostering partnerships among multiple stakeholders (including the United Nations [UN] system, the technology sector, media, and civil society), and advocating for the issue through UN and WHO resolutions and community outreach and training [12,14]. These efforts have helped the concept of infodemiology gain traction among policy makers and public health professionals alike, though the scope of infodemiology is broader than a singular focus on managing infodemics.

Importantly, the convergence of factors—volume and speed of information, misinformation, and disinformation flow combined with political polarization [15-18]—makes the goal of forging a community of evidence-based practice for infodemic management one that we share as well. Supporting these shared goals of advancing the science of infodemiology; ensuring broad dissemination and translation of research; and, most importantly, pursuing science-based advocacy, findings from the WHO's first Infodemiology Conference were published in the inaugural issue of JMIR Infodemiology [19]. In a relatively short period of time, JMIR Infodemiology has published several papers that address urgent needs of the COVID-19 infodemic (including studies addressing information demand and behavior [20], leveraging social listening across multiple data sources and languages [21], using mixed methods approaches blending online and offline data [22], and large-scale big data studies examining misinformation narratives [23] to name a few).

Crucially, though vaccines, public health interventions, and other medical countermeasures may ultimately lead to the halt or mitigation of the COVID-19 spread, the infodemic generated by this global pandemic will persist and mutate into new topics and opportunities for disinformation/misinformation in other health spaces. Who generates and shares information, how they use or share it and to what end, and how people respond to and contest information is already shaping the contours within which everyday health decisions, as well as the next public health emergency, are likely to occur. Although the COVID-19 pandemic is not the first instance in which digital media fueled global, national, and local struggles to define an information ecosystem [6], COVID-19's residue along with the broad-ranging promise this field holds is an appropriate basis for a new multidisciplinary effort to foster and report on the science of infodemiology.

## *Shaping the Field: Goals and Key Themes of Infodemiology*

### Next Gen Supply and Demand

Eysenbach introduced the concepts of supply- [1] and demand-based [5] infodemiology that continue to provide a framework for identifying and exploring novel methods and applications of infodemiology and infoveillance [10]. The construct of supply-based infodemiology may be increasingly more robust than the earliest days of conceptualization, when supply focused more on *what* was published, especially measuring for or analyzing the quality of health information. Today, supply-based infodemiology could have as much focus on *how* information is published, republished, translated, and adapted, all with the need for a reflexive understanding of the sociocultural dynamics of influence and trust as well as the technical factors of communication timing, real-time monitoring, and automated responses or adaptations, among other variables. Public health communication may never have been a one-and-done effort, but with the pace of information transmission and potential distortion of that information (eg, in the case of the current COVID-19 infodemic), the evolving practice of information-sharing will continue to be an especially dynamic research area.

Demand-based infodemiology methods and applications have also become increasingly varied and more robust. Search and click measures continue to offer baseline insights, and yet more sophisticated capturing of a user's entire journey on the internet or through smartphone searches and apps offers myriad ways to explore and track information-seeking behaviors. Regardless of the evolution of supply and demand methods, the ongoing need for novel methods for consumer and public health informatics to measure the epidemiology of information, describing and analyzing health information and communication patterns in "electronic media," remains. What is more, we invite social and behavioral scientists to interpret measurements in different ways, further exploring the sociocultural and political dimensions that we may have otherwise tried to control for in the past but now acknowledge that we must engage with to make better sense of the variety of knowing-doing behavior patterns and gaps.

### Goals of Infodemiology

Earlier studies in the field of infodemiology include articles that set up early infoveillance systems and argued that public health agencies should prepare for the next pandemic by implementing social listening and media monitoring tools into pandemic preparedness plans, often framed in the context of syndromic surveillance [6,7,9]. Many of these applied infodemic concepts were tested to track misinformation and communication patterns


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on social media during the 2009 H1N1 pandemic, which was the first pandemic in the age of social media [6]. The idea that social media communication patterns may be predictive for other events was also used in the establishment of altmetrics to measure the uptake and knowledge translation of scientific work [24].

Since these early works that set the foundation of infodemiology research, the field has grown in data sources, methodologies, and practitioners. Despite these gains, deficits remain in maturing infodemiology into a more diverse, inclusive, and truly interdisciplinary field of practice, most of which focuses on the need for greater diversity of data sources, better triangulation of infodemiology insights from novel sources of online and offline information, and the need for greater inclusion of other health challenges that have traditionally been neglected or overlooked. One critical challenge to ensuring advancement of the field is bridging pre-existing disciplinary silos, where much of the innovation in methods, experimentation, and evaluation of data science approaches (eg, data mining, natural language processing, and forms of machine learning) still occur in the computer science (ACM) and engineering (IEEE) literature. However, this literature is often limited in its translation of research to real-world public health application, with studies in the social science (JSTOR, SSRN) and health and life sciences (PubMed-indexed articles) often filling this gap but inherently less technically rigorous. For example, studies of algorithmic bias, eHealth literacy, and cultural influences on online health information seeking are some areas where data and social science researchers can more actively collaborate to address existing gaps.

More generally, Mavragani's [11] review discovered that the most popular data sources for infodemiology research are social media, search queries, websites and internet platforms, and mobile apps. The most frequently studied topics included epidemics, infectious diseases, flu, HIV/AIDS, measles, and other outbreaks, with drugs, tobacco and marijuana use, depression, suicide, cancer, and chronic disease also receiving attention [11]. Hence, the tracking of misinformation is but one line of infodemiology research, and harnessing the study of information patterns in cyberspace for other critical research questions is another, also envisioned in 2009 [7]. Additional findings from this review highlighted the following issues that need to be addressed for their implications to the field:

- Twitter and Google dominate as research data sources
- The need to take into account demographic differences in social media channel preferences
- The concentration of specific topics that may or may not represent people's everyday health concerns and the most common causes of illness, injury, and death

This also requires us to ask more critical questions that advance and shape health policy and practice, and further extend the application of infodemiological principles to domains beyond health. Infodemiology has several advantages to that end. Web-based data makes data access and analysis faster than traditional research methods and at scale. It is also possible to retain anonymity while researching broad and distinct populations, though many ethical principles of conducting research using online data are still maturing [25]. It is also critical to make more intentional connections between information-seeking actions and real-world behavior through innovative study designs, such as using digital mixed methods approaches. Responding to these needs, JMIR Infodemiology aims to also explore infodemiology's current limitations, such as research driven by current events and perpetuating population and channel biases, among others.

We see a unique opportunity, therefore, to accelerate the coordination of this broad-ranging research to greater effect on public health policy and practice and other pressing global issues. Our specific goals for the journal are to:

- Share what researchers from different disciplines are doing in how they collect and analyze online data
- Understand what online data say about offline human behavior
- Provide an intellectual space for researchers from different disciplines to cross theoretical and methodological boundaries
- Provide equal attention to supply-side and demand-side dynamics in an information-abundant global society
- Innovate and advance research design and practice by trialing and sharing new data sources and methods including through development of unique scientific content types and interaction tools
- Highlight biases, inequities, and limitations of digital spaces and claims about online behaviors

Key themes and research aims we will support, some of which we expound on briefly in the following section, will include exploring the supply and demand infodemiology framework; expanding and diversifying data sources; broadening the range and scope of global health challenges studied; supporting a multidisciplinary approach to infodemiology; supporting exploration of a range of analytical methods that can be applied to infodemiology; studying eHealth literacy and its connection to infoveillance; exploring population, algorithmic, descriptive, or sociocultural biases; and addressing issues relating to health equity.

## Infodemiology in a Digital Intensive Era

With over half of the world's population currently on the internet and other connected devices, information access and availability can seem ubiquitous, while public opinion polls show many people are confused, unsure, or disbelieving of official information sources [26]. An increase in information and communication technology (ICT) access has led to a proliferation of data sources, including the evolution of the internet from web 1.0 (static websites and the dot-com boom) to 2.0 (software applications built on the web and the rise of social media and other interactive digital platforms), moving toward 3.0 (emergence of the semantic web, artificial intelligence imbedded on the web, and decentralized and distributed applications), and now discussions of a metaverse (generally the connection of networks of cyberspace and virtual worlds focused on social connection). The opportunity to leverage these data sources to improve individual and population health is now paramount, but equally important is ensuring that



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these sources do not lead to offline health harms or harms within digital communities themselves.

The expansion and evolution of the ICT ecosystem provides new opportunities to characterize and assess changes in large-scale human behavior. Understanding how data and behavior interact also requires recognition of the complex interplay between how people now increasingly rely on and are influenced by information exposure on these digital platforms that are increasingly primary sources of communication and health seeking behavior. Key pillars of infodemiology remain its ability to analyze (nowcast) and predict (forecast) forms of health behavior, diseases (especially those with behavioral risk factors), and epidemics, and to generate insights closer to real time; though as mentioned, the scope of the field is rapidly expanding, and other data sources such as digital biomarkers, including data from wearables, may enhance our ability to measure information and communication patterns for public health purposes [11].

As exponential growth in data generation and access has catalyzed the infodemiology field, the breakneck pace of successive complex global public health emergencies (including the 2003 severe acute respiratory syndrome outbreak, the 2009 H1N1 pandemic, the 2015 Zika outbreak, multiple Ebola virus outbreaks, the ongoing antimicrobial resistance crisis, the current opioid public health emergency, and the current 2019 COVID-19 global pandemic as a few examples) further necessitates its maturation to meet 21st century health challenges that the world now faces together. Supporting the future development of infodemiology also aligns with broader international goals of creating a more sustainable future for humanity, many outlined in the Goal 3 and Goal 9 health and technology and innovation targets of the UN's Sustainable Development Goals. Hence, now represents a crucial time for society to leverage "data for good" through the research and practice of infodemiology, leading to the generation of actionable public health intelligence to address current and future global health challenges as they may arise.

## Call to the Infodemiology Community

The primary goal of JMIR Infodemiology is to foster the development of a multistakeholder and multidisciplinary community of researchers, practitioners, and advocates with shared goals of advancing the field of infodemiology to improve health outcomes and tackle other critical social challenges in what is now a digitally intensive era. This includes challenging ourselves to continuously innovate in our methods, including adding new sources of data, conducting more multimodal research, and exploring new methodological approaches to bridge infodemiology with health education, promotion, interventions, and policy. Equally important is the need to generate public health intelligence that is meaningful and actionable, including exploring new content types that the journal will launch in the future that are more responsive to detecting infodemic events and rapidly reporting them to our infodemiology community for real-world impact. Supporting more robust translation and dissemination efforts, the journal will also support more enhanced content such as data visualizations and dashboards that can further augment infodemiology findings. The journal will also purposefully help to ensure adequate representation of neglected health topics and provide dedicated space to discuss important practical, ethical, policy, and e-governance considerations that arise from the evolution of infodemiology and the information ecosystem itself. We invite suggestions for theme issues or special issues, which can be outputs from infodemiology-related conferences and workshops. We welcome authors, reviewers, editors, and other stakeholders who can help us achieve these shared goals of advancing the field of infodemiology and infodemic management, which we agree has—in the words of Chris Zielinski [27]—"a short history, a long future."

## Authors' Contributions

All authors contributed to the design, formulation, drafting, completion, and approval of the final manuscript.

## Conflicts of Interest

TM serves as editor in chief for JMIR Infodemiology and is an employee of the startup company S-3 Research LLC. S-3 Research is a startup funded and currently supported by the National Institutes of Health–National Institute of Drug Abuse through a Small Business Innovation and Research contract for opioid-related social media research and technology commercialization. CB serves on the editorial board for JMIR Infodemiology. GE is the CEO and executive editor of JMIR Publications.

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## Abbreviations

**ICT:** information and communication technology
**JMIR:** Journal of Medical Internet Research
**UN:** United Nations
**WHO:** World Health Organization

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Viewpoint

# Health Literacy, Equity, and Communication in the COVID-19 Era of Misinformation: Emergence of Health Information Professionals in Infodemic Management

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## Abstract

The health information management (HIM) field's contribution to health care delivery is invaluable in a pandemic context where the need for accurate diagnoses will hasten responsive, evidence-based decision-making. The COVID-19 pandemic offers a unique opportunity to transform the practice of HIM and bring more awareness to the role that frontline workers play behind the scenes in safeguarding reliable, comprehensive, accurate, and timely health information. This transformation will support future research, utilization management, public health surveillance, and forecasting and enable key stakeholders to plan and ensure equitable health care resource allocation, especially for the most vulnerable populations. In this paper, we juxtapose critical health literacy, public policy, and HIM perspectives to understand the COVID-19 infodemic and new opportunities for HIM in infodemic management.

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**KEYWORDS**

COVID-19; social media; infodemiology; infoveillance; equity; health literacy; digital literacy; health information management; pandemic; health information; public policy; infodemic

## Introduction

Researchers in the field of health literacy have argued that health literacy has been vastly undervalued and unrecognized in the fight against COVID-19 [1] and ought to be considered the quintessential "social vaccine" for preventing COVID-19 in populations [2]. Indeed, as an essential self-management skill and community resource for health, the effects of low population health literacy are likely to be much more pronounced under the current infodemic, in which volumes of disparate quality information are rapidly being disseminated through mediums of public communication, consumption, and information sharing.

*Health literacy* is broadly defined as the cognitive and social skills that determine individuals' motivation and ability to gain



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access to, understand, and use information in ways that promote and maintain good health in a variety of settings across the life course [3]. A health literate individual can comprehend and comply with self-care instructions, plan to make changes in their lifestyle, consent to procedures, make decisions that are informed by different types of information (including quantitative health risk information), and engage in community dialogues on health and health care through lay engagement [4]. Research has shown that health literacy contributes to differences in patient knowledge, self-efficacy, self-care behavior, and health status [5-7]. It is also positively associated with vital skills that are needed for patients to function in health contexts, including the improvement of the quality and clarity of communication, patients' involvement in clinical decision-making, patients' willingness to express health concerns, and compliance with clinical orders [8,9]. However, despite the importance of health literacy, several countries still struggle to attain high degrees of health literacy. For instance, in Canada, an estimated 60% of adults and 88% of older adults are not health literate, and as a result, this barrier may affect their ability to make informed decisions or exert some control over their health [10]. Population health literacy also presents a concern in other high-income countries, with population health literacy levels among European countries varying widely from 71% in the Netherlands to 38% in Bulgaria [11].

*Digital literacy* can be conceived as health literacy in digital information and technology spaces [12,13]. An important point to acknowledge is that digital technology in health and social contexts presents both new risks and opportunities for equity in different information audiences. Digital health will increasingly influence social values that are based on the principles of health care systems and the experiences of those who seek health and health care. On the one hand, inequities in health are exaggerated by a widening digital divide [14]. For example, it has also been argued that digitalism and growing technocratic involvement in consumer health and health care are yet more indications of the trend toward less government involvement and more health care privatization in social democratic and liberal welfare states [15,16]. However, digital health adoption, such as the uptake of personal health records, also offers new opportunities to democratize information, improve health care navigation and access, strengthen community and social support, and reshape the patient-doctor relationship through improved communication and shared decision-making [17].

## The COVID-19 Infodemic

### Critical Health Literacy Perspective

The burden of low health literacy disproportionately affects the most socially and economically marginalized groups [18-21]. Through an intersectional lens, we can see the cumulative effects in health care through the experiences of those with low health literacy and other vulnerabilities. This can be rife with issues in navigating care; difficulties with accessing health-related information; and stigma and discrimination, which have a disempowering effect that can diminish the motivation to seek care [22]. It is not surprising then that low health literacy is associated with the greater use of emergency care, the lower utilization of preventive services, and a higher risk of poorer health outcomes, with an estimated attributable cost to health care systems of 3% to 5% of annual health care expenditures [23-26].

Nutbeam [27] first proposed a 3-tier view of health literacy—functional, interactive, and critical health literacy—whereby critical health literacy is considered the highest order of health literacy cognition and skill. de Leeuw [28] later describes critical health literacy as the "skills, capacities and knowledge required to access, understand and interact with social and political determinants of health and their social discourse." Through critical health literacy, individuals and communities are empowered to engage in the social and political processes to jointly address the social determinants of health. Communities with high critical health literacy can strategically translate their lived health experiences into shared understandings to influence decision makers and, through collective action, address the social determinants of health that most impact them.

Although being in a more favorable socioeconomic position, including attaining higher education, is generally considered a protective factor, one of the challenges of COVID-19 misinformation and other types of health misinformation is that their effects do not just move along socioeconomic gradients. The sociocultural-driven healthism phenomenon, as defined by Crawford [29] and Greenhalgh and Wessely [30], concerns the emergence of a subculture of socioeconomically advantaged citizens who are nonetheless more likely to propagate misinformation, demand ineffective or unnecessary care, and reject high-impact health interventions under the guise of postmodern or luxury medicine. Canadians, for instance, receive more than 100 million unnecessary medical tests and treatments every year [31]. Similar trends have been found worldwide [32-34]. There is also no shortage of medical myths and misconceptions on the internet (eg, antivaccination misinformation) [35]; celebrity endorsements of harmful health products, treatments, and practices (eg, colonic hydrotherapy in general populations) [36]; organized community efforts that are in opposition to evidence-based public health measures (eg, water fluoridization) [37]; or physician reports about the pressures they receive from patients to provide treatments that have been shown to be ineffective, inefficient, or harmful (eg, inappropriate antibiotic prescribing) [38]. For individuals who engage in low-value or harmful practices, seemingly personal decisions can have broader consequences for society and the economy at large. This is especially true in the case of emerging and re-emerging infectious diseases, given the challenges of preventing or controlling them in the earliest stages. The high population-attributable risk of death due to personal exposure to COVID-19 misinformation is a reminder of such impacts [39].

The sheer volume and virality of misinformation during the current COVID-19 pandemic led the director-general of the World Health Organization (WHO), Tedros Adhanom Ghebreyesus, to declare this phenomenon an *infodemic* at the February 2020 Munich Security Conference [40]. The widespread adoption of the internet has made information more


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accessible. Although technology is beneficial in disseminating information rapidly, in some ways it has also played a crucial role in the dissemination of false and misleading information found on the internet, resulting in negative consequences [41]. There is also a critical health literacy aspect of this infodemic phenomenon that is often overlooked—how power and privilege manifest in the COVID-19 misinformation discourse [42]. In general, socially and economically disadvantaged groups (based on racism or ethnic identity, ableism, class, education, sexual orientation, gender identity, etc) are at a greater risk of exposure to COVID-19 [43]. Nevertheless, their voices and experiences are often sidelined. This favors those who are the least exposed to and possess more human and economic resources for bracing the impacts of the disease [44]. Making matters worse are communication inequalities. Many disadvantaged populations experience barriers to information exposure that go beyond digital access and literacy, as previously mentioned; for example, they may have fewer social ties or earn lower wages, and this requires them to work longer hours [45]. As a result, messages should be tailored based on the underlying cause of the misinformation problem, and efforts should ensue to increase people's exposure to accurate, low-barrier, targeted health risk messaging to account for this disparity [46].

The infodemic crisis is not merely a health and digital literacy issue; it may stem from other causes, including a vulnerability to persuasive communication from broader sociocultural forces and individual psychology. When pervasive misinformation and disinformation are a problem, consideration should be given to the prime movers and beneficiaries of misinformation, who use such information to drive sociopolitical agendas and weaponize disinformation to entrench asymmetrical power, especially in times of uncertainty and threat. It can be counterproductive, when addressing the social determinants of health, to construe pervasive perceptions of attitudinal or partisan influence or identity as merely a health literacy problem. Instead, it can be acknowledged that health literacy coexists and interacts with diverse influences and, perhaps most importantly, that it can be seen as a mechanism of individual and systems change.

## Public Policy Perspective

The failure to adopt evidence-informed decision-making is not only a health spending dilemma but also, perhaps more importantly, an ethical one. According to Ciliska, Ward, Datta, and Jiwani [47], investing in treatments that do not work should be seen as an opportunity cost, which includes the direct costs diverted from doing something more effective and the indirect costs of the resultant poorer health impact. The extent to which governments communicate effectively and engage in evidence-informed decision-making plays a significant role in an individual's acceptance of health risk messages, their perceptions of vulnerability, and the subsequent adoption and outcomes of health-protecting behaviors [48]. It is imperative that government officials and various health authorities take responsibility to ensure the reliability of COVID-19 information that is shared within public domains, especially for information in their respective jurisdictions. However, several instances can be seen in which government actors in positions of legitimate authority have demonstrated a poor recognition of misinformation, have published or disseminated inconsistent or inaccurate information, or have otherwise not adequately used evidence- and information-based decision-making processes [49].

The United Kingdom's herd immunity strategy—an approach that relies on SARS-CoV-2 indiscriminately spreading to a critical mass in order to build up population immunity—is a particularly concerning example of evidence framing by a government [50]. When actors use scientific terminology, they can also evoke confidence and gain public trust in health policy decisions. For example, the Government of Alberta's [51] premature and costly relaxation of COVID-19 measures, including the removal of testing and isolation, was largely established based on its premier's, chief medical officer of health's, and health minister's framing and strategic use of scientific concepts and terminology. These actors declared that the province was "moving from a 'pandemic' to an 'endemic' state of COVID-19." Indeed, most immunologists agree that an endemic state is expected at some point in the future [52]; however, Alberta's modeling (informed by preliminary data on first-dose Delta vaccine effectiveness in the United Kingdom) did not agree with broader expert consensus [53], nor were other Canadian jurisdictions with higher population vaccine coverage rates generating similar models or making similar claims. In the end, Alberta's endemic state measures were considered a failure. Government leaders apologized for propagating fear and anger as a fourth wave of infections overwhelmed the health care system and intensive care unit patients were transferred out of the province to receive care [54].

## Health Information Management Perspective

It is vital that during infectious disease pandemics, such as the current COVID-19 pandemic, accurate and reliable syndromic and discharge data are collected to assist with the public health response. Health information management (HIM) professionals have an enviable role in ensuring and maintaining the reliability and integrity of protected health information coming from health system encounters. According to Stanfill et al [55], "it is essential that Health Information Management (HIM) professionals ensure COVID-19 documentation, data capture, data analysis and reporting, as well as coding, are accurate and reliable to support clinical care, organizational management, public health reporting, population health management, and scientific research." Additionally, health information managers can support contact tracing and syndromic surveillance and also assist with the mapping and forecasting of health data by applying and using various data visualization tools and techniques. Health information managers have a unique appreciation for the use of health information. HIM professionals possess the requisite skill sets for accurately coding and classifying morbidity and mortality data to validate a final diagnosis or underlying cause of death by applying the WHO rules and regulations. The health information generated has countless purposes; it supports the continuum of care and the development of targets and indicators to facilitate the planning, monitoring, and evaluation of health programs locally, regionally, and internationally. The health information produced also underwrites the development of equitable, efficient, and accessible health care systems, contributing to overall national



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development, which will inevitability improve public health initiatives and outcomes.

Advocating for patients and bringing attention to disparities that underlie the differential access and use of quality health information is another role in which health information managers are well positioned. Such efforts may need to start with addressing disparities in the profession, such as gender inequities and diversity within the profession, which can be seen as an indirect strategy toward building capacity for disadvantaged groups to govern and control their information to better support decision-making within communities. Beyond the profession, there has been an articulated need from racialized and ethnic minorities for more evidence on differential COVID-19 health outcomes and health system responses that is relevant to them [56,57]. The access, ownership, control, and protection of COVID-19 information have also been needs, as concerns about community privacy and risks of stigma and discrimination persist among racialized and ethnic communities [58]. As health information managers, to generate and responsibly exchange this evidence, we needed first to standardize the collection of rich, high-quality information of various types, including patient-reported experience and outcome measures and culturally appropriate, race-based, and Indigenous identity data (and this work is still in its infancy). We also needed to quickly adopt new international coding standards and work with clinicians and public health advisors serving the hardest-hit communities to improve their COVID-19 documentation practices in culturally sensitive and safe ways under the pressures and constraints of working frontline during the pandemic. The US Gravity Project, the Canadian Institute for Health Information's Interim Standards for Race-Based and Indigenous-Identity Data Collection and Reporting, and the work of Canada Health Infoway and others on sex and gender identity terminologies could not be timelier in this regard [59-62].

The aphorism of "knowledge is power" is a useful reminder when managing an infodemic. Although HIM has been traditionally concentrated at lower levels of the Data, Information, Knowledge, Wisdom (DIKW) hierarchy, in which the veracity of knowledge is dependent, the DIKW hierarchy's boundaries are increasingly becoming blurred. Understandings of knowledge translation may be more dynamic and data-driven than ever before due to the growing acceptance of discovery-based approaches, such as data mining and statistical modeling. In addition, advances in technology, such as artificial intelligence, are changing the way we work, allowing us to broaden our role in knowledge evaluation, management, and translation [63] and engage in more patient-facing activities. The content expertise of health information managers can serve them well as knowledge brokers who lead activities, including delivering patient-facing information triaging services; constructing user-friendly knowledge representations, such as data visualizations; and developing information interpretation tools, such as decision aids, plain language summaries, and supplementary explanatory information and metadata. In this new reality, health information managers will need to lean into their interdisciplinary underpinnings to make essential contributions in educational, informational, decision support, and behavioral informatics areas to address current and future infodemic management crises. Capacity building and skills sharing are also encouraged and are promising ways of increasing reach to individuals and communities who may not have access to the services of health information managers. Community health workers have demonstrated significant relevance in contributing to halting the spread of a pandemic and dispelling misinformation at the community level, especially in underserved communities [64]. HIM professionals can draw on the strength and reach of this cadre of health workers by building their capacity for basic documentation and information management practices. This approach ensures that information management support is available when shortages of critical human resources for health arise, as was the case at the height of the COVID-19 pandemic when the Canadian Institute for Health Information expressed the need for HIM surge capacity to support the timely capture and reporting of COVID-19 data [65].

In a recent report, the WHO Department of Infectious Hazard Preparedness outlined 5 action areas (ie, identifying evidence; translating knowledge and science, amplifying action, quantifying impact, and coordination and governance) and close to 600 specific actions to implement a comprehensive infodemic management strategy (in which strengthening health, digital, and media literacy is a significant category) [66]. Health information managers can make significant contributions to infodemic management at all levels of the DIKW hierarchy through practices such as improving the linkage and timely access to information; creating methodologies for valid and accurate data collection and analytics, especially in service of big data and artificial intelligence; and mobilizing knowledge for policy and programmatic planning. Textbox 1 provides a real-world example of an action area that health information managers are uniquely positioned to address.


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**Textbox 1.** A health information manager's role in translating knowledge and science.

**Action area**

- Translating knowledge and science

**Specific action**

- Strengthening the interpretation and explanation of what is known, fact-checking statements, and addressing misinformation

**Case example**

- On September 1, 2020, the US White House advisor and director of the National Institute of Allergy and Infectious Diseases, Dr Anthony Fauci, appeared on the American Broadcast Company's *Good Morning America* show to address a spurious social media claim that had gone viral via a retweet by then US President Donald Trump. The claim suggested that the Centers of Disease Control and Prevention "quietly updated" guidance on provisional COVID-19 death counts, leading the public to believe that only 6% of the over 150,000 US COVID-19 deaths reported died from SARS-CoV-2 infection, which was in fact a gross misinterpretation. In response, Fauci stated, "the point that the CDC was trying to make was that a certain percentage of [Americans who have died of COVID-19] had nothing else but just COVID. That does not mean that someone who has hypertension or diabetes who dies of COVID didn't die of COVID-19. They did" [67].

**How can health information managers help?**

- Public demand for the near–real-time and real-time public reporting of COVID-19 data has grown; however, how mortality and morbidity statistics are reported and how they should be interpreted are not common knowledge. The above case requires an understanding of the differences between underlying and contributing causes of death. Health information managers can provide guidance and share resources [68-71] to help the general population understand COVID-19 comorbidities and clinical manifestations and how these are documented, statistically classified, and reported.

## Conclusion

Without strategies for strengthening the accuracy of judgements and individual, evidence-informed decision-making capacities, pervasive misinformation will continue to influence personal decision-making, prevent or delay public health efforts for reaching herd immunity through vaccination, and pose a threat to overall global health security, disproportionately affecting the most vulnerable and resource-limited populations.

In this paper, we present an analysis of the infodemic management crisis from critical health literacy, public policy, and information management perspectives and elucidate the role of health information managers in infodemic management responses. We argue that health information managers can draw on both technical skills and content expertise across the WHO action areas; however, as infodemiologists, they will need to reimagine how their skills can be used in different and new ways to address gaps in information quality during the era of misinformation.

Overall, combating the misinformation of the COVID-19 pandemic and any future infectious disease pandemic has to be a collaborative effort that involves all stakeholders at different decision-making levels. For example, social media outlets have a civic responsibility to verify information and to correct misinformation, and governments need to engage in evidence-informed decision-making and equip populations with the technical and cognitive tools required to interpret and use information appropriately. Health information managers are also playing a crucial role in using evidence to disseminate accurate information during this current pandemic. By using various means of improving equitable access to timely, accurate, and complete health information, health information managers are stewards of accountability, transparency, quality, and patient safety. As health information managers manage, protect, and validate the lifecycle of COVID-19 evidence (whether it be data, information, or knowledge); improve the availability of and access to relevant evidence among communities; and build individual capacity for interpreting and using evidence accurately; their work becomes further rooted in health equity. Through their work, health information managers may act as capacity builders, knowledge brokers, and agents of change in the infodemic management crisis to improve population health literacy and strengthen evidence-informed decision-making at all levels.

## Conflicts of Interest

None declared.

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## Abbreviations

**DIKW:** Data, Information, Knowledge, Wisdom
**HIM:** Health Information Management
**WHO:** World Health Organization



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Original Paper

# Understanding the #longCOVID and #longhaulers Conversation on Twitter: Multimethod Study

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## Abstract

**Background:** The scientific community is just beginning to uncover the potential long-term effects of COVID-19, and one way to start gathering information is by examining the present discourse on the topic. The conversation about long COVID-19 on Twitter provides insight into related public perception and personal experiences.

**Objective:** The aim of this study was to investigate the #longCOVID and #longhaulers conversations on Twitter by examining the combined effects of topic discussion and social network analysis for discovery on long COVID-19.

**Methods:** A multipronged approach was used to analyze data (N=2500 records from Twitter) about long COVID-19 and from people experiencing long COVID-19. A text analysis was performed by both human coders and Netlytic, a cloud-based text and social networks analyzer. The social network analysis generated Name and Chain networks that showed connections and interactions between Twitter users.

**Results:** Among the 2010 tweets about long COVID-19 and 490 tweets by COVID-19 long haulers, 30,923 and 7817 unique words were found, respectively. For both conversation types, "#longcovid" and "covid" were the most frequently mentioned words; however, through visually inspecting the data, words relevant to having long COVID-19 (ie, symptoms, fatigue, pain) were more prominent in tweets by COVID-19 long haulers. When discussing long COVID-19, the most prominent frames were "support" (1090/1931, 56.45%) and "research" (435/1931, 22.53%). In COVID-19 long haulers conversations, "symptoms" (297/483, 61.5%) and "building a community" (152/483, 31.5%) were the most prominent frames. The social network analysis revealed that for both tweets about long COVID-19 and tweets by COVID-19 long haulers, networks are highly decentralized, fragmented, and loosely connected.

**Conclusions:** This study provides a glimpse into the ways long COVID-19 is framed by social network users. Understanding these perspectives may help generate future patient-centered research questions.

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**KEYWORDS**

COVID-19; postacute sequela of COVID-19; PASC; patient-centered care; social media; social network analysis; long term; symptom; Twitter; communication; insight; perception; experience; patient-centered



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## Introduction

The use of social networking sites (SNSs) has grown extensively over the past 10 years, as platforms such as Facebook, Twitter, and Instagram increased in popularity worldwide [1]. Globally, as of January 2021, an estimated 3.6 billion people are using SNSs and use is expected to continue to grow as previously underserved markets gain mobile device usage [2]. SNSs are technologies that support a culture of community sharing, and allow for communication between friends, family members, and strangers spanning geographical, political, or economic borders [3,4]. Typically, SNSs are described as being user-friendly, and include a variety of functions that allow users to communicate with one another while fostering a sense of interpersonal connectedness, as many share their personal stories, struggles, or successes [3]. The reach, engagement, accessibility, collaboration, and advocacy, as well as the research potential of the digital environment can include health messaging, which in turn can influence the attitudes, beliefs, and behaviors of its users [3,5-8].

SARS-CoV-2, and the resulting COVID-19, has contributed to the body of health-related messaging on SNSs, with SNSs serving as a preferred space for communities to connect and share information in real time [9]. A recent scoping review assessing the role of SNSs and COVID-19 suggested six overarching themes in the 81 articles reviewed, including "surveying public attitudes, identifying infodemics, assessing mental health, detecting or predicting COVID-19 cases, analyzing government responses to the pandemic, and evaluating quality of health information in prevention education videos" [10]. Moreover, information about COVID-19 protocols, treatment, personal protective equipment, and allocation of needed resources was disseminated rapidly through platforms such as Twitter [4,10]. Twitter is an SNS that enables users to post short, 280-character messages called "tweets" to their public platform. Data from the first quarter of 2019 show that there were approximately 330 million monthly active Twitter users globally [2]. Recent research has found that throughout COVID-19 (from January 28, 2020, to January 1, 2021), over 132 million tweets from more than 20 million unique users included key words referencing the pandemic [11]. SNSs such as Twitter have fostered a sense of community and togetherness during the social isolation resulting from physical distancing measures and stay-at-home orders [4]. It has now been over 1 year since the onset of the pandemic, and those who were affected by COVID-19 continue to share their experiences on Twitter. In some cases, this includes their experience of being a "COVID-19 long hauler" or having "long COVID-19."

Describing the 10%-30% of patients diagnosed with COVID-19 that continue to experience symptoms after their infectious period is over [12,13], the terms *COVID-19 long hauler* (ie, the patient) and *long COVID-19* (ie, the disease/symptoms) appear to be common and familiar among both patient-led support groups [14] and the media [15]. COVID-19 long haulers are growing in number, perplexing clinicians and researchers. There is no formal definition or consensus on the terminology for long COVID-19, risk factors for who will be more likely to experience long COVID-19 are still emerging, and there is uncertainty regarding how to alleviate the symptoms of long COVID-19 [16]. The medical and academic communities have described these long-term effects of COVID-19 in several ways. Prolonged symptomatic periods are classified as either "postacute COVID-19," if the patient is experiencing symptoms for a period greater than 3 weeks, and "chronic COVID-19," if the patient experiences symptoms for greater than 12 weeks [12]. More recently, the term *postacute sequelaof COVID-19* has been used to describe symptoms that follow the acute period and can persist for several months [17,18]. As of April 23, 2021, over 144 million people worldwide have been affected by COVID-19 [19] and the unexpectedly high incidence of sequela has become a public health priority.

As the COVID-19 pandemic remains at the forefront of society, and with the debilitating effects of long COVID-19 beginning to surface, research is needed. Leveraging SNSs to understand how this health issue is being framed allows for a unique bottom-up emergent conceptualization. That is, as opposed to traditional media outlets shaping the narrative on a topic, any SNS user is able to control the telling of a story [20,21]. Framing refers to "the process by which people develop a particular conceptualization of an issue or reorient their thinking about an issue" [20]. With the power to share a story from their own perspective through the content they view, share, create, and interact with, SNS users influence how issues are framed, a contrast to the hierarchical gatekeepers of traditional media framing stories and developing headlines. Therefore, the aim of this study was to investigate the #longCOVID and #longhaulers conversations on Twitter by examining the combined effects of topic discussion and social network analysis (SNA) for discovery on long COVID-19. A specific objective included comparing the conversations, understanding the differences and similarities, on Twitter between those discussing long COVID-19 to those narratives created by users identifying as a COVID-19 long hauler.

Specifically, we had the following research questions:

1. What popular/emerging text around #longCOVID and #longhaulers conversations exists on Twitter?
2. What frames did Twitter users employ when discussing long COVID-19?
3. What frames did Twitter users employ when sharing narratives about being a COVID-19 long hauler?
4. What inferences can we draw from the network properties regarding the transmission and adoption of long COVID-19 discourse on Twitter?

## Methods

### Study Design

A multimethod approach was used, which enabled different facets of long COVID-19 on Twitter to be highlighted, leveraged the strengths of two different methods of analysis, and offered several combinatory tactics toward exploration and understanding. In this study, there was an interest in both who is talking with whom and what they are talking about. This emphasizes the interest in both the network of social connections and the nature of the tie that underpins these connections



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[22]. Data collection for Twitter was performed using the Netlytic program [23], followed by text and social network analyses.

### Ethical Considerations

The Netlytic program uses application programming interfaces (APIs) to collect publicly accessible posts from Twitter [23]; therefore, the activities described do not meet the definition of human subjects research and did not require institutional review board review.

### Netlytic Analysis

Using the Netlytic program [23], an open-source software, all publicly accessible, tagged media with the #longCOVID AND/OR #longhaulers hashtag on Twitter were downloaded (ie, when the tweet was tagged, not necessarily when it was posted). The download, initiated by the lead author (SS), was specified to remove all non-English tweets and retweets, and occurred on February 23, 2021 (data were pulled until the maximum data set allowed by the software was built; N=2500). A tweet is a post made on Twitter and the term *record* will be used interchangeably throughout the article. The data set consisted of records retrieved from February 18, 2021, to February 23, 2021. Specifically, for this study, Netlytic [23] was used to identify popular topics in the #longCOVID AND/OR #longhaulers data set, as measured by word frequency. Furthermore, Netlytic [23] was used to perform a network analysis around #longCOVID AND/OR #longhaulers, including both a *Name* network (ie, who mentions whom) and a *Chain* network (ie, who replies to whom).

The Twitter records (N=2500) were downloaded as an output file (in Excel) for further analysis. The Netlytic program [23] produced an output file (in Excel) that recorded the link to the tweet, including the publication date, number of times the tweet was liked, and number of times the tweet was retweeted. The output file also included information about the author of the tweet, including their Twitter handle, link to their profile image, frequency counts on the author's total number of tweets (including retweets), total number of followers, and total number of users the account is following.

The data-cleaning process as well as the multimethod approach utilized (ie, text and network analyses) are discussed in further detail below.

### Data Cleaning

Four independent coders were each provided an equal portion (n=625 records) of the output file (N=2500 records). The terms "records" and "tweets" are used synonymously. To address the research questions of the study, two distinct groups of records were created: (1) *tweets about long COVID-19* and (2) *tweets by COVID-19 long haulers*. To specifically delineate these two groupings of records, each coder was instructed to read and identify the record as to whether it had been constructed/posted by a self-identified COVID-19 long hauler. Those records constructed/posted by a self-identified COVID-19 long hauler were labeled as *tweets by COVID-19 long haulers*, with remaining records falling into the *tweets about long COVID-19* data set. To accomplish this delineation, coders were trained to review the record holistically and to specifically look for personal pronouns (eg, I, my). The holistic approach and personal pronouns were used to identify *tweets by COVID-19 long haulers* because it appeared that these records were of self-reflection and/or a Twitter user sharing their narrative about being a COVID-19 long hauler. In addition, coders were required to read all records thoughtfully and with an objective lens.

During this data-cleaning process, which was considered a time of familiarization with the data, the coders were also instructed to record meaningful units of text or codes that they felt were emerging from the records. As a holistic approach was utilized, while analyzing tweets, coders were instructed to view any emojis used as part of the record. The final data corpus consisted of 2010 *tweets about long COVID-19* and 490 *tweets by COVID-19 long haulers*. These data sets were considered separately in the text and network analyses.

### Text Analysis

#### *Computer Coding to Identify Popular/Emerging Text*

The final data corpus was uploaded back into Netlytic [23] and the Keyword Extractor tool was used. This computer-automated coding first removes all common words such as "of," "will," and "to" from a list of stop words in the English language. It then counts the number of records where a unique word appears, thus identifying popular topics in the data set, as measured by keyword frequency. Although Netlytic [23], as a qualitative data collection tool, provides several advantages (eg, objective, ability to analyze a large data set), it can miss the nuances or specifics within the data set. Therefore, human coding was also performed to further contextualize the content.

#### *Human Coding to Identify Emerging Frames*

Although there are no uniform measurement standards on how to identify/define a frame in communications, the most persuasive studies use a four-step method [20], which was utilized in this study. The first step requires that an issue or event is identified [20], which in this study is that of long COVID-19 and those suffering from the aftermath. The second step involves isolating a specific attitude [20], which in this study was the overall attitudes toward long COVID-19. In the third step, an initial set of frames is identified inductively to create a coding scheme [20]. In this study, this third step was developed after the familiarization period, and then the four independent coders discussed possible codes and themes within the data sets. Separate codebooks for *tweets about long COVID-19* and *tweets by COVID-19 long haulers* were mutually agreed upon. All coding of themes (12 themes for *tweets about long COVID-19*, 13 themes for *tweets by COVID-19 long haulers*) was completed independently, and records could have been coded into different themes (thus potentially overlapping). Each coder revisited their originally assigned data set (n=625); however, at this stage, records were organized by *tweets about long COVID-19* and *tweets by COVID-19 long haulers*. For trustworthiness and rigor, the lead author (SS) also coded ~10% of the other three coders' data (n=63 records/coder for a total of 189). Similar to previous studies [24,25], 30% of the data corpus was selected by the authors as a feasible and manageable



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strategy that would still capture sufficient variation in responses [26]. It has been suggested that multiple coding can be a valuable process for interrater reliability and refining interpretations or coding frameworks, but multiple coding of entire data sets is not recommended [26].

The fourth and final step involves using the coding scheme to complete a content analysis [20]. Thus, once a complete understanding of the themes was attained, the four coders engaged in axial coding as a group, which consisted of regrouping or reducing themes into frames based on similar dimensions [27]. In total, four prominent frames were identified for *tweets about long COVID-19* ("research," "support," "medical care," and "political") and four prominent frames were identified for *tweets by COVID-19 long-haulers* ("advocacy," "symptoms," "building a community," and "medical care"). In *tweets about long COVID-19*, 79 records (3.9% of the sample) did not fit into any of the themes and subsequent frames. In *tweets by COVID-19 long haulers*, 7 records (1.4% of the sample) did not fit into any of the themes and subsequent frames. For both data sets, these "outlier" records consisted of tweets comprised of only hashtags as well as tweets that were too out of context to interpret confidently and objectively (eg, tweet comprised of single words or emojis, replies to other threads). Thus, the remaining 1931 and 483 records for *tweets about long COVID-19* and *tweets by COVID-19 long haulers*, respectively, were included in axial coding and overall frames (see the Manual Coding to Identify Emerging Frames subsection in the Results).

Lastly, intraclass correlations were computed using IBM SPSS Statistics (version 25) to determine the interrater reliability of the frames using a two-way random, single-rater, average measures model [28]. Minimum acceptable levels of agreement (0.40-0.75) [29] were observed for all frames.

### Network Analysis

SNA can help in understanding how and why COVID-19 long haulers in a network are connected; how they seek each other out; and how their connections, configurations, and interaction patterns support information and knowledge sharing. Thus, a network perspective can provide several novel ways that long COVID-19 can be represented and addressed, guide efforts in medical care, and aid in designing future research questions. To explore the social connections underlying the online conversations being examined, the final data corpus was uploaded back into Netlytic and the Network Analysis tool was used [23].

Both *Name* and *Chain* networks were generated for both *tweets about long COVID-19* and *tweets by COVID-19 long haulers.* The *Name* network was used to show connections between online participants based on direct interactions such as replies or based on indirect interactions such as mentions or retweets [23]. A person's mentions capture a sense of acknowledgment and their retweets capture instances of endorsements. The *Chain* network connects participants based on their posting behavior and usually includes only direct interactions [23], meaning a tweet that includes a username. Both *Name* and *Chain* networks have been validated and applied in different contexts, including Twitter communities [30,31].

## Results

### Tweet Characteristics

Table 1 summarizes the overall descriptive statistics of the Netlytic output file for both *tweets about long COVID-19* and *tweets by COVID-19 long haulers*. On average, *tweets by COVID-19 long haulers* are liked more (ie, favorite count) than *tweets about long COVID-19*. Conversely, *tweets about long COVID-19* are retweeted more, on average, than *tweets by COVID-19 long haulers*.

**Table 1.** Descriptive statistics of Twitter records (ie, tweets) from a one-time Netlytic data pull in February of 2021.

| Characteristic | *Tweets about long COVID-19* (n=2010) | | *Tweets by COVID-19 long haulers* (n=490) | |
|---|---|---|---|---|
| | Range | Mean (SD) | Range | Mean (SD) |
| Favorite count[a] | 0-1067 | 10 (52.0) | 0-4614 | 17.2 (209.1) |
| Retweet count[b] | 0-498 | 3.6 (23.1) | 0-1039 | 3.3 (47.2) |
| User statuses count[c] | 6-1.69×10$^6$ | 3.00×10$^4$ (7.48×10$^4$) | 5 (1.69×10$^6$) | 4.56× 10$^4$ (2.16×10$^5$) |
| User friends count[d] | 0-3.80×10$^5$ | 2.33×10$^3$ (1.22×10$^4$) | 0 (3.07×10$^4$) | 1.65×10$^3$ (3.03×10$^3$) |
| User followers count[e] | 0-2.57×10$^6$ | 7.30×10$^3$ (6.62×10$^4$) | 0 (4.48×10$^5$) | 9.54×10$^3$ (5.69×10$^4$) |

[a]Number of times the tweet has been liked.

[b]Number of times the tweet has been retweeted.

[c]Number of tweets (including retweets) issued by the user.

[d]Number of users the account is following.

[e]Number of followers the account currently has.

### Computer Coding to Identify Popular/Emerging Text

Among the 2010 *tweets about long COVID-19*, 30,923 unique words were found. Among the 490 *tweets by COVID-19 long haulers*, 7817 unique words were found. Figure 1 provides an exploration of frequently tweeted words (a larger, more pronounced word reflects a greater frequency), allowing for a


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possible text-mining approach that can be applied to our data set.

For both *tweets about long COVID-19* and *tweets by COVID-19 long haulers* "#longcovid" and "covid" were the most frequently mentioned words. With *tweets about long COVID-19*, "#longcovid" was mentioned 1951 times (n=1913 records, 95.2%) with "covid" mentioned 479 times (n=429 records, 21.3%). In the *tweets by COVID-19 long haulers*, "#longcovid" was mentioned 478 times (n=470 records, 95.9%) with "covid" mentioned 96 times (n=83 records, 16.9%). Of interest in the current study were the nuanced differences between the *tweets about long COVID-19* and *tweets by COVID-19 long haulers*. By visually inspecting the data, it appears that words relevant to having long COVID-19 (ie, symptoms, fatigue, pain) are more prominent in the *tweets by COVID-19 long haulers*. Further comparisons in the most frequently used words for both *tweets about long COVID-19* and *tweets by COVID-19 long haulers* can be found in Table 2.

**Figure 1.** Word cloud of tweets about long COVID-19 (left) and tweets by COVID-19 long haulers (right) based on number of instances from a one-time Netlytic data pull in February of 2021.




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**Table 2.** Top 30 words in tweets about long COVID-19 and tweets by COVID-19 long haulers conversations on Twitter from a one-time Netlytic data pull in February of 2021.

| Term | Number of records | Number of instances |
|---|---|---|
| ***Tweets about long COVID-19*** **(n=2010 tweets; 30,923 unique words)** | | |
| #longcovid | 1913 | 1951 |
| covid | 429 | 479 |
| people | 308 | 344 |
| #covid19 | 272 | 277 |
| long | 253 | 279 |
| symptoms | 197 | 209 |
| patients | 146 | 157 |
| issues | 139 | 140 |
| suffer | 135 | 136 |
| lives | 132 | 134 |
| schools | 131 | 131 |
| death | 131 | 132 |
| thousands | 129 | 133 |
| follow | 126 | 128 |
| #mecfs | 123 | 130 |
| @borisjohnson | 121 | 126 |
| health | 117 | 126 |
| spread | 116 | 116 |
| #longhaulers | 116 | 116 |
| lost | 115 | 115 |
| families | 114 | 114 |
| research | 114 | 132 |
| dangerous | 111 | 111 |
| respiratory | 110 | 110 |
| causing | 106 | 106 |
| opening | 106 | 106 |
| suffering | 105 | 107 |
| @parents_utd | 105 | 105 |
| ***Tweets by COVID-19 long haulers*** **(n=490 tweets; 7817 unique words)** | | |
| #longcovid | 470 | 478 |
| covid | 83 | 96 |
| symptoms | 64 | 69 |
| months | 61 | 64 |
| year | 59 | 64 |
| long | 54 | 59 |
| it’s | 43 | 51 |
| people | 41 | 45 |
| back | 38 | 41 |
| i’ve | 37 | 37 |
| fatigue | 35 | 40 |


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| Term | Number of records | Number of instances |
|---|---|---|
| pain | 35 | 40 |
| good | 35 | 36 |
| #covid19 | 34 | 34 |
| work | 32 | 34 |
| time | 31 | 34 |
| today | 31 | 35 |
| feel | 27 | 28 |
| days | 27 | 30 |
| #longhaulers | 24 | 25 |
| hope | 24 | 25 |
| March | 23 | 23 |
| sick | 22 | 25 |
| life | 21 | 23 |
| week | 20 | 23 |
| brain | 20 | 21 |
| feeling | 20 | 21 |
| suffering | 19 | 20 |

## Manual Coding to Identify Emerging Frames

### *Overview*

The results are presented in multiple formats to demonstrate the similarities and differences within the frames, and between *tweets about long COVID-19* and *tweets by COVID-19 long haulers*. Examples and the prevalence of each frame are provided in Table 3.



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**Table 3.** Prevalence and examples of emerging frames identified by manual coding in *tweets about long COVID-19* and *tweets by COVID-19 long haulers* conversations on Twitter from a one-time Netlytic data pull in February of 2021.

| Frame | Themes | Prevalence, n (%) | Examples[a] |
|---|---|---|---|
| ***Tweets about long COVID-19* (n=1931)** | | | |
| Support | resources/ information, advocacy, financial, well wishes, skepticism | 1090 (56.4) | "The weekly @LongCOVIDGuide newsletter is your guide to the latest news and research about Long Covid! #LongCovid"<br>"When Does COVID-19 Become A Disability? 'Long-Haulers' Push for Answers, and Benefits #Pharma #Rx #COVID19 #LongHaulers"<br>"#LongCovid is forcing thousands of people --likely millions in US-- to leave their jobs and stop working. The health impacts from Covid may be lifelong and disabling many people. The impact this will have on our long-term economy is MASSIVE. Plus the massive health care costs."<br>"Thanks to journalists who continue to investigate & share important articles. Thanks to #LongHaulers who share their stories. Our community knows it is not easy but it can be powerful."<br>"So sorry you are having to scale back & modify things. As discouraging as it is, it looks like you are doing what you need to...to preserve function and get through your day. Big air hugs to you. Will continue to wish you well as you navigate living w #LongCovid [prayer hands emoji]"<br>"Do you remember the 34 pandemics we had in the 1970s/80s/90s and 2000s, before the 2020 Covid pandemic - all worse? Do you remember the 34 previous lockdowns? No, me neither. Maybe I've got brain fog as a result of unknowingly contracting #LongCovid." |
| Research | research needed, ongoing research/research findings, research funding, research on self/home or alternative remedies | 435 (22.5) | "Any experts /trial to see if monoclonal antibodies may help in viral persistence / #LongCovid?"<br>"We have open sourced our #LongCOVID survey and it's available to use (with citation) in 9 languages"<br>"The hypothesis that viral persistence of #SARSCOV2 in the body causes an ongoing immune response in patients with #longcovid is gaining ground. From Spain, this rationale written by our patient-led research team: https://t.co/o26apP0zOa #MedTwitter #Covid19 #covidpersistente"<br>"Or, expand your study - suspect given the large numbers of #LongCOVID patients without a history of positive tests, esp antibody tests (incl those who tested + for infection) that they represent an important immunological phenotype to study"<br>"Some interesting data regarding gender and Covid-19. Back in April I mentioned men are far more likely to die of Covid-19 than women. This is still true to this day but also very interesting is that women are significantly more likely to get #LongCovid than men. [confused face emoji]"<br>"The 2021 RFA for our Ramsay Grant Program, which funds pilot studies into #ME/CFS + #LongCovid, is now open! For information on types of grants, previously funded research, how to apply, + more please visit https://t.co/PLHJbr4uUt"<br>"#LongCovid - @groundology - UK - Grounding/Earthing - solution to get out of Covid ill-health. Medical drugs will not resolve ALL. Ancient remedy modernised. Read research first" |



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| Frame | Themes | Prevalence, n (%) | Examples[a] |
|---|---|---|---|
| Medical care | treatment, links to chronic disease | 396 (20.2) | "Geez, we're up to 3 #LongCOVID clinics in Vancouver now. I hope Ohio gets with the program." |
| | | | "Disturbing news: #Covid19/ #Longcovid, maybe an early way for some towards Alzheimer disease. Biochemical pathways activated by #SarsCoV2 infection." |
| | | | "I've spent the last 11 years waiting for a cure for #mecfs but nothing yet I'm afraid. I think #LongCovid will actually help because so many more people are unwell and we can join forces to get this looked into!" |
| | | | "I can not help but wonder, if the medical community had taken Chronic Fatigue Syndrome (#CFS/#MECFS/#CFIDS/#SEID) more seriously, instead of trivializing the illness, could they have been prepared for these perplexing #LongCovid abnormalities that emulate #CFS? #SARSCoV2 #COVID19" |
| Political | politicians/ parties/plans | 311 (16.1) | "what is the government doing for #LongCovid they never seem to answer" |
| | | | "Really want to see questions and discussion on the BIG issue of #LongCovid now in these government broadcasts." |
| | | | "#LongCOVID: The disease UKGOV barely acknowledges, doesn't care enough to mitigate against, and refuses to name. [angry face emoji]" |
| | | | "Well said @GwynneMP - we need access to clinics and therapeutics for everyone with #LongCovid Thank you for reminding the PM about this issue!" |
| ***Tweets by COVID-19 long haulers* (n=483)** | | | |
| Symptoms | mental health, physical health, comparing health time points | 297 (61.5) | "I learned around month 5 not to self cheer so much after feeling 'a little better' one day. Long haul was such an appropriate term! Mind game... do you still tell anyone when a symptom improved? I've been on both sides of that answer, just as #LongCovid said 'nah, im still here'" |
| | | | "Day 320 of living with #LongCovid and the relapse continues. My body and brain were so exhausted today I struggled to get out of bed all day. Fatigue has reduced around 6pm but very aware that energy could evaporate very quickly, so still focused on rest" |
| | | | "Yup. In the beginning, I got sick (like a bronchitis) once a month. Now I get better once a month. My asthmatic lungs are worse than ever. EVERYTHING is too much. It's been 1 year. I do all the things they say and keep getting worse. #longcovid" |
| Building a community | pride/ accomplishment, well wishes, advice, searching for support | 152 (31.5) | "Recommendations for a winter running jacket? Now doing intermittent jog/walks. Jog for 1 count of 8, walk for 3-5x8. This is how a dancer builds up reconditioning ;) [dancer emoji] It's a HUGE improvement. I'm hoping in 4-8weeks I'll be able to go on a full run. #LongCovid #LongCovidRecovery" |
| | | | "TaiChi, Wild swimming, meditation, mindfullness have all been in my #LongCovid tool kit along with all the conventional treatment and rehab... https://t.co/0uu9HVgxfH" |
| | | | "Anyone have any good tips/tricks/home remedies for the #longcovid GI flare up (nausea, vomiting, gastritis-type pain, all the GERD stuff)? I have a doctors appt in 10 days ish so more looking for recommendations for teas, supplements etc than meds" |
| | | | "Finding an online #longcovid FB group in early May last year was a godsend. To just know others were going through the same thing was weirdly reassuring, despite the snakes and ladders nature of this beast. Solidarity is so powerful." |



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| Frame | Themes | Prevalence, n (%) | Examples[a] |
|---|---|---|---|
| Advocacy | awareness, employment, disability | 106 (22.0) | "Please read. This is so true. We need research. We need help. We are #longhaulers #COVID19"<br>"It's really hard to hear 'it's not your fault, you're doing everything right, but you're still going to lose your job' #COVID19 #LongCovid #longhaulers"<br>"According to NHS, in January, 25% of hospital admissions were for people under 55. And ONS found that 10% of CV19 sufferers will go on to develop debilitating #longcovid at cost to individual, families and economy. As a 48yo with #longcovid I can confirm this thing is a shit." |
| Medical care | access to care, experience with clinicians/health care, COVID-19 vaccine | 79 (16.4) | "I am rapidly approaching a year now with no let up of #longcovid symptoms. No Long Covid clinic in Sunderland so no programmes of support being offered. But things have improved incrementally. Vit D helps"<br>"Even doctors also not believe my symptoms then how my company HR? #LongCovid"<br>"I had a very rough time of it; now back to the previous #LongCovid symptoms. Vaccine hasn't had any positive effect, at least not yet. It's been 13 days..." |

[a]Example tweets have been paraphrased/slightly modified so they are not easily searchable for user identification.

### *Tweets About Long COVID-19*

#### Main Frames

Analysis of the *tweets about long COVID-19* revealed that the most discussed frames were "support" and "research," followed by "medical care" and "political" (Table 3). Frames are discussed in further detail below.

#### Support

Records in this frame contained messaging indicating some form of support for long COVID-19. For almost all the records coded in this frame, the support was viewed with a positive connotation, including mention of support groups, petitions, the need for long COVID-19 to be recognized as a disease and serious health problem, and supportive messaging and/or advice.

> *How many Long Haulers are there? They matter - everyone matters. Never forget them; [or] stop supporting them. Let's use an orange heart to support them. Never forget the over 500,000 Americans who lost their lives - many could have been prevented #LongHaulers #MaskUp*

There were 29 records that were against supporting long COVID-19 and discussed conspiracy, used cynicism, or criticized long COVID-19 and the long haulers: "#LongCovid is an absolute myth. Even if it were real - there is no threat of death from it. Therefore no excuse for more lockdowns."

#### Research

This frame included records that focused on all aspects of research, including funding available, recruitment of ongoing research, and findings, with links to publications. Interestingly, Twitter users were posing research questions or calls to action, such as "Is anyone studying - or even publicly questioning - whether and how environmental factors may be influencing or contributing to people's experiences of #LongCovid?" In addition, this frame also included records mentioning home remedies or alternative medicine being researched for long COVID-19, such as "The #longcovid snake oil treatments and medicines popular in the patient-led covid groups are horrifying and profoundly sad. There must be light shed here."

#### Medical Care

This frame discussed the current views on treatment and/or the need for treatment options, which encompassed clinical services available, diagnostics, as well as denial of care: "#LongCovid clinics out there requiring a positive PCR/serology, think long and hard about what you're doing." In addition, this frame included records that mentioned the COVID-19 vaccine as a possible treatment method: "Is there any evidence that vaccine prevents #LongCovid or covid lung? Are we sure it prevents other long-term issues from vaccinated infection?" Lastly, this frame delved into the narrative around how long COVID-19 is related to or associated with diseases or the development of comorbidities.

> *Encouraged by coordination of the #Covid-19 research points to the role of post viral inflammation from SARS-CoV-2, leading researchers to compare Covid-19 to other chronic diseases such as #MEcfs #pwme #myalgicE #millionsmissing #longhauler #LongCovid #COVID19.*

#### Political

Records in this frame focused on content that was politically driven, mentioning political parties, policy decisions, or specific politicians.

> *#COVID19 is not like the flu @BorisJohnson. It leaves 10% of people with long-term morbidity - did you forget? If we don't control it this will have a significant impact on society and the economy #LongCovid.*

#### Overlap

All *tweets about long COVID-19* frames experienced some overlap, with 702 (36.3%) records having been coded in multiple


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frames. Frames that overlapped the most were "support" with "medical care" in 289 records, or 15.0% of the entire data set, followed by "research" with "medical care" in 233 records, or 12.1% of the entire data set. Frames that overlapped the least were "research" with "political" in 4 records, or 0.2% of the entire data set.

### *Tweets by COVID-19 Long Haulers*

#### Main Frames

Most of the *tweets by COVID-19 long haulers* focused on "symptoms" the individuals were experiencing and "building a community," followed by "advocacy" and "medical care" (Table 3). Frames are discussed in further detail below.

#### Symptoms

Records in this frame made mention of mental and/or physical health status, linking their experiences to other medical conditions, and COVID-19 long haulers making comparisons to their life before and after having COVID-19.

> *Day 321 of living with #LongCovid. After yesterday's extreme fatigue where in the day I often didn't have the energy to move my arms. The night was the other extreme, insomnia so bad that I couldn't sleep all night as if someone had put me on an IV drip of caffeine. Bonkers*

#### Building a Community

This frame emphasized COVID-19 long haulers sharing their stories of accomplishments and failures, providing supportive and/or empathetic messages, offering advice and/or treatment modalities, as well as those seeking to gain a support network of others experiencing long COVID-19: "Feeling a little blue because I'm suffering from #longcovid... Anyone out there going through the same? Would love to chat..."

#### Advocacy

This frame discussed the need for long COVID-19 to be recognized as a disease and as a disability: "Right now I write #LongCovid on my dashboard to park in the handicapped spot can't wait to have a ribbon for my car instead." Records in this frame also consisted of messages around the negative impact of being a COVID-19 long hauler on employment, a need for resources, petitions, crowdsource funding, and the importance of research.

#### Medical Care

Records in this frame describe the perspective of someone with long-haul COVID-19 on access to care, and experience with clinical services, providers, and/or treatments.

> *The medical community is still in denial of #LongCovid/#PACS, so how could the public be understanding? Doctors are blaming my symptoms on anxiety, supplements...anything but COVID. Infectious disease doc still using lack of positive test against me (both for Lyme and COVID).*

In addition, records that discussed the pros and cons of getting the COVID-19 vaccine as a treatment for or protection against long COVID-19 were also grouped under this frame.

> *I hope #LongCovid suffered see this. From what I'm reading, sufferers are getting dreadfully hammered by the vaccine. Don't forget, we have an autoimmune problem that cause serious trauma brain cytokine storms. Get the vac if you want, but don't feel forced or coerced.*

#### Overlap

All of the *tweets by COVID-19 long haulers* frames experienced some overlap, with 100 (20.70%) records having been coded in multiple frames. Frames that overlapped the most were "symptoms" with "building a community" in 38 records, or 7.87% of the entire data set, and "symptoms" with "advocacy" in 27 records, or 5.59% of the entire data set. Frames that overlapped the least were "building a community" with "medical care" in 4 records, or 0.83% of the entire data set.

### Social Network Analysis

Table 4 highlights the findings of the network analysis generated by Netlytic [23]. Two Twitter accounts will be connected in the *Name* network if one replies to or mentions another in their message. The *Chain* network is a subset of the *Name* network because it only connects people if one replied to another.

**Table 4.** Social network analysis of tweets about long COVID-19 and tweets by COVID-19 long haulers conversations on Twitter from a one-time Netlytic data pull in February of 2021.

| Characteristic | *Tweets about long COVID-19*, n | | *Tweets by COVID-19 long haulers*, n | |
|---|---|---|---|---|
| | Name network[a] | Chain network[b] | Name network | Chain network |
| Network actors with ties[c] | 648 | 396 | 156 | 121 |
| Ties (including self-loops) | 2923 | 1653 | 478 | 389 |
| Names found[d] | 2406 | N/A[e] | 608 | N/A |

[a]Who mentions whom: a communication network built from mining personal names in the messages.

[b]Who replies to whom: a communication network built based on participants' posting behavior.

[c]Network actors are members connected together based on some common form of interaction ("ties") [23].

[d]Number of unique personal names that Netlytic found in this data set.

[e]N/A: not applicable.



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Figure 2 and Figure 3 show the *Name* and *Chain* networks built from the #longcovid #longhaulers data set, split by *tweets about long COVID-19* and *tweets by COVID-19 long haulers,* constructed using a Dr L layout [32] and a Fruchterman-Reingold layout [33], respectively, which are force-directed graph–drawing algorithms effective for large networks (<1000 nodes). The node colors are assigned automatically (based on the "Fast Greedy" community detection algorithm) [34]. Each color represents a group of nodes more likely to be connected to each other than with the rest of the network. Based on visual inspection of the networks, the *Chain* network has fewer nodes. This is somewhat expected since it only represents direct replies between Twitter users. The clustering and network fragmentation aspects at the macrolevel are discussed in the following section.

**Figure 2.** *Name* (left) and *Chain* (right) networks for tweets about long COVID-19 conversations on Twitter from a one-time Netlytic data pull in February of 2021, presented using a Dr L layout [30].

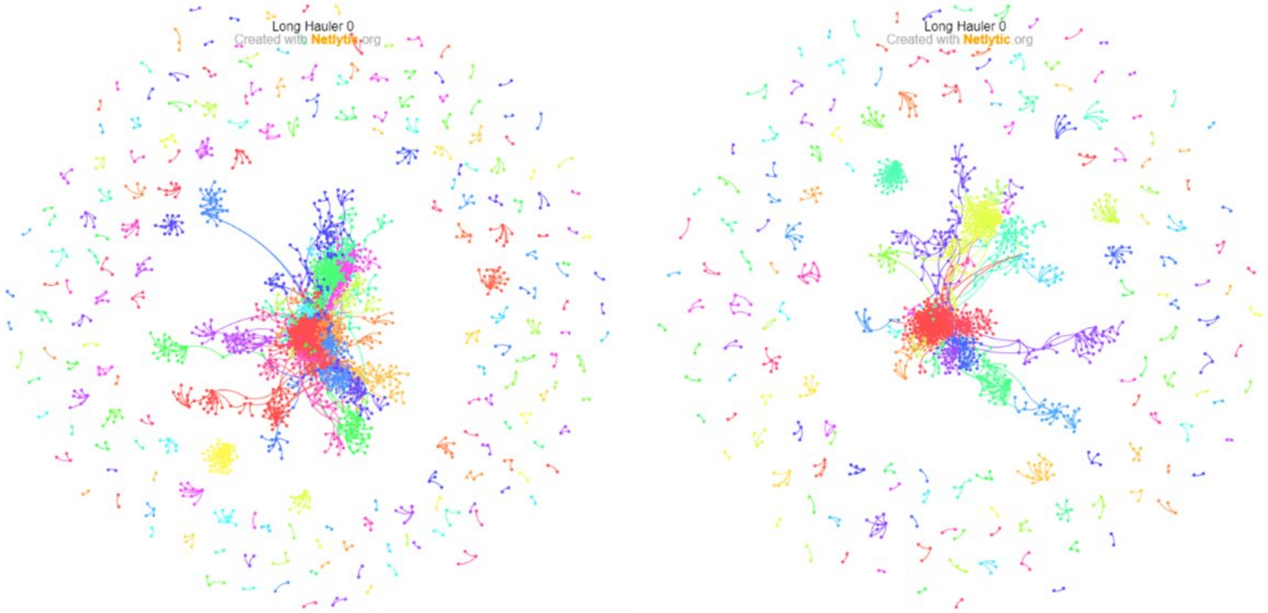
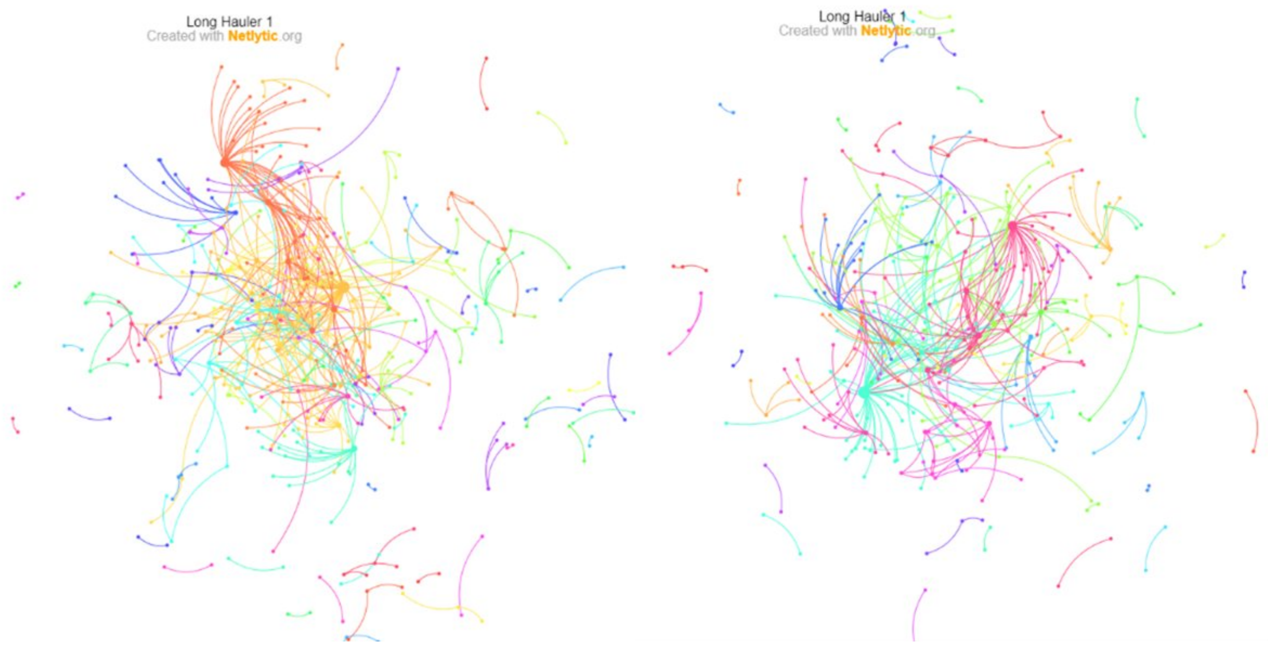



**Figure 3.** *Name* (left) and *Chain* (right) networks for tweets by COVID-19 long haulers based on conversations on Twitter from a one-time Netlytic data pull in February of 2021, presented using a Fruchterman-Reingold layout [31].




## Macrolevel SNA Measures

Macrolevel SNA measures that are found to be useful when analyzing and comparing different social networks include density, reciprocity, centralization, and modularity [35]. Table 5 depicts Netlytic's five measured network properties, which describe network characteristics such as how individuals interact with each other, how information flows, and whether there are distinct voices and groups within the network [23].

The diameter property provides a measure of network size. The diameter property was different between the *Name* network and



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the *Chain* network in *tweets about long COVID-19*. For the *Name* network in *tweets about long COVID-19*, it may take up to 100 connections for information to travel from one side of the network to the other. Smaller values for the diameter indicate a more highly connected network, which is true for the *Chain* network in *tweets about long COVID-19* as well as the *Name* and *Chain* networks in *tweets by COVID-19 long haulers*. The density property is complementary to diameter, as both assess the speed of information flow, with density helping to illustrate how close participants are within a network. As the density property is closer to zero for both network types, in the *tweets about long COVID-19* and *tweets by COVID-19 long haulers*, this suggests there is not a close-knit community and participants are not talking with others.

The conversations for both *tweets about long COVID-19* and *tweets by COVID-19 long haulers* appear to be one-sided, with little back-and-forth conversation, as indicated by the low reciprocity values for all networks. Moreover, the conversations for both *tweets about long COVID-19* and *tweets by COVID-19 long haulers* show decentralization (ie, closer to 0). This low centrality score suggests that the networks contain a number of influential participants, but there is not a single opinion leader (eg, informed, respected, and well-connected individuals) controlling the conversation [8]; there was a free flow of information between the users. Finally, the last property, modularity, is dependent on clusters within the network. A cluster is a group of densely connected nodes that are more likely to communicate with each other than to nodes outside of the cluster. The higher value of modularity (>0.5) both for *tweets about long COVID-19* and *tweets by COVID-19 long haulers* in all networks indicates clear divisions between communities, and thus the clusters do not overlap. The network does not consist of a core group of nodes and consists of different conversations as well as communities with weak overlap.

**Table 5.** Detailed network property descriptions and results for Twitter social network analysis in *tweets about long COVID-19* and *tweets by COVID-19 long haulers* conversations on Twitter from a one-time Netlytic data pull in February of 2021.

| Network properties | Description[a] | Tweets about long COVID-19 | | Tweets by COVID-19 long haulers | |
|---|---|---|---|---|---|
| | | Name network | Chain network | Name network | Chain network |
| Diameter | Calculates the longest distance between two network participants | 100 | 9 | 5 | 5 |
| Density | A proportion of existing ties to the total number of possible ties in a network | 0.000588 | 0.000828 | 0.002362 | 0.002778 |
| Reciprocity | The number of reciprocal ties (two-way conversations) compared to the total number of ties | 0.021690 | 0.022550 | 0.031110 | 0.027400 |
| Centralization | How freely information flows within a network | 0.020630 | 0.030920 | 0.049470 | 0.058320 |
| Modularity | Whether the clusters found indicate distinct communities in a network | 0.819600 | 0.850600 | 0.802400 | 0.805100 |

[a]Descriptions are based on Mitchell et al [36] and Gruzd et al [22].

## Discussion

### Principal Findings

The objective of this study was to use a multimethod approach to compare the conversations on Twitter between those discussing long COVID-19 to the narratives created by users identifying as COVID-19 long haulers. Selected findings reflect that many of the users who tag their tweets with #longCOVID and #longhaulers seem to be doing so to highlight the outcomes and implications of the COVID-19 pandemic, similar to previous Twitter studies on COVID-19 [4,10]. In addition, compared to *tweets about long COVID-19*, *tweets by COVID-19 long haulers* appear to be more frequently mentioning words relevant to having long COVID-19. Manual coding identified that the most prominent frames employed when discussing long COVID-19 were “support” and “research.” Conversely, “symptoms” and “building a community” were the frames most prominent in conversations by COVID-19 long haulers. Lastly, SNA provided insight into network typologies, and inferences were drawn regarding the transmission and adoption of long COVID-19 discourse on Twitter. For both *tweets about long COVID-19* and *tweets by COVID-19 long haulers*, networks appear highly decentralized, fragmented, and loosely connected. Overall, the results provide insight into how long COVID-19 is being framed from the perspective of SNS users, and allows for those users to decide what and how topics and issues are being presented to the broader health community.

Regarding long COVID-19, this study has important clinical and academic relevance, and can act to inform care and research moving forward. Our findings can influence clinical practice guidelines for long COVID-19, playing an important role in ensuring the delivery of high-quality health care. As clinical practice guidelines provide recommendations for how best to treat a typical patient with a given condition [37], utilizing Twitter conversations can provide broad perspectives and experiences from various stakeholders. Previous literature has indicated that engaging stakeholders with legitimate interests in the development of clinical practice guidelines can improve quality and utility [38]. Long COVID-19 is currently understood and defined by patient-reported symptoms; therefore, the *tweets by COVID long haulers* are critical to separate out of the overall conversation, as they provide direct insight into the concerns and experiences of this community. Of interest, however, was the finding of “medical care” as a frame in both data sets. Although themes within the frame differed based on record type, overall undertones for the urgency to diagnose and treat



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long COVID-19 appropriately as a medical condition existed, further acknowledging the clinical significance of this study. In addition, research methods that support higher levels of participant/patient engagement as well as study designs that are participant/patient-centered have been found to yield more successful study outcomes [39-41]. This study provides findings that may help to generate future research questions in a participant/patient-centered way as the discourse provided from Twitter indicates frames of interest. When it comes to those experiencing long COVID-19, Twitter users included in this study emphasized the need for support as well as describing their unresolved symptoms. These frames may be important topics for future research studies, placing a focus on patients' immediate needs. Since COVID-19 is novel, and long COVID-19 is an emerging health crisis [16], the frames patients are interested in should have urgency.

Confirmation bias, the mechanism of seeking out and/or preferring information supporting prior beliefs [42,43], can offer an explanation into how both the framing and valence of tweets surrounding the topic of long COVID-19 develop and evolve. Within the employed frames, a trend of needing, seeking, or wanting to provide support can be identified across the two delineated conversations in this analysis. The frames "support" and "building a community" were predominant for *tweets about long COVID-19* and *tweets by COVID long haulers*, respectively. The suggestion of support and community building within each frame included various aspects of championing long COVID-19, containing financial, emotional, and informational context. Importantly, for the patient population, Twitter may be acting as a space for COVID-19 long haulers to validate their experiences and create a sense of community. The suggestion that SNSs give a lexicon by which users explain what they are going through emphasizes the bottom-up emergent conceptualization of this health issue and the connection with others that support their beliefs. Moreover, supportively framed tweets were most often of positive valence. However, the 29 records in *tweets about long COVID-19* exposing mistrust and conspiracy concerning long COVID-19 reflects a broader conversation about the politics of crisis and relates to confirmation bias [44]. The pandemic itself has been highly politicized, and political ideology has heavily influenced the way people conceptualized the pandemic and followed regulations such as social distancing, even more so than demographics such as age and income [45]. Our finding may be explained in part by the fact that sharing intention of health messaging on SNSs increases if it is appropriately leveraging the users' confirmation bias, regardless of content valence [46]. In addition, Twitter users tend to reuse hashtags that were used very recently by their own and/or by their Twitter followees, indicating the temporal influence of confirmation bias [47]. Therefore, evaluating the influence of social hashtags exposure by investigating retweet or mention networks in Twitter has been identified as a future direction to study confirmation bias [47], and using SNA can assist in better understanding these phenomena.

The transmission and adoption of long COVID-19 discourse on Twitter appear to be highly decentralized, fragmented, and loosely connected. These findings are similar to a recent study that also used Netlytic to understand public discourse on Twitter around the COVID-19 pandemic [31]. This network type is not entirely surprising due to the nature of Twitter, as it was not designed to support the development of online communities but rather was imagined as a tool to share updates with others [30]. Moreover, online conversations are typically dominated by the few who are willing to post, resulting in predominantly parasocial or one-sided interactions, and research suggests that individuals are less likely to participate in conversations on sensitive topics because of the possible associated stigma [48]. Stigma and discrimination have been associated with those that have become ill with COVID-19 [49,50], which may in turn be impacting the network typology. Although previous literature has reported that SNSs offer a space for patients with newly described or rare heath concerns to find and connect with others similar to them [51,52], it appears that users in this study are participating in "lurking" behavior (ie, silently observing tweets and do not communicate) [53]. Knowing and understanding how this community of users typical behaves online can provide guidance for those attempting to disseminate health information and messaging on long COVID-19.

Overall, the network typology presented here (decentralized, fragmented, and loosely connected) has been shown to hinder the successful dissemination of risk communication by public health officials and health agencies across the network [31]. This is an important consideration due to the novelty of long COVID-19, and the way in which COVID-19 long haulers appear to be utilizing SNSs and the digital environment to find support and connect to others with similar experiences. However, it is important to examine the network properties individually and interpret how measures could potentially be leveraged within networks. In *tweets about long COVID-19*, the diameter property was larger than that in *tweets by COVID-19 long haulers*. A larger diameter can suggest that that information originating inside the core nodes also reaches people and communities far outside its core group of participants, which could be positive for spreading health messaging. Within both data sets, it appears that users are broadcasting information and not having conversations. This again may be beneficial for informational aspects of conversations about long COVID-19, such as resources and research findings and funding, all of which appeared as themes in this study. Moreover, there might be individual clusters in the network that are higher in density and reciprocity. Within these theoretical, closely knit clusters or niches, back-and-forth conversation would be occurring and thus satisfying the ideals of support conveyed in the data set. Future research using a microlevel SNA would be needed to explore this potential phenomenon.

## Limitations

Several limitations of this study need to be acknowledged. First, qualitative data have the potential for researcher bias; however, using Netlytic to complement the manual coding provided a more objective analytic tool as researcher bias, coder reliability, and subjectivity were diminished. Second, the data analysis and interpretation of social media were limited to Twitter; therefore, examining a wider array of user-generated comments on a variety of websites (eg, newspaper websites, discussion forums) and other SNSs would provide additional context. Although a



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contextually purposeful window of data collection [54,55] was chosen by the authors, future studies could include a more longitudinal design, thus following the trend of hashtags over time. In addition, including a geographic analysis might be of interest as the COVID-19 pandemic and subsequent long COVID-19 have had a global impact. Lastly, due to Twitter's API restrictions, Netlytic limits data collection to 1000 tweets every 15 minutes, based on the data specifications given by the research. In other words, the tweets analyzed do not represent all of the tweets that were posted and do not include tweets from people who wrote about long COVID-19 but did not use the #longCOVID and #longhaulers hashtags. However, this study has important strengths, including frame overlap with human coding, as this allowed for a more robust interpretation of the data. Additionally, involving patients in clinical practice guidelines or the development of research questions typically is limited to a few representatives due to budgetary and logistical constraints [56,57]. In utilizing Twitter conversations, this study has proactively engaged a wider group of patients.

### Conclusion

Our results suggest that a popular SNS such as Twitter can effectively serve as a platform for the sharing of information and personal experiences related to long COVID-19. Records about long COVID-19 and records posted by users experiencing long COVID-19 exposed a variety of perspectives, including calls for research, political opinions, and the sharing of personal struggles. The findings indicated that tweeting about long COVID-19 is more commonly for informative purposes than for starting conversation. Future research may look at discourse occurring on SNSs that are aimed at facilitating group conversation, such as Facebook. Additionally, long COVID-19 research generally should seek to address the thoughts and experiences of the people affected by the disease to maximize impact.

## Conflicts of Interest

None declared.

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## Abbreviations

**API:** application programming interface
**SNA:** social network analysis
**SNS:** social networking site

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Original Paper

# US Black Maternal Health Advocacy Topics and Trends on Twitter: Temporal Infoveillance Study

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## Abstract

**Background:** Black women in the United States disproportionately suffer adverse pregnancy and birth outcomes compared to White women. Economic adversity and implicit bias during clinical encounters may lead to physiological responses that place Black women at higher risk for adverse birth outcomes. The novel coronavirus disease of 2019 (COVID-19) further exacerbated this risk, as safety protocols increased social isolation in clinical settings, thereby limiting opportunities to advocate for unbiased care. Twitter, 1 of the most popular social networking sites, has been used to study a variety of issues of public interest, including health care. This study considers whether posts on Twitter accurately reflect public discourse during the COVID-19 pandemic and are being used in infodemiology studies by public health experts.

**Objective:** This study aims to assess the feasibility of Twitter for identifying public discourse related to social determinants of health and advocacy that influence maternal health among Black women across the United States and to examine trends in sentiment between 2019 and 2020 in the context of the COVID-19 pandemic.

**Methods:** Tweets were collected from March 1 to July 13, 2020, from 21 organizations and influencers and from 4 hashtags that focused on Black maternal health. Additionally, tweets from the same organizations and hashtags were collected from the year prior, from March 1 to July 13, 2019. Twint, a Python programming library, was used for data collection and analysis. We gathered the text of approximately 17,000 tweets, as well as all publicly available metadata. Topic modeling and k-means clustering were used to analyze the tweets.

**Results:** A variety of trends were observed when comparing the 2020 data set to the 2019 data set from the same period. The percentages listed for each topic are probabilities of that topic occurring in our corpus. In our topic models, tweets on reproductive justice, maternal mortality crises, and patient care increased by 67.46% in 2020 versus 2019. Topics on community, advocacy, and health equity increased by over 30% in 2020 versus 2019. In contrast, tweet topics that decreased in 2020 versus 2019 were as follows: tweets on Medicaid and medical coverage decreased by 27.73%, and discussions about creating space for Black women decreased by just under 30%.

**Conclusions:** The results indicate that the COVID-19 pandemic may have spurred an increased focus on advocating for improved reproductive health and maternal health outcomes among Black women in the United States. Further analyses are needed to capture a longer time frame that encompasses more of the pandemic, as well as more diverse voices to confirm the robustness of the findings. We also concluded that Twitter is an effective source for providing a snapshot of relevant topics to guide Black maternal health advocacy efforts.



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**KEYWORDS**

Black maternal health; disparity; COVID-19; Twitter; topic modeling; digital humanities; infoveillance; maternal health; minority; women; advocacy; social media; model; trend; feasibility

## Introduction

Compared to White women, Black women are 3 times more likely to have pregnancy-related deaths in the United States (13 deaths per 100,000 births compared to 41 deaths per 100,000 births) [1]. Black infants also die at twice the rate of White infants (10.8 deaths per 1000 compared to 4.6 deaths per 1000) [2]. The COVID-19 pandemic, combined with endemic vulnerabilities of structural racism and biased care, has further exacerbated these disparities. Blacks are disproportionately impacted by COVID-19, dying at 3 times the rate of Whites [3], and in some cities, pregnant Black women were found to be 5 times more likely to be exposed to COVID-19 compared to pregnant White women [4]. As evidenced by several articles in the popular press, Black women continue to experience biased care during the pandemic [5]. Black women have more risk factors (eg, obesity) for COVID-19 and are more likely to work in occupations (eg, nurses' aides) that increase exposure to COVID-19 [6]. Policies that were implemented to reduce the spread of COVID-19 (eg, increased use of telemedicine for patient visits, separation of mothers from newborns) may further place Black mothers at increased risk due to increased social isolation [1,7]. Additionally, structural racism, as evidenced by acts of police violence against Blacks, have continued since the beginning of the pandemic [8].

Persistent poor reproductive and birth outcomes among Black women precipitated the introduction of H.R. 6142, the Black Maternal Health Momnibus Act of 2021, by members of the US Congress in July 2020 [9]. The bill seeks to address social factors driving the Black maternal health crisis in the United States, such as housing, nutrition, and access to culturally responsive care, in addition to supporting robust metrics to evaluate impact. The Black maternal health crisis is so entrenched in the United States, however, that several states have also sought various legislative avenues for amelioration while federal efforts play out. In Illinois, for example, House Bill 1, which created a Task Force on Infant and Maternal Mortality Among African Americans, was passed in July 2019 [10]. In January 2020, Illinois passed House Bill 2, which includes additional rights for pregnant women as part of the Medical Patients' Rights Act, including "the right to be treated with respect at all times before, during, and after pregnancy by [...] health care professionals and to have a health care professional that is culturally competent and treats her appropriately regardless of her ethnicity, sexual orientation, or religious background" [11]. California, cognizant that the observed racial disparities in maternal and birth outcomes cannot be entirely explained by education or access to prenatal care, passed Senate Bill 464, the California Dignity in Pregnancy and Childbirth Act, in 2019 [12]. In addition to tracking and publishing data on maternal mortality rates, the legislation also requires implicit bias training for all perinatal health care providers. The hope is that providers will learn to recognize their unconscious prejudices or stereotypes in their interactions with Black and other minoritized women, resulting in more empathetic care that reduces adverse pregnancy and birth outcomes. The importance of the aforementioned legislative efforts around the Black maternal health crisis have clearly been amplified by the COVID-19 pandemic, with recent exhortations from maternal and child health experts to develop policies to immediately and effectively address this crisis [13].

Social media offers an important window into public discourse on maternal and birth outcomes, and our study looks particularly at Twitter. Twitter is 1 of the most popular social networking sites, with 192 million daily active users and approximately 500 million tweets shared per day [14]. It has been used to study a variety of issues of public interest, including health care and mental health, among others [15]. Although approximately 9% of Black US adults indicate noninternet usage [16], a recent study found that racial and ethnic minority groups were more likely to post COVID-19-related content on social media [17]. Moreover, Twitter is considered a social media platform that may accurately capture public discourse during the COVID-19 pandemic and is being used in several infodemiology studies by public health experts [17]. As such, we found Twitter to be an appropriate platform to examine public discourse from Black maternal health organizations and influencers on Twitter within the context of COVID-19.

In this paper, we are particularly interested in the impact of COVID-19 on advocacy issues for Black maternal health and whether advocacy efforts have changed or remained the same as a consequence of the pandemic. Specifically, we are interested in understanding public discourse related to social determinants of health and advocacy that influence maternal health among Black women in the United States and examining topics and trends in sentiment between 2019 and 2020 in the context of the COVID-19 pandemic. We hypothesize that there will be an increase in tweets related to advocacy efforts for Black women, as the COVID-19 pandemic has exacerbated existing disparities in maternal and child health in this group.

## Methods

### Data Collection

Tweets were collected from March 1 to July 13 for 2019 and 2020 from 21 organizations and influencers and from 4 hashtags that focused on Black maternal health. Twint, a Python programming library, was used for data collection and analyses [15]. We gathered the texts of approximately 17,000 tweets, as well as all publicly available metadata. Topic modeling and k-means clustering were used to analyze the tweets.

To gather relevant tweets for analysis, we researched organizations and influencers who are focused on supporting Black maternal health. We also identified hashtags that people



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often used to communicate about Black maternal health. We curated a list of accounts, in part, by researching organizations that supported the Black Maternal Health Momnibus Act of 2021 [9]. Second, we identified which organizations in that list had active Twitter accounts. Our criteria for "active user" included regular tweets posted throughout the 2 time periods we wanted to collect material: March 1-July 13 in both 2019 and 2020. We wanted to gather tweets that were shared from these organizations and influencers during the early period of the pandemic and compare those tweets with the same period the year prior to the pandemic. We started collecting tweets on March 1, a week or two before most cities in the United States shut down, because the US Centers for Disease Control and Prevention (CDC) concluded that COVID-19 was heading toward pandemic status even before lockdowns began [18]. Although not every tweet gathered contained the word "COVID" or "pandemic," each tweet collected within the 2020 data set was shared during the pandemic. By gathering both a data set from 2020 and from the year prior, we can start to understand how the messaging from advocates of Black maternal health changed during the pandemic to support Black women and families.

The study was deemed IRB-exempt due to the use of publicly available Twitter data that was anonymized.

We gathered the text of the tweets, as well as all publicly available metadata from organizations, influencers, and hashtags that advocate for Black maternal health. They are (with the exclusion of names of personal accounts) listed in Table 1.

**Table 1.** Twitter accounts, hashtags, and geographic locations.

| Twitter account or hashtag | Location of organization, if available |
|---|---|
| Black Mamas Matter Alliance (BlkMamasMatter) | —[a] |
| Black Women's Health (blkwomenshealth) | Washington, DC |
| National Birth Equity Collab (BirthEquity) | New Orleans, LA |
| In Our Own Voice (BlackWomensRJ) | Washington, DC |
| Sister Reach (SisterReach) | Memphis, TN |
| Sister Song (SisterSong_WOC) | Atlanta, GA |
| MS Black Women's Roundtable (msblackwomensr1) | Jackson, MS |
| Moms Rising (MomsRising) | United States |
| Shades of Blue (shadesofblueprj) | Houston, TX |
| Mount Sinai Health System (MountSinaiWHRI) | — |
| Black Maternal Health Caucus (BMHCaucus) | Washington, DC |
| Mama Glow (MamaGlow_MGFF) | New York City, NY; Los Angeles, CA; Miami, FL; Paris, France |
| The National Association to Advance Black Birth (thenaabb) | Washington, DC |
| Balanced Black Girl (balancedblkgirl) | Los Angeles, CA |
| California Black Women's Health Project (cabwhp) | Inglewood, CA |
| The Frugal Feminista (frugalfeminista) | New York |
| JOY Collective (aJOYcollective) | United States |
| Abiola Abrams (abiolatv) | — |
| Loretta J. Ross (lorettajross) | Atlanta, GA |
| Linda Goler Blount (lindagblount) | Washington, DC |
| Dr. Joia Crear-Perry (doccrearperry) | New Orleans, LA |
| #blackmaternalmortality | N/A[b] |
| #blackmaternalhealth | N/A |
| #bwwday | N/A |

[a]Not available.

[b]N/A: not applicable.

We included the hashtags #blackmaternalmortality, #blackmaternalhealth, and #bwwday as they are popular hashtags that capture general content about Black maternal health and wellness.

Although we originally sought out to collect tweets by searching for mentions of text such as "Black maternal health" and "Black women" and discussions around pregnancy complications, our resulting data set was not as focused as we wanted it to be on Black maternal health. Specifically, searching for phrases on


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Twitter gathers tweets that are not on Black maternal health but contain the phrase "Black women." Gathering tweets from organizations, in contrast, and hashtags that are specific enough about Black maternal health produces a data set that is more specific to Black maternal health. Although we could have "cleaned" the data set to omit tweets that did not make sense to include because they were not about Black maternal health, such cleaning would have added bias to the data set as the choices about what to include or not would have been determined by the authors. Thus, we focused our data set on organizations and a few specific hashtags to gather a sample data set on Black maternal health.

Although we set our parameters for data collection so that retweets were not included, the texts and hashtags of all other tweets were gathered from the accounts, influencers, and hashtags we selected. Our tweets did include "quoted tweets" or tweets that cited another user and shared what they wrote but without retweeting them. Although the existence of quoted tweets in our data set introduced some bias as it potentially amplified the text of a given tweet, retweets were not a large portion of the data set.

To analyze the tweets, we used 2 methods: topic modeling and k-means clustering. We found that topic modeling yielded the most useful results, and those are described next. Notable results from k-means clustering are available in Multimedia Appendix 1.

Topic modeling attempts to detect groups of words that occur together frequently in the same document. In our case, each tweet was a document. In topic modeling, the "topics" are composed of words within the documents as a whole that co-occur; they are not necessarily words or phrases that a human might use to summarize a topic. It is common practice within the digital humanities to produce human labels to describe the topics [19]. We worked in pairs to determine labels for each topic using an iterative process. Each reviewer first examined the topics independently to determine a label and then met with the second reviewer to reach agreement on the final labels assigned.

Our data preprocessing steps were as follows. We merged the tabular data from 2019 and 2020 into a single Pandas Python Data Analysis Library DataFrame, retaining the tweets themselves along with the year portion of the date [20]. We extracted the tweets from the DataFrame into a list. Then, we cleaned the data by removing uniform resource locators (URLs), newlines, and apostrophes. We also temporarily removed "@" tags to prevent them from being modified by other steps in the preprocessing. We then used the Gensim (RARE Technologies Ltd) built-in simple preprocess function to further clean the text and convert each tweet from a string into a list of lowercase words [21]. We largely used the default parameters, except that we converted accented characters to their unaccented equivalents. We removed the default Natural Language Toolkit (NLTK) English stop words [22]. We cleaned our tweets in this way because we wanted the algorithm to read the words as close to their context as possible. So, for example, had we not changed the words to lowercase, the algorithm would have seen "Dance" as different from "dance" and counted them as separate. Cleaning the text in this way allows researchers to identify how the words co-occur in the tweets without considering capitalization.

We then wanted to make sure our analysis could differentiate between phrases and individual words. For example, we did not want to count the word "three" in "The Three Musketeers" the same as the word "three" in other contexts. So, we then used the Gensim *Phrases* function to combine words that commonly occurred together into word compounds [21]. This was done twice to join together phrases with more than 2 words. Then, we lemmatized the words and filtered out words that were not nouns, adjectives, verbs, adverbs, or proper nouns. Adding the hashtags and "@" tags back in at this point allowed us to later analyze the tweets by hashtag or mention. Finally, we removed words that occurred only once, and removed any word lists that were blank as a result of performing the previous steps. In addition, we converted the word lists to bag-of-words model ID and frequency pairs.

To create our topic models, we used Gensim's Latent Dirichlet Allocation (LDA) model [21]. We set the number of topics to 109 because that is where we noticed a peak of the coherence score at 0.5318. Above this number, the score initially decreased. Although the score did eventually begin to increase again with more topics, even with several hundred topics the score remained below this peak. In addition, based on our human readings of the topics, 109 topics generated the most coherent models. We determined that analysis would become unwieldy beyond a few hundred topics, and therefore, it would not be worth increasing the number of topics further in search of a higher score.

We set the *random state* parameter to 100 arbitrarily. We set the number of passes to 10. We set the *alpha* parameter to "auto." All other parameters used the default value. For each topic, we calculated its composition of tweets from 2019 to 2020 and used this to determine which topics increased or decreased in significance between the 2 time periods.

## Results

### Trends Observed

We saw a variety of trends when we analyzed 17,000 tweets in our corpus and compared the 2020 data set to the 2019 data set from the same period. Based on the results of the topic models, tweets on reproductive justice, maternal mortality crisis, and patient care increased by over 65% in 2020 versus 2019. Topics on community, advocacy, and health equity increased by over 30% in 2020 versus 2019. In contrast, tweet topics that decreased in 2020 versus 2019 included tweets on Medicaid and medical coverage, which decreased by 27.73%, and discussions about creating space for Black women, which decreased by just under 30%. This change in what Black maternal health activists discussed on Twitter indicates a shift in their concerns from Medicaid and medical coverage to reproductive justice, the maternal mortality crisis, and health equity more broadly.

Our results indicate that the COVID-19 pandemic may have spurred an increased focus on advocating for improved



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reproductive health and maternal health outcomes among Black women in the United States. Although the terms “COVID” and “pandemic” are not grouped into 1 topic in the 2020 data set, all of the tweets within this data set were shared during the early stages of the pandemic and, therefore, speak to the messaging by Black maternal health organizations and advocates during the COVID-19 pandemic. All the content of the tweets from both the 2019 and 2020 data sets was included in the topic models; we then analyzed the results to understand how messaging had shifted during the pandemic. We manually annotated the tweets that were correlated with the topics outputted by LDA. Further analyses are needed to capture a longer time frame that encompasses more of the pandemic, as well as additional analysis of messaging by Black maternal health advocates on other platforms to confirm the robustness of our findings.

A sample of the topic models is available in Multimedia Appendix 1. The percentages listed for each word are probabilities of that word occurring in the given topic. As an example, the top words within the reproductive justice topic model were birth (45% of the topic), black (21% of the topic), support (14% of the topic), and body (7% of the topic). The words within each topic model were both weighted and counted. For words that appeared frequently within our corpus, such as “black,” the word had a lower weight value but a high word count. In contrast, a word like “birth” had a high weight value but a low word count value. Each weight and word count were determined using TfidfVectorizer (Sklearn). Figure 1 highlights the weighted word counts for one of our topics, “Reproductive Justice.”

The “Word Count” listed in the chart refers to the number of times each respective word appeared in the text. For example, the word “remind” appeared less than 500 times. The “weight” of a word refers to how common the word is in association to the rest of the corpus. The less common the word, the higher the weight of the word. So, for example, the word “birth” had a high word count but a low weight; this is because the word “birth” appeared so frequently in our corpus that it was less significant when the word appeared. However, the word “black,” had a lower word count and a higher weight as it appeared less frequently in our data set compared to the rest of the corpus. A word cloud visualizing topic 59 can also be found in Multimedia Appendix 2.

Here is an example tweet associated with this topic:

> *Advocating for the rights of Black birthing people is always important, but even more so in the midst of the COVID19 pandemic. The National Association to Advance Black Birth- NAABB just launched a bill of rights for Black birthing people: https://thenaabb.org/index.php/black-birthing-bill-of-|rights/ …. #BMHW20 pic.twitter.com/5c8PhtwQQY*

The topic model on advocacy showed a 33.3% increase in prevalence in 2020 versus 2019. The graph in Figure 2 displays the weights and word counts for top words within the topic.

We manually annotated the topic “Advocacy” as the majority of documents that make up this topic are related to equity in health. The term “ensure” is often used within the context of ensuring equity. For example, 1 tweet asks, “How do we ensure that minorities are no longer underrepresented in precision medicine? #SaludTues.” The hashtag #SaludTues is a monthly Tweetchat on Latino health hosted by the Institute for Health Promotion Research (IHPR) at University of Texas Health at San Antonio, which directs *Salud America!*

To understand the topic models produced by the LDA algorithm, we found it essential to combine manual reading of the tweets that most heavily make up a given topic with the quantitative results of the LDA algorithm. This is perhaps especially important when reviewing a largely general topic, such as this one. A word cloud visualizing topic 76 can also be found in Multimedia Appendix 3.

**Figure 1.** Topic 59 (“Reproductive Justice”) with weighted word counts.

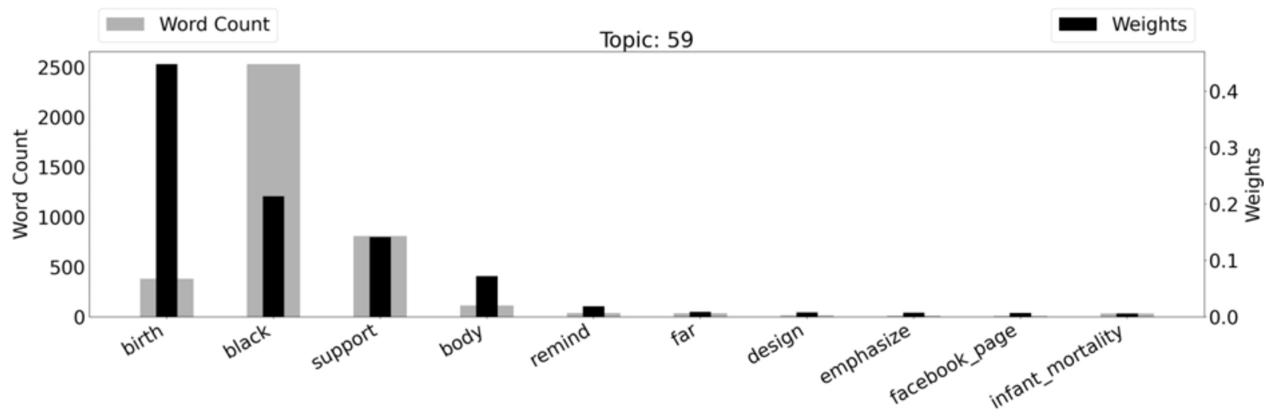




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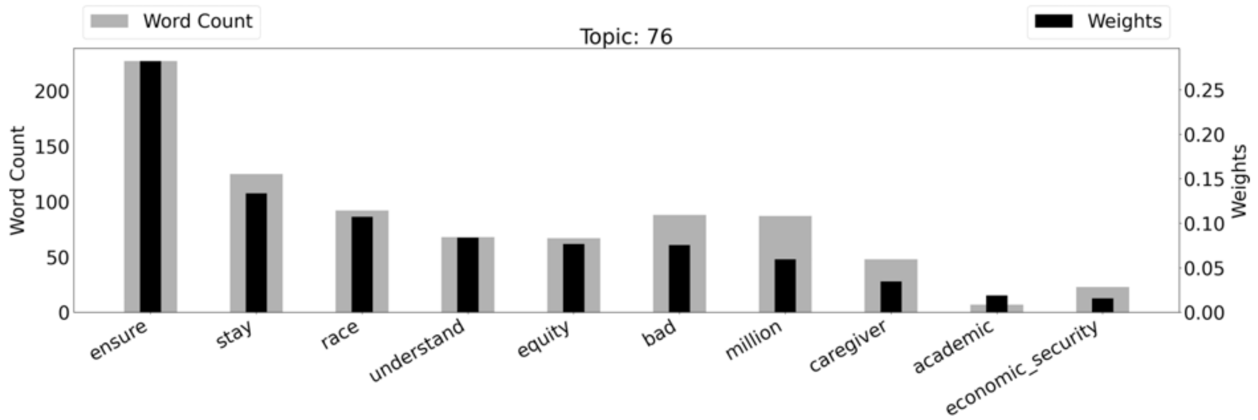
**Figure 2.** Topic 76 ("Advocacy") with weighted word counts.




Another tweet topic that increased by 31.53% in 2020 versus 2019 centered on health equity. This topic (assigned topic 49) included stories ranging from C-section problems to celebrations of midwives and doulas to posts advocating for policies for maternal health. Figure 3 is a graph of the weighted word counts and top words within this topic.

Topic 49, in contrast to topic 76, was more focused: this topic focused on equity and rights within health care. The word "right" that appeared so heavily both in the word count and as a weighted word, appeared in tweets advocating for the rights of Black women that have historically been, and still are, neglected in health care. A word cloud visualizing topic 49 can also be found in Multimedia Appendix 4.

Here are some example tweets within this topic on health equity:

> *I had "fluid overload" from the c-section and was drowning . . .There's warnings everywhere saying you can experience this after a c-section, and no one at the hospital told me. #blackmaternalhealth https://twitter.com/Essence/status/1103766054566805504*
>
> *…*
>
> *Happy #InternationalDayoftheMidwife! We salute and honor the historical contributions and traditions of #BlackMidwives and #BlackBirthWorkers on the front lines of #BlackMaternalHealth. #BlackMamasMatter pic.twitter.com/waA67xNBJM*

In contrast, in 2020 versus 2019, tweet topics on Medicaid and medical coverage decreased by 27.73% and discussions about creating space for Black women decreased by just under 30%.

Topic 93, which focuses on Medicaid and medical coverage, included tweets about protecting care, the Affordable Care Act, and equal pay. The topic was focused; the words "coverage," "medicaid," and affordable" and the hashtag "#protectourcare" featured heavily. Figure 4 is a graph of the weighted word counts and top words within this topic. Topic 93 is also visualized in a word cloud in Multimedia Appendix 5.

**Figure 3.** Topic 49 ("Health Equity") with weighted word counts.

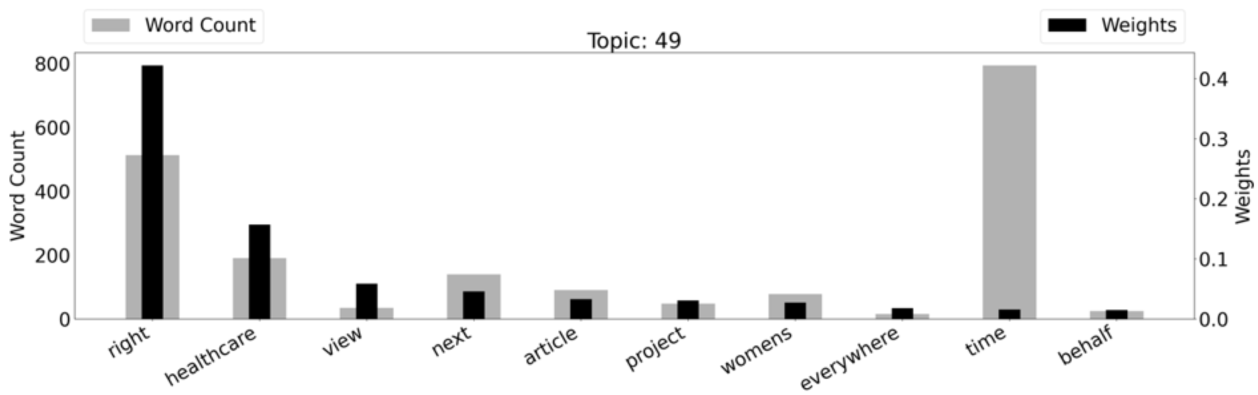





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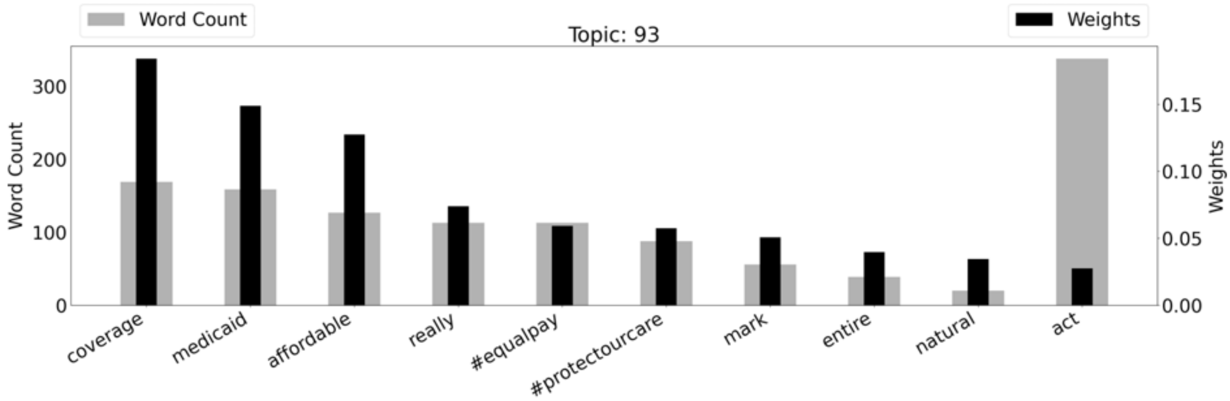
**Figure 4.** Topic 93 (“Medicaid and Medical Coverage”) with weighted word counts.



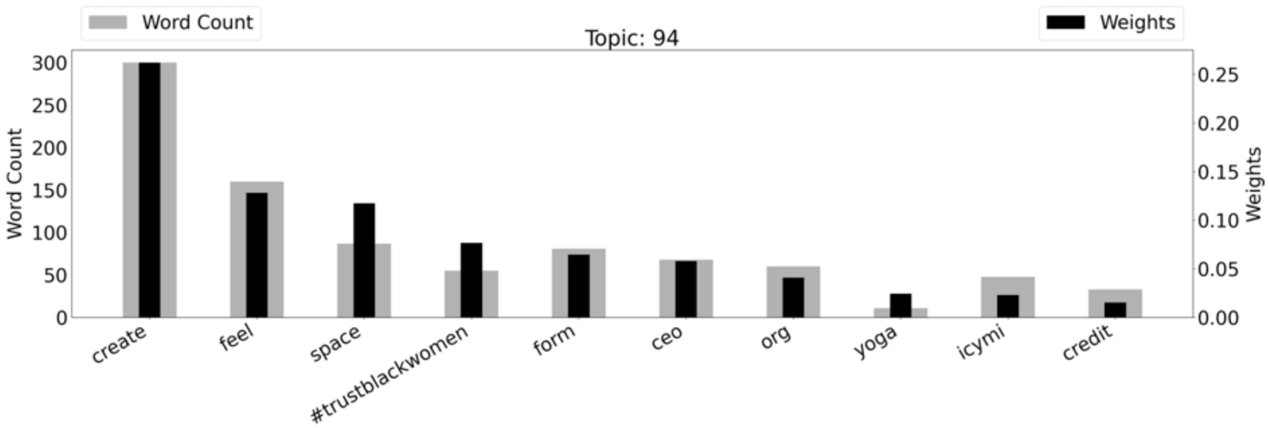

Several relevant tweet examples that were included in this topic are as follows:

> *MOMMIES Act Seeks To Expand Medicaid Coverage For Pregnant Women*
>
> *https://www.essence.com/news/mommies-act-cory-booker-ayanna-pressley-medicaid/?utm_source=twitter.com&utm_medium=social&utm_campaign=social-button-sharing … via @ESSENCE #MaternalJustice*
>
> *#PaycheckFairness Act is part of the solution for #EqualPay, but we also need #paidsickdays,*
>
> *#paidleave, affordable #childcare & #raisethewage to close the wage gap. #EqualPayDay*

The decline in how much Black maternal health advocates talked about Medicaid and coverage in 2020 versus 2019 suggests that the topic was of more central importance before the pandemic. As the pandemic began, Black maternal health advocates began focusing more on health equity and advocacy more broadly.

The “Creating Space” topic included discussions around giving Black women credit for the work they do, creating inclusive spaces, and trusting Black women. This topic decreased by almost 30% in 2020 compared to the same period in 2019. Figure 5 is a graph of the weighted word counts and top words within this topic. Topic 94 is also visualized in a word cloud in Multimedia Appendix 6.

**Figure 5.** Topic 94 (“Creating Space”) with weighted word counts.




A few example tweets for this topic include:

> *We're live! #MissionHearHer #TrustBlackWomen #StandWithBlackWomen @missionprtnrs https://www.facebook.com/BlackWomensRJ/videos/409856806524798/ …*
>
> *#BlackMaternalHealth Policy should center solutions with supporting resources for those actually doing the work in black communities across the nation, including our Kindred Partner members! #BMHCSummit #BMHCaucus #BlackMamasMatter #TrustBlackWomen #MaternalJustice https://twitter.com/BlkMamasMatter/status/1118650545869393922*

Due to the decline in Black maternal health advocates sharing information about supporting and trusting Black women, this topic suggests that Black maternal health advocates need to focus more on health equity within health care systems and reproductive justice. Because our topic models were created with the same corpus, over 20,000 tweets in total, each topic included both the 2019 data set and the 2020 data set. Tweets were removed when they appeared from accounts that were only active in 2019 versus 2020 or vice versa, as our goal was to understand how discourse changed, if at all, in the early pandemic months versus the same set of time within 2019, before the pandemic. Thus, our results show that there was an increase in tweets about reproductive justice and advocacy and a significant decrease in conversations on medical coverage and



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Medicaid; there was also a significant decrease in posts devoted to trusting Black women and creating inclusive spaces, although that support for Black women was focused on other solutions, such as economic policies (eg, paid family leave and support for Black women's bodies).

## Discussion

### Principal Findings

Our findings are consistent with previous studies showing the importance of using Twitter to capture authentic expressions of experiences with health care and other aspects of life by minoritized groups in the United States [23] and the increased use of Twitter by Blacks [15]. We found this particular social media platform useful for assessing public discourse around Black maternal health issues in the context of COVID-19.

The discourse we studied on Twitter is congruent with national and local efforts that align with the US Department of Health and Human Services' objective of reducing maternal mortality by 50% in the next 5 years [24]. Specific examples of recent legislative efforts include S.916/ H.R. 1897, the Mothers and Offspring Mortality and Morbidity Awareness Act (the MOMMA's Act), re-introduced by Congresswoman Robin D. Kelly from Illinois to the 117th Congress [25]. The MOMMA's Act seeks to improve and standardize reporting on maternal health care issues, in addition to reducing implicit bias and improving postpartum care. The Connected Maternal Online Monitoring Act -Mom Act (S.801) would protect the bodies of all mothers through remote monitoring of physiologic processes, such as blood pressure and blood glucose, as part of an expansion of telehealth efforts for pregnant and postpartum women [26]. In addition, the Family and Medical Insurance Leave (FAMILY Act) would result in a national insurance fund to cover 12 weeks per year to support the postpartum period as well as other health conditions [27]. Specific policies that would be helpful for Black mothers are being developed or waiting for movement in Congress or state legislatures. Those efforts, and their heightened importance due to COVID-19, are reflected in our results concerning advocacy and health equity.

We were less likely, however, to find legislation that focused specifically on the importance of having Black women at the forefront of efforts to ensure maternal justice exists. This is clearly a critical area of advocacy for Black maternal health in the United States, as only 5% of physicians are Black [28]. Moreover, there is some evidence to suggest that Black babies are more likely to thrive when they are cared for by Black physicians [29]. However, the extant literature highlights implicit bias in prenatal and postpartum care, as noted by 1 representative tweet:

> *There's a lot of interest in health equity, without an understanding of what health equity is. Let's fix that!*

Anyone who is interested in addressing the Black maternal health crisis in the United States must also gain a true understanding of the inequities that lead to the disparities between Black women and other racial and ethnic groups. This study highlights the importance of that research.

Our analysis is also important for showing the utility of Twitter as a platform for gaining insight into Black maternal health issues both in terms of messaging and as a tool for future advocacy efforts. First, a recent analysis by the Pew Research Center found that Blacks (45%) are more likely to use Twitter for political activism, such as "encouraging others to take action about issues important to them," compared to Whites (30%) and Hispanics (33%) [30]. Consequently, although a higher percentage of US adults use Facebook (69%) and YouTube (81%) compared to Twitter (23%), Blacks are more likely to not only use Twitter (29%) but also use it to advocate for political and social issues [30,31]. Additionally, increased use of Twitter for advocacy has been tied to recent current events of concern among Blacks in the United States, such the killing of unarmed Black men (eg, George Floyd) [30,31]. Twitter has also been the social media platform of choice to advocate for #AmberIsaac, a Black woman who died following childbirth after high-risk symptoms were possibly missed due to COVID-19 restrictions on in-person prenatal care visits [32]. Thus, our use of Twitter to examine public discourse around legislative and policy efforts supporting Black maternal health in the United States is warranted by the literature. Notwithstanding, our analysis showed that Twitter is used primarily to share and amplify messages but less for articulating specific steps to move legislation forward. For example, although members of Congress [33] have some presence on Twitter and other social media platforms, few tweets specifically encouraged contacting or engaging members of Congress about advocating for specific policies or legislation. Future studies could use findings from Twitter content on advocacy to engage in more explicit efforts to push for policy changes, in addition to sharing messages or information about events of interest.

During a period with limited opportunity for primary data collection, Twitter served as a tool for identifying organizations engaged in advocacy efforts for Black women, and the topics identified were aligned with the extant literature, providing a timely snapshot for areas of focus. Future work could also use Twitter to identify issues of importance for Black maternal health and use the platform to garner support for specific legislative efforts and policies at federal, state, and local levels.

### Limitations

As with any social media platform, Twitter has population bias. A study by Ruths and Pfeffer [34] noted that there are sampling biases in every social media platform: "Instagram is 'especially appealing to adults aged 18-29, African-American, Latinos, women, urban residents' whereas Pinterest is dominated by females, age between 25-34, with an average annual household income of $100,000" [34]. The Pew Research Center notes that Twitter users tend to be younger and have higher incomes than people in the United States overall, although the race and ethnicity of Twitter users largely mirrors that of all US adults [35]. Additionally, it is important to note that the tweets we analyzed come from a specific subset of Twitter users who are primarily Black women involved in advocacy efforts for Black maternal health. Thus, although Twitter has population bias, we gathered tweets specifically by Black women and organizations in support of Black women in order to yield a relevant data set for our study. Additionally, Jules et al [36]


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note ethical issues in collecting Twitter data, 1 of which is that users have not necessarily given informed consent for researchers to gather their tweets and analyze them [36]. In response, we anonymized our data set to protect users.

It is also important to note that the results of this analysis are not generalizable due to the small sample size of posts reviewed (approximately 10%). As such, our results are mostly exploratory and should be followed up with further study.

### Conclusion

The disparities present in maternal mortality between Black and White women have persisted for the past 100 years [37]. Non-Hispanic Black women suffer from the highest rates of 22 (88%) of 25 severe maternal morbidity indicators, according to the CDC [37], and non-Hispanic Black infants have the highest rates of infant mortality and preterm birth in the United States, being more than twice as likely to die during their first year of life compared with their White counterparts [38]. The entrenched US Black maternal and infant health crisis has been heightened due to the disproportionate impact of COVID-19 on Blacks and other minoritized groups, with higher prevalence and mortality rates due to SARS-CoV-2 compared to Whites [7]. Prior to the pandemic, several efforts were underway at the federal, state, and local levels to address the maternal and infant health crisis [11-14]. However, at the time that this study was conducted, there was no other systematic social media analysis of how Black maternal health advocacy issues were impacted by the pandemic. In our Twitter analysis, we found that discussion of issues of reproductive justice, equity, and advocacy increased considerably between 2019 and 2020. The high presence of these important issues in our topic models further confirms the ongoing nature of the Black maternal health crisis. Interestingly, issues around health care coverage, such as Medicaid or medical coverage in general, decreased, which may be due to the possibility that simply having access to care does not eliminate adverse maternal and birth outcomes for Black Americans. Rather, addressing issues around implicit bias and social determinants of health may play a greater role in mitigating the Black maternal health crisis. Our analysis is important for thinking about effective national policies that may improve the long-term health and safety of Black women and their children.

## Acknowledgments

We appreciate the efforts of the organizations and individuals advocating for equitable care for Black mothers.

## Conflicts of Interest

None declared.

Multimedia Appendix 1
Topic models and results from k-means clustering.
[DOCX File , 312 KB - infodemiology_v2i1e30885_app1.docx ]

Multimedia Appendix 2
Topic 59 (“Reproductive Justice”) visualized in a word cloud.
[PNG File , 237 KB - infodemiology_v2i1e30885_app2.png ]

Multimedia Appendix 3
Topic 76 (“Advocacy”) visualized in a word cloud.
[PNG File , 125 KB - infodemiology_v2i1e30885_app3.png ]

Multimedia Appendix 4
Topic 49 (“Health Equity”) visualized in a word cloud.
[PNG File , 228 KB - infodemiology_v2i1e30885_app4.png ]

Multimedia Appendix 5
Topic 93 (“Medicaid and Medical Coverage”) word cloud.
[PNG File , 237 KB - infodemiology_v2i1e30885_app5.png ]

Multimedia Appendix 6
Topic 94 (“Creating Space”) visualized in a word cloud.
[PNG File , 245 KB - infodemiology_v2i1e30885_app6.png ]

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## Abbreviations

**CDC:** Centers for Disease Control and Prevention
**MOMMA's Act:** Mothers and Offspring Mortality and Morbidity Awareness Act

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Original Paper

# Integrating Google Trends Search Engine Query Data Into Adult Emergency Department Volume Forecasting: Infodemiology Study

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## Abstract

**Background:** The search for health information from web-based resources raises opportunities to inform the service operations of health care systems. Google Trends search query data have been used to study public health topics, such as seasonal influenza, suicide, and prescription drug abuse; however, there is a paucity of literature using Google Trends data to improve emergency department patient-volume forecasting.

**Objective:** We assessed the ability of Google Trends search query data to improve the performance of adult emergency department daily volume prediction models.

**Methods:** Google Trends search query data related to chief complaints and health care facilities were collected from Chicago, Illinois (July 2015 to June 2017). We calculated correlations between Google Trends search query data and emergency department daily patient volumes from a tertiary care adult hospital in Chicago. A baseline multiple linear regression model of emergency department daily volume with traditional predictors was augmented with Google Trends search query data; model performance was measured using mean absolute error and mean absolute percentage error.

**Results:** There were substantial correlations between emergency department daily volume and Google Trends "hospital" ($r$=0.54), combined terms ($r$=0.50), and "Northwestern Memorial Hospital" ($r$=0.34) search query data. The final Google Trends data–augmented model included the predictors Combined 3-day moving average and Hospital 3-day moving average and performed better (mean absolute percentage error 6.42%) than the final baseline model (mean absolute percentage error 6.67%)—an improvement of 3.1%.

**Conclusions:** The incorporation of Google Trends search query data into an adult tertiary care hospital emergency department daily volume prediction model modestly improved model performance. Further development of advanced models with comprehensive search query terms and complementary data sources may improve prediction performance and could be an avenue for further research.

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**KEYWORDS**

infodemiology; patient volume forecasting; emergency medicine; digital health; Google Trends; infoveillance; social media; prediction models; emergency department



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## Introduction

### Background

Internet-based technologies and web-based services have facilitated new ways of seeking and communicating health-related information. A valuable aspect of web-based information transactions is the record of communication itself, which, in aggregate, may reflect population-level behaviors. For example, researchers have used search engine queries and volumes, such as Google Trends, to attempt to recognize population behavior–based patterns. Examples of this research are found in many industries, such as finance [1] and criminology [2].

The emerging field of infodemiology is defined by Eysenbach [3] as "the science of distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy." The major debut application of infodemiology within the health care industry involved monitoring the seasonal emergence and peak of influenza with Google Flu Trends [4], which initially outperformed the extant gold standard FluNet from the Centers for Disease Control and Prevention; however, Google Flu Trends later suffered from poor predictions attributed to model overfitting, among other reasons [5].

The field of infodemiology has grown substantially in the past decade, in terms of disease applications and data sources. In early infodemiology research, the majority of papers involved the study of influenza; more recent reviews [6,7] detail an expanded scope of subject matter, such as influenza, multiple sclerosis, suicide, prescription drug abuse, and e-cigarettes, and the most common data sources included Twitter (45%), Google (24.6%), other websites (13.9%), blogs (10.1%), and Facebook (8.9%). In addition to research applications, one review [8] described the following practical applications of infodemiology by health care organizations: infoveillance, dissemination of health information, misinformation management, and health interventions. Most recently, during the COVID-19 pandemic, researchers have used infodemiology to study public opinion toward COVID-19 vaccines [9] and public health containment measures [10], capture the most frequently asked questions regarding COVID-19 vaccines [11], augment the performance of conventional prediction models for COVID-19 infections [12], and characterize the partisan differences of US legislators in the initial phase of this pandemic [13].

### Prior Work

In infodemiology, data reflecting the use of the internet in seeking health information have been used to improve emergency department patient volume predictions and optimize emergency department resource allocation [14-16]. A Swedish study [14] of emergency department patient volume found that the use of a popular public health website's traffic volume as a predictor yielded an impressive mean absolute percentage error (MAPE) of 4.8%, which demonstrated that web-based information seeking behaviors can be a useful leading indicator of acute care encounters [14]. A study in the United States found that 86% of participants, who had been recruited from an emergency department waiting room, utilized Google search in the week prior to their emergency department visit; 15% of their searches had been health-related and two-thirds of these searches had been either related to their current chief complaint or for information related to the emergency department and hospital [15]. In addition, internet health information–seeking behavior has been described as a method for patients to prepare questions for upcoming medical appointments with health care providers [16].

Prior studies have used Google Trends search query data to forecast influenza-like illness cases [17] and pediatric daily volumes [18]; however, no studies have evaluated the ability of Google Trends search query data related to chief complaints and health care facilities to predict the overall daily volume in an adult emergency department.

### Study Goal

The ability to predict deviations in typical weekly patterns of emergency department patient volumes could provide emergency department administrators with a valuable tool to optimize resource allocation. We explored the use of Google Trends search query data of chief complaints and health care facilities to improve the prediction performance of adult emergency department daily patient volume.

## Methods

### Emergency Department Encounter Data

Emergency department daily patient volume data were collected from Northwestern Memorial Hospital, a tertiary care adult center located in Chicago, Illinois with an annual volume of 88,000 patient encounters. Data were collected retrospectively from the institution's databases and included 159,769 emergency department patient encounters that occurred in the period from July 1, 2015 to June 30, 2017. These data included patient arrival date and time, and Emergency Severity Index (levels 1 through 5 in decreasing order of case urgency) [19]. For analysis, data were aggregated by date and Emergency Severity Index.

### Environmental Data

To develop prediction models to be used as a point of reference, we used calendar day (ie, day of week, month) and weather-related variables to derive a traditional emergency department forecasting model. Daily weather data were obtained from the National Centers for Environmental Information and included average temperature, maximum temperature, minimum temperature, precipitation (categorical), and snow (categorical) [20].

### Google Trends Data

#### *Data Collection*

Google Trends search query data were accessed from the Google Trends API service on June 19, 2018 [21].

#### *Keyword Selection*

Based on clinical experience and expert opinion, we generated a list of Google Trends terms that would be relevant to an individual seeking health information (ie, terms that would be


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part of their search engine query) prior to a health care encounter. The terms, which included “emergency department,” “Northwestern Memorial Hospital,” “hospital,” “WebMD,” “chest pain,” “back pain,” “abdominal pain,” “stomach pain,” “side pain,” “fever,” “cough,” “shortness of breath,” “headache,” “numbness,” “weakness,” “blood urine,” and “blood stool,” corresponded to 3 broad categories: health care facility, reputable website, and general chief complaints encountered in the emergency department.

### *Region and Period Selection*

Google Trends search query data were limited to the Chicago metropolitan area by constraining the API request to the Chicago Nielsen Designated Market Area (code 602) and to daily relative search frequencies from July 1, 2015 to June 30, 2017.

### *Feature Engineering*

To engineer a feature that reflected a more precise region around the study hospital, we derived an independent variable: the search query ratio of “Northwestern Memorial Hospital” over “hospital.” We also created a combined variable, which aggregated all Google Trends search query data into a single measure. We performed the following transformations on Google Trends search query variables to explore temporal associations and to engineer features that smooth out short-term fluctuations: 1-day lag, 1-day percentage change, 3-day moving average, and 7-day moving average. After these transformations, a total of 85 Google Trends search query terms were included in the candidate set of predictor variables. Given the difference in scales, Google Trends search query data were standardized before their inclusion as predictor variables in the regression analysis.

### Exploratory and Correlational Analysis

We performed visual analysis of Google Trends search query data and calculated Pearson correlation coefficients between emergency department daily volume and Google Trends variables.

### Model Development and Evaluation

We utilized multiple linear regression, one of the most common methods for emergency department patient volume forecasting and for predictive modeling with Google Trends search query data [22], to create separate predictive models for overall emergency department patient volume and for patient volume by Emergency Severity Index (ie, 1 through 5).

We also created a baseline model with traditional variables, such as calendar day and weather, similar to prior literature [23]. Predictor variable selection was performed using recursive feature elimination, which is a type of backward selection algorithm that offers a systematic approach to variable selection by constructing multiple models with permutations of predictor variables and selecting a parsimonious model that optimizes a prediction performance metric [24]. To evaluate the ability of Google Trends search query data to improve forecasting performance, we augmented the baseline model with Google Trends variables and used recursive feature elimination to identify the highest impact predictor variables.

Models were trained using 10-fold cross-validation, and model performance was assessed using mean absolute error (MAE) and MAPE of prediction values in relation to actual values. Analysis was conducted using R software (version 4.1.0; The R Project) and utilized the caret package (version 6.0-88; Max Kuhn) [25].

### Ethics

This study was considered exempt from review by the Northwestern Memorial Hospital Institutional Review Board because emergency department data were deidentified and contained no protected health information.

## Results

### Exploratory Analysis

The median total emergency department daily volume over this period was 242 patients per day (range 152-305 patients per day; Emergency Severity Index 1: 4043/159,769, 2.5%; Emergency Severity Index 2: 63,611/159,769, 39.8%; Emergency Severity Index 3: 64,091/159,769, 40.1%; Emergency Severity Index 4: 23,773/159,769, 15.0%; Emergency Severity Index 5: 2300/159,769, 1.4%; Emergency Severity Index not available: 1951/159,769, 1.2%).

The daily Google Trends relative frequency for most terms demonstrated properties of a normal distribution, with the exception of those for “shortness of breath,” “hospital,” or for all terms combined (Figure 1). The relative search frequencies for “hospital” and all terms combined exhibited a bimodal distribution; the bimodal distribution for “hospital” data was largely explained by weekday and weekend differences (Figure 2). A similar pattern was evident in emergency department daily volume (Figure 3). Two terms, “blood stool” and “blood urine,” did not yield any relative frequency data and, therefore, were excluded from subsequent analyses. When search terms occur infrequently, Google does not share these data in order to safeguard user privacy.

Visual analysis of Google Trends search query data time series demonstrated 3 patterns (Figure 4): seasonal, for example, “hospital” and “fever” data exhibited weekly and annual periodicity, respectively; a declining trend, such as that for “WebMD, ” and random (ie, white noise), such as that exhibited by “Northwestern Memorial Hospital” and “emergency department.”



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**Figure 1.** Histograms of candidate Google Trends search query data. N: count; NMH: Northwestern Memorial Hospital.

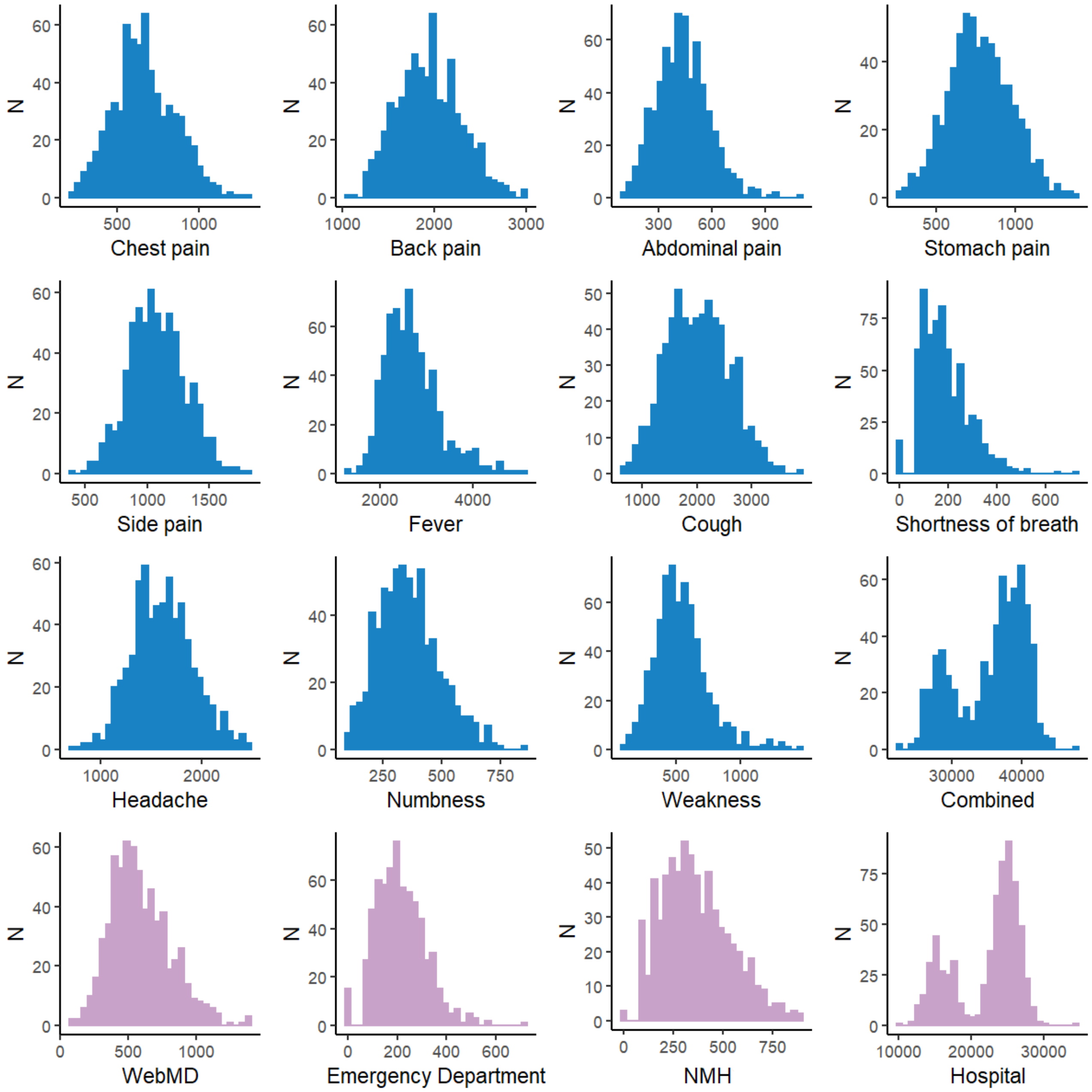




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**Figure 2.** Density plot of Google Trends “hospital” data.

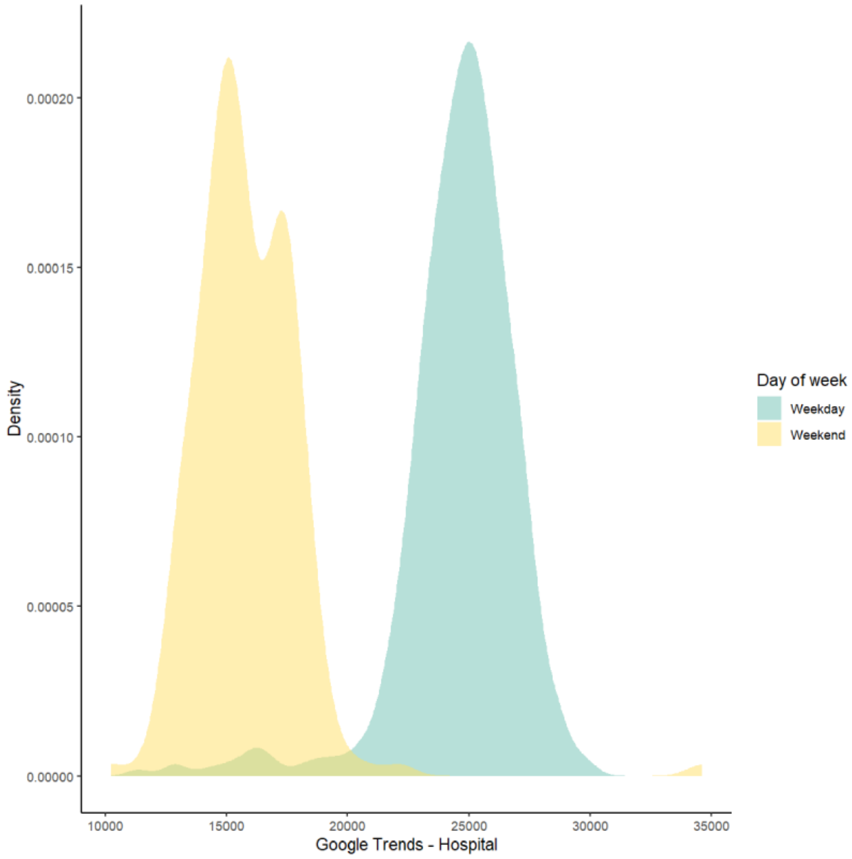


**Figure 3.** Density plot of emergency department (ED) daily volume.

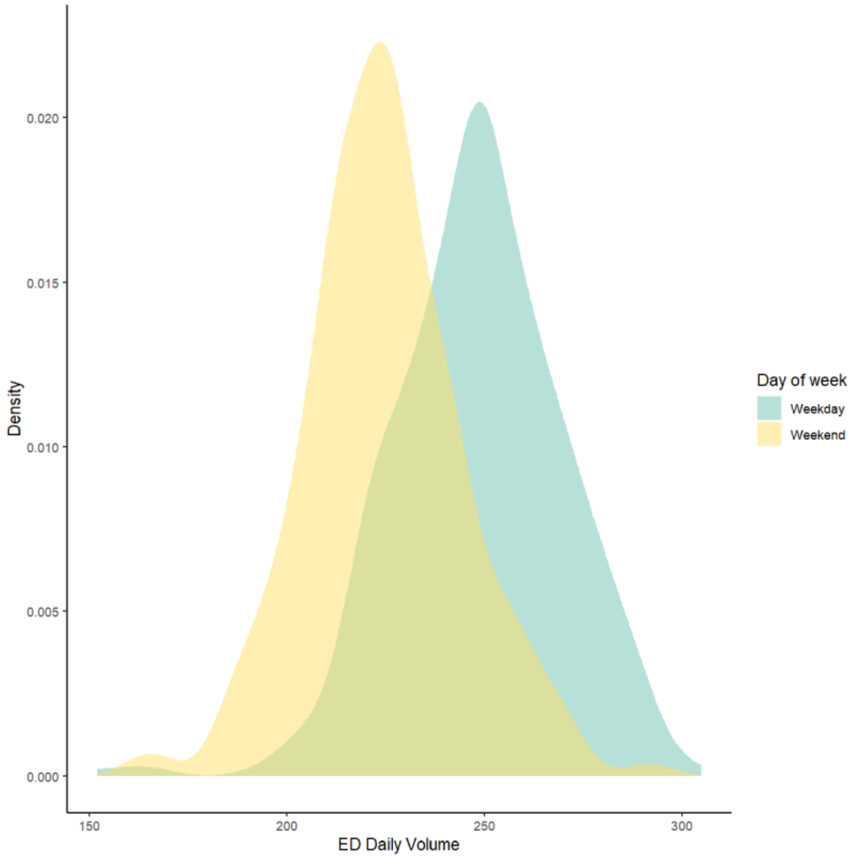




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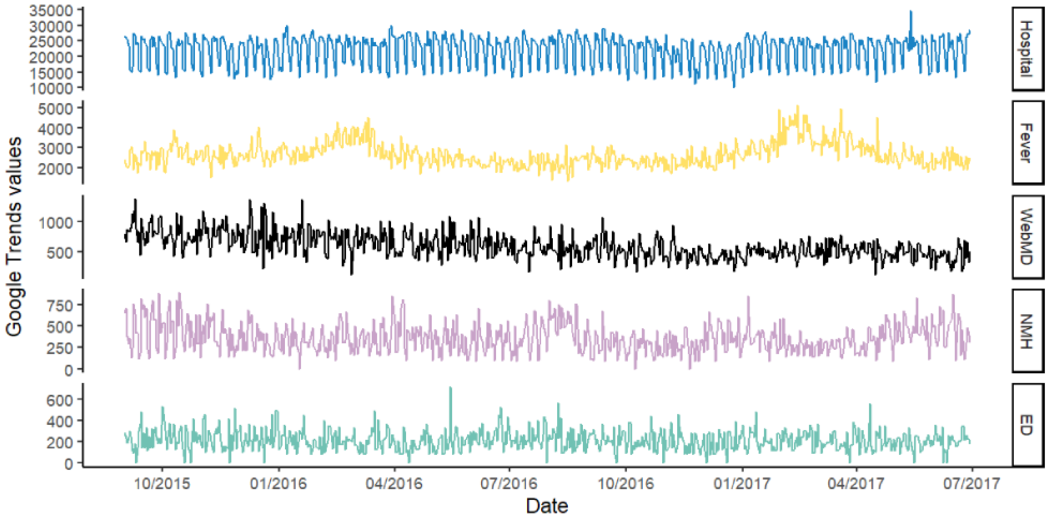
**Figure 4.** Google Trends search query data time series for the terms "hospital" (blue), "fever" (yellow), "WebMD" (black), "Northwestern Memorial Hospital" (NMH, pink), "emergency department" (ED, green).




## Correlation Analysis

Emergency department daily volume data were moderately correlated with "hospital" ($r$=0.54, $P$<.001) and combined ($r$=0.50, $P$<.001) Google Trends search query data and were weakly correlated with "Northwestern Memorial Hospital" ($r$=0.34, $P$<.001) Google Trends search query data (Table 1).

**Table 1.** Pearson correlations between Google Trends data and emergency department daily volume.

| Google Trends | None | | 1-day lag | | 1-day percentage change | | 3-day moving average | | 7-day moving average | |
|---|---|---|---|---|---|---|---|---|---|---|
| | $r$ | $P$ value | $r$ | $P$ value | $r$ | $P$ value | $r$ | $P$ value | $r$ | $P$ value |
| Chest pain | 0.00 | .98 | 0.01 | .89 | 0.00 | .91 | 0.05 | .18 | 0.05 | .25 |
| Back pain | 0.11 | .005 | 0.16 | <.001 | –0.04 | .31 | 0.05 | .20 | 0.09 | .02 |
| Abdominal pain | –0.04 | .26 | 0.00 | .92 | –0.01 | .77 | –0.02 | .63 | –0.02 | .53 |
| Stomach pain | 0.00 | .95 | 0.04 | .32 | –0.03 | .38 | 0.03 | .40 | 0.04 | .30 |
| Side pain | 0.05 | .17 | 0.01 | .86 | 0.01 | .81 | 0.05 | .22 | 0.06 | .16 |
| Fever | –0.06 | .10 | –0.03 | .48 | –0.02 | .56 | 0.03 | .49 | 0.05 | .20 |
| Cough | –0.21 | <.001 | –0.18 | <.001 | –0.01 | .89 | –0.03 | .44 | 0.01 | .89 |
| Shortness of breath | 0.02 | .54 | 0.02 | .54 | 0.03 | .44 | 0.03 | .42 | 0.02 | .70 |
| Headache | –0.04 | .27 | 0.05 | .17 | –0.08 | .04 | –0.05 | .21 | –0.01 | .76 |
| Numbness | 0.15 | <.001 | 0.05 | .19 | 0.05 | .17 | 0.11 | .003 | 0.09 | .02 |
| Weakness | 0.11 | .004 | 0.10 | .007 | 0.00 | .95 | 0.09 | .03 | 0.07 | .07 |
| Combined | 0.50 | <.001 | –0.04 | .35 | 0.49 | <.001 | 0.52 | <.001 | 0.52 | <.001 |
| WebMD | 0.10 | .007 | 0.09 | .03 | 0.02 | .53 | 0.11 | .006 | 0.09 | .02 |
| Emergency department | 0.02 | .61 | 0.01 | .81 | –0.05 | .19 | –0.04 | .30 | –0.03 | .43 |
| Hospital | 0.54 | <.001 | –0.04 | .27 | 0.51 | <.001 | 0.53 | <.001 | 0.53 | <.001 |
| NMH[a] | 0.34 | <.001 | 0.02 | .53 | 0.30 | <.001 | 0.34 | <.001 | 0.30 | <.001 |
| NMH share | 0.12 | .002 | 0.04 | .25 | 0.07 | .06 | 0.09 | .02 | 0.08 | .048 |

[a]NMH: Northwestern Memorial Hospital.



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The transformations of Google Trends search query data to explore lagging or leading indicators did not uncover hidden correlations with emergency department daily volume.

## Predictive Model Development

The application of recursive feature elimination to the candidate set of traditional variables resulted in an optimal model that utilized the Day-of-week predictor; with Sunday as the reference level, this traditional model is characterized by decreasing magnitudes of regression coefficients as the week progresses from Monday to Sunday (Table 2).

**Table 2.** Regression coefficients for traditional and Google Trend data–augmented linear regression models for total emergency department daily volume.

| Variable | Traditional, beta (95% CI) | Google Trends, beta (95% CI) |
|---|---|---|
| Intercept | 223 (219, 227) | 242 (240, 243) |
| **Day of week** | | |
| Sunday | Reference | Reference |
| Monday | 40 (35, 46) | —[a] |
| Tuesday | 27 (22, 33) | — |
| Wednesday | 18 (12, 23) | — |
| Thursday | 17 (11, 23) | — |
| Friday | 25 (19, 30) | — |
| Saturday | 3.1 (–2.5, 8.7) | — |
| Northwestern Memorial Hospital | — | 3.5 (1.8, 5.1) |
| Hospital 1-day percentage change | — | 5.5 (–4.0, 15) |
| Hospital 3-day moving average | — | 17 (4.4, 29) |
| Combined 1-day percentage change | — | 1.6 (–8.3, 11) |
| Combined 3-day moving average | — | –11 (–24, 1.7) |

[a]The predictor was not included in the model.

For the model augmented with Google Trends predictor variables, the application of recursive feature elimination yielded a model that excluded *Day of week* and contained the *Northwestern Memorial Hospital*, *Hospital 1-day percentage change*, *Hospital 3-day moving average*, and *Combined 1-day percentage change* Google Trends predictors (Table 2). When comparing the traditional and Google Trends data–augmented models, the *y*-axis intercepts were largely similar, although the *y*-axis intercept of the Google Trends data–augmented model was identical to the median emergency department daily volume of this data set.

For emergency department daily volume predictions by Emergency Severity Index level, recursive feature elimination produced models that utilized *Combined 3-day moving average* for every level and *Hospital 3-day moving average* for level 2 (Table 3).



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**Table 3.** Regression coefficients for traditional and Google Trends data–augmented linear regression models for daily volume by Emergency Severity Index.

| Model and variable | ESI[a] 1, beta (95% CI) | ESI 2, beta (95% CI) | ESI 3, beta (95% CI) | ESI 4, beta (95% CI) | ESI 5, beta (95% CI) |
|---|---|---|---|---|---|
| **Traditional model** | | | | | |
| Intercept | 5.9 (5.3, 6.5) | 83 (80, 85) | 93 (91, 95) | 36 (34, 37) | 3.3 (2.9, 3.7) |
| **Day of week** | | | | | |
| Sunday | Reference | Reference | Reference | Reference | Reference |
| Monday | 1.0 (0.20, 1.9) | 24 (21, 28) | 12 (8.4, 15) | 2.2 (–0.11, 4.5) | 0.44 (–0.16, 1.0) |
| Tuesday | –0.08 (–0.92, 0.75) | 19 (16, 23) | 6.9 (3.6, 10) | –0.40 (–2.7, 1.9) | 0.30 (–0.30, 0.90) |
| Wednesday | 0.46 (–0.37, 1.3) | 16 (12, 20) | 2.4 (–0.90, 5.7) | –1.1 (–3.4, 1.3) | 0.21 (–0.39, 0.81) |
| Thursday | 0.06 (–0.78, 0.90) | 15 (11, 19) | 2.8 (–0.53, 6.1) | –1.2 (–3.5, 1.1) | 0.38 (–0.22, 1.0) |
| Friday | 0.29 (–0.55, 1.1) | 19 (15, 23) | 4.7 (1.4, 8.0) | 0.30 (–2.0, 2.6) | 0.27 (–0.33, 0.88) |
| Saturday | –0.30 (–1.1, 0.54) | 1.8 (–1.8, 5.4) | –0.62 (–3.9, 2.7) | 1.7 (–.059, 4.1) | –0.24 (–0.85, 0.36) |
| **Augmented model** | | | | | |
| Intercept | 6.1 (5.9, 6.3) | 96 (95, 97) | 97 (96, 98) | 36 (35, 37) | 3.5 (3.3, 3.6) |
| Combined 3-day moving average | 0.30 (0.08, 0.53) | –7.0 (–12, –1.6) | 3.8 (2.9, 4.7) | 0.33 (–0.30, 1.0) | 0.18 (0.01, 0.34) |
| Hospital 3-day moving average | —[b] | 15 (9.2, 20) | — | — | — |

[a]ESI: Emergency Severity Index.

[b]The predictor was not included in the model.

### Model Performance

We observed that Google Trends data–augmented models generally had superior prediction performance compared to the traditional model, when based on MAE; however, these improvements were minimal (Table 4).

**Table 4.** Predictive performance of total and Emergency Severity Index daily volume for traditional and Google Trends data–augmented models.

| Model | Traditional model, mean absolute error[a] | Augmented model, mean absolute error | Change (%) |
|---|---|---|---|
| All visits | 15.69 | 15.21 | –3.1 |
| **Emergency Severity Index** | | | |
| 1 | 2.52 | 2.41 | –4.7 |
| 2 | 10.37 | 10.66 | 2.8 |
| 3 | 9.55 | 9.12 | –4.5 |
| 4 | 6.93 | 6.85 | –1.2 |
| 5 | 1.80 | 1.74 | –3.6 |

[a]In units of patients/day.

The MAPE of the traditional model was 6.67%, and the MAPE of the Google Trends data–augmented model was 6.42%; MAPE was not calculated for models by Emergency Severity Index since they contained records with 0 daily volume, which would produce an undefined result (ie, the denominator would have been 0 in these instances).

## Discussion

### Principal Results

The goal of this study was to evaluate the potential of Google Trends search query data of healthcare facilities and chief complaints to improve the prediction performance of ED daily volume of a large-volume, tertiary-care, adult hospital. The use of Google Trends search query data to forecast emergency department daily volume resulted in a marginal improvement (MAE 3.1%) in prediction performance compared to that of a traditional prediction model. This is a small but notable improvement; when one considers that the original Google Flu Trends model included data from a set of 45 unique search queries, the ability of this study's narrow list of Google Trends terms to produce forecast results similar to traditional models highlights the potential for this alternative real-time data source to be honed further with more advanced models and a more expansive set of Google Trends term candidates [4]. Alternatively, one may conclude that the prediction capabilities



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of traditional and Google Trends data–augmented models were roughly similar. The finding that Google Trends search query data alone reproduced similar predictions to those made with conventional calendar day variables demonstrates the utility of Google Trends search query data in signaling health information–seeking behavior from prospective emergency department patients.

A notable strength of this study was the use of daily emergency department encounter data. A common obstacle that infodemiology researchers face is the lack of accessible, high-frequency, and recent hospital data, which constrains their ability to leverage the real-time and high-volume attributes of Google Trends and other social media data sources (ie, big data). As more and more collaborations leverage health care organization databases for service operations data, researchers will accelerate the development of nowcasting services that have the potential to inform and optimize service operations decisions. For example, a robust nowcasting service for emergency department daily volumes could provide hospital administrators with advanced notice of impending emergency department overcrowding and trigger the coordination of earlier mitigating responses throughout the hospital.

Unexpectedly, model coefficients for the *Combined 3-day moving average* variable were negative in the Google Trends data–augmented models of total volume (β=–11.0, 95% CI –24 to 1.7) and Emergency Severity Index 2 (β=–7.0, 95% CI –12 to –1.6). Negative coefficients may reflect that sicker patients present rapidly to emergency departments and do not have time to contemplate their illness and search the internet for information. Although, this negative coefficient result was not found in the Google Trends data–augmented Emergency Severity Index 1 model, we suspect this could be due to the small proportion of Emergency Severity Index 1 encounters that were available in this data set (4043/159,769, 2.5%). Analysis of a data set with more Emergency Severity Index 1 encounters could show results consistent with other Emergency Severity Index levels. Given that low-acuity encounters (Emergency Severity Index 3, 4, and 5) were the majority, with approximately 60% (95,861/159,769), the implication that individuals with high-acuity cases may not consult the internet prior to arriving at the emergency department would not have applied to a majority of emergency department encounters at this study site. Alternatively, these counterintuitive results of a negative coefficient value for the *Combined 3-day moving average* variable may be explained by the proximity of coefficients' 95% confidence intervals to 0; nonetheless, it is important to present these model outputs to highlight the unbiased results from a systematic approach to model generation. Altogether, these findings of illogical regression coefficients remind us of the need exercise caution with data mining exercises and predictive models that emphasize error metrics while overlooking meaningful causal relationships.

### Comparison With Prior Work

The traditional model using a day-of-week predictor in a prior study [18] that explored forecasting daily volume at an academic children's hospital emergency department in Boston had a larger error (MAPE 10.99%) and their Google Trends search query data–based model had a smaller improvement (MAPE 1.67%) than those found in our study (traditional day-of-week model: MAPE 6.67%; improvement: MAPE 3.1%). Although the reason for the differences in MAPE for models that employed day-of week predictors is not obvious, we hypothesize that the differences in the impact of Google Trends search query data could be due to a greater utilization of the internet to understand symptoms of an acute illness among adults compared to pediatric patients and their adult guardians. There may be a population subset whose health activity is better measured by internet and social media activity data such as in the case of suicide surveillance among 25- to 34-year-old adults in the United Kingdom [26].

### Limitations

There are several limitations that are important to consider. We only utilized the emergency department daily volume from a single hospital in Chicago, whereas the Google Trends search query data pertained to the entire metropolitan area; we may have failed to identify more meaningful predictive relationships between Google Trends search query data and emergency department daily volume since we did not include the metropolitan-wide emergency department daily volume data, nor could we identify Google Trends search queries that occurred within our study site's geographic service area.

Moreover, we only analyzed Google Trends search query data in English, which limits our ability to extrapolate these results to regions of the country where there may be greater segments of the population that use search engines in non-English languages.

Similar limitations exist in regions of the country that face barriers to internet access, such as rural areas, although a recent survey [27] found that the gap in home broadband internet between rural and nonrural homes has decreased from 16% to 7% and overall smartphone ownership has increased from 81% to 85% between 2019 to 2021; in addition, 72% of nonbroadband users reported the ability of smartphones to accomplish all desired internet tasks [27]. Therefore, as market penetration of home broadband and smartphone ownership increases, limitations due to barriers to the internet may become less prominent.

In addition, we did not attempt to predict emergency department daily volume by type of chief complaint (eg, cardiac, respiratory, neurologic). Given the difference in scale of the Google Trends search query data across types of chief complaints, future work should focus on predicting daily volumes of categories of chief complaints using an expanded set of symptom-specific Google Trends search query data.

Lastly, we only leveraged a single source of internet data, which may have only provided a glimpse into health information–seeking behaviors from prospective emergency department patients. Other data sources, such as news media and social media platforms could be incorporated [28,29]. While more resources would be required to leverage additional data sources for more complex and potentially more accurate prediction models of emergency department daily volumes, the ability for health care systems to anticipate increased demand


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for emergency department services would be valuable in terms of reduced health care expenses and improved patient experiences. For instance, the potential for health care systems to identify when and where low-acuity emergency department encounters may occur could guide the strategic expansion of clinic appointment availability and required advertisements to divert potential emergency department patients into less costly and more convenient venues of care.

It is worth discussing the ongoing debate regarding the ability of infodemiology data such as Google Trends search queries to reliably supplement or entirely replace traditional epidemiological data. While Google Trends search query data offers an enticing value proposition in providing insights into a population's internet health information–seeking behaviors in a cost-efficient manner compared with traditional epidemiology data-gathering processes, it is important to remain critical of this emerging source of population health data. In some instances, Google Trends search query data reasonably mirror traditional epidemiology data. For example, tobacco use search query data were well correlated with findings from Youth Risk Behaviors Surveillance System and National Survey on Drug Use and Health data in the United States [30], and Google Trends search query data for chest pain were found to be strongly correlated with hospital admission data for coronary heart disease from the US Centers for Disease Control and Prevention Atlas of Heart and Stroke Statistics [31]. More recently, it was also demonstrated that Google Trends COVID-19 symptom search query data were significantly correlated with new cases and deaths from this disease [32,33]. However, potential confounders such as media influence have been found to effect Google Trends data. For instance, correlations between Google Trends search query data for anosmia and ageusia and COVID-19 cases were inconsistent early in the COVID-19 pandemic, and Google Trends search query volumes showed a marked increase following the beginning of the media's coverage of these two prominent symptoms of COVID-19 [34]. In addition, COVID-19 Google Trends search query data from Europe were poorly correlated with COVID-19 epidemiological measures and were well correlated with the occurrence of pandemic-related press releases from the World Health Organization [35]. Overall, the ability to use Google Trends search query data for epidemiologic purposes remains an active area of inquiry, and these types of data must be used cautiously for such purposes.

## Conclusion

Emergency department daily volume prediction models augmented with Google Trends search query data performed similarly to baseline models utilizing traditional variables; error metrics demonstrated modest improvements in model accuracy for overall volume and nearly all Emergency Severity Index volumes. Our results suggest that even greater improvements in emergency department daily volume predictions can be attained with a more comprehensive set of Google Trends search query terms or the addition of complementary internet data sources such as social media.

The potential for these types of prediction models to leverage near real-time information to capture health information–seeking behavior preceding emergency department encounters and to be used as a tool for health care system administrators to better anticipate patient demands and optimize resource allocation warrants further investigation.

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## Conflicts of Interest

None declared.

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## Abbreviations

**MAE:** mean absolute error
**MAPE:** mean absolute percentage error


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Original Paper

# Unsupervised Machine Learning to Detect and Characterize Barriers to Pre-exposure Prophylaxis Therapy: Multiplatform Social Media Study

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## Abstract

**Background:** Among racial and ethnic minority groups, the risk of HIV infection is an ongoing public health challenge. Pre-exposure prophylaxis (PrEP) is highly effective for preventing HIV when taken as prescribed. However, there is a need to understand the experiences, attitudes, and barriers of PrEP for racial and ethnic minority populations and sexual minority groups.

**Objective:** This infodemiology study aimed to leverage big data and unsupervised machine learning to identify, characterize, and elucidate experiences and attitudes regarding perceived barriers associated with the uptake and adherence to PrEP therapy. This study also specifically examined shared experiences from racial or ethnic populations and sexual minority groups.

**Methods:** The study used data mining approaches to collect posts from popular social media platforms such as Twitter, YouTube, Tumblr, Instagram, and Reddit. Posts were selected by filtering for keywords associated with PrEP, HIV, and approved PrEP therapies. We analyzed data using unsupervised machine learning, followed by manual annotation using a deductive coding approach to characterize PrEP and other HIV prevention–related themes discussed by users.

**Results:** We collected 522,430 posts over a 60-day period, including 408,637 (78.22%) tweets, 13,768 (2.63%) YouTube comments, 8728 (1.67%) Tumblr posts, 88,177 (16.88%) Instagram posts, and 3120 (0.6%) Reddit posts. After applying unsupervised machine learning and content analysis, 785 posts were identified that specifically related to barriers to PrEP, and they were grouped into three major thematic domains: provider level (13/785, 1.7%), patient level (570/785, 72.6%), and community level (166/785, 21.1%). The main barriers identified in these categories included those associated with knowledge (lack of knowledge about PrEP), access issues (lack of insurance coverage, no prescription, and impact of COVID-19 pandemic), and adherence (subjective reasons for why users terminated PrEP or decided not to start PrEP, such as side effects, alternative HIV prevention measures, and social stigma). Among the 785 PrEP posts, we identified 320 (40.8%) posts where users self-identified as racial or ethnic minority or as a sexual minority group with their specific PrEP barriers and concerns.

**Conclusions:** Both objective and subjective reasons were identified as barriers reported by social media users when initiating, accessing, and adhering to PrEP. Though ample evidence supports PrEP as an effective HIV prevention strategy, user-generated posts nevertheless provide insights into what barriers are preventing people from broader adoption of PrEP, including topics that are specific to 2 different groups of sexual minority groups and racial and ethnic minority populations. Results have the potential to inform future health promotion and regulatory science approaches that can reach these HIV and AIDS communities that may benefit from PrEP.


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*(JMIR Infodemiology 2022;2(1):e35446)* doi:10.2196/35446

**KEYWORDS**

infoveillance; HIV; minority health; PrEP; social media

## Introduction

### Pre-exposure Prophylaxis Use Among Minority Populations

HIV remains one of the world's most pressing global public health challenges. According to the Joint United Nations Programme on HIV and AIDS, there were approximately 38 million people across the world living with HIV in 2019 [1], and in the same year, an estimated 1.7 million people became newly infected with HIV [2]. Concomitantly, only about 24.5 million people had access to antiretroviral therapy, including pre-exposure prophylaxis (PrEP), a proven and safe method to prevent HIV transmission [2-6]. For example, in the United States, only approximately 7% of people who meet the indication for use of PrEP are prescribed PrEP and adhere to protocols [7,8]. These numbers fall well short of the ambitious *90-90-90* targets set by Joint United Nations Programme on HIV and AIDS to have 90% of HIV-infected individuals diagnosed, receiving antiretroviral therapy, and achieving viral suppression, which is also impacted by challenges associated with adherence to treatment [6,8]. Among those at risk for HIV, certain racial and ethnic minorities remain disproportionately impacted and may face structural and economic barriers associated with the access and ability to start HIV prevention and treatment services such as PrEP [9-11].

For example, according to data from the US Center for Disease Control and Prevention, Blacks or African Americans and Hispanics or Latinos comprised 41% and 23% of people living with HIV, respectively, and Black or African American and Hispanic or Latino men who have sex with men accounted for 26% and 22% of new HIV infections in 2018, respectively [12]. In addition, Black or African American women remain at higher risk for HIV transmission than White and Hispanic or Latina women, and African American or Black and Hispanic or Latina women's PrEP uptake lags behind that of White women [13,14]. Hence, even though PrEP is a highly effective HIV prevention modality, its adoption has not yet become the standard of care among certain racial and ethnic minority populations and sexual minority groups who are at heightened risk for HIV [15,16].

Clinical studies have demonstrated the effectiveness of PrEP in preventing HIV when taken as prescribed, with data from the Center for Disease Control and Prevention finding that it reduces HIV transmission from sex by approximately 99% and by at least 74% for people who inject drugs [17,18]. However, self-perceived and objective barriers continue to hinder PrEP's widespread use [13]. For example, barriers across the PrEP continuum of care in an integrated health care setting were more pronounced for racial and ethnic minority patients, individuals with lower socioeconomic status, and those with substance use disorder, with PrEP attrition associated with HIV infection [19].

### Social Media Platforms, HIV, and Infodemiology

To further encourage PrEP uptake, social media platforms have increasingly evolved into spaces to deliver health information and for users to actively report and discuss their health behavior, including in the context of HIV [20-22]. Owing to the ability of these platforms to share information and reach diverse audiences, health communication and promotion efforts aimed at increasing awareness about PrEP and destigmatizing its use are a possibility [1,23]. Certain platforms, such as Instagram and Twitter, are also popular among Black or African American and Hispanic or Latino youth, highlighting the potential for social media to generate better understanding into the knowledge, attitudes, and behaviors of specific minority groups for health topics [1]. Leveraging publicly available social media data using *infodemiology* approaches (ie, the science of distribution and determinants of information in an electronic medium, with the aim of informing public health), this study analyzed user-generated conversations about PrEP from a multiplatform perspective, including examining the experiences of racial and ethnic groups and sexual minorities [24].

## Methods

### Ethics Approval

This study has been approved by WCG IRB. WCG IRB is registered with the Office for Human Research Protections and US Food and Drug Administration (FDA) as IRB00000533.

### Data Collection

We first generated a list of PrEP- and HIV-associated keywords and hashtags by manually searching posts on social media platforms that were selected for this study. These included a baseline set of general terms associated with HIV, PrEP, and FDA-approved PrEP medications. We searched this initial set of keywords on Twitter, Tumblr, Reddit, YouTube, and Instagram, which enabled us to collect additional hashtags and keywords associated with HIV prevention, HIV treatment, and HIV disease experiences, which also included concurrent user discussions about PrEP therapy as observed in results from the first 100 returned posts for each searched term. This enabled us to generate a more comprehensive list of associated keywords and hashtags specific to social media conversations related to HIV prevention and PrEP, which were then further used for a broader and structured data collection approach on the 5 study platforms selected (refer to Table 1 for the full list of study keywords and hashtags). We chose these platforms based on their general popularity, accessibility of publicly available data, and diversity in methods of web-based and social communication and interaction (eg, microblogging sites [Twitter and Tumblr], a news aggregation and discussion site [Reddit], a video sharing site [YouTube], and a photo and video social networking site [Instagram]). We also decided to pursue a multiplatform infodemiology study on the basis of seeking a variety of user discussions from different and diverse web-based



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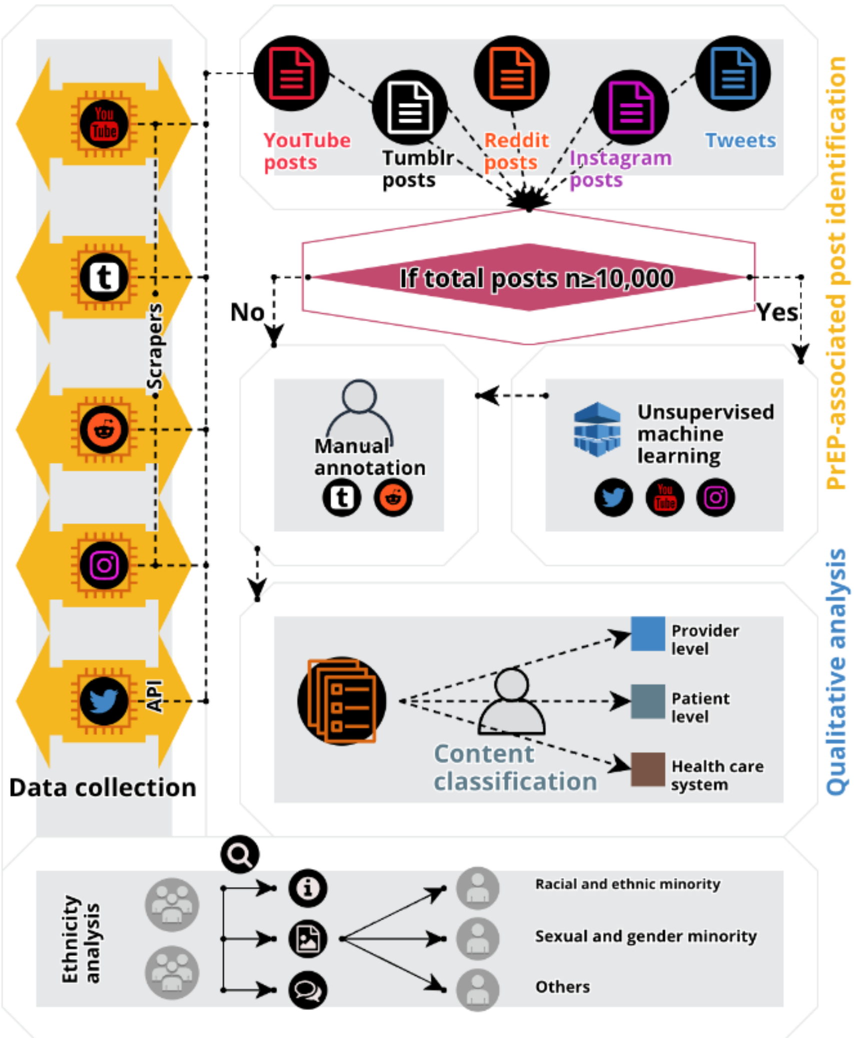
communities (eg, social media platforms chosen for this study have different user demographics and audiences), whereas a single platform study may have yielded less diversity of users, topics, and themes related to PrEP. We used the public streaming Twitter application programming interface to collect tweets on Twitter and an automated web scraper developed in the programming language Python using the Beautiful Soup package to collect publicly available posts from Tumblr, YouTube, Reddit, and Instagram. Posts were collected from all 5 platforms simultaneously over a 60-day study period (from October 13, 2020, to December 11, 2020) and contained both retrospective data (eg, posts that occurred before the date of collection) and prospective data (eg, Twitter posts were collected starting on the date of querying the application programming interface). A visual summary of the study methodology used is provided in Figure 1.

**Table 1.** Selected pre-exposure prophylaxis (PrEP)- and HIV-related keywords and hashtags.

| | Additional keywords | Hashtags |
|---|---|---|
| PrEP-related keywords or hashtags | *PrEP; Post-exposure prophylaxis* | #Iwantprepnow; #PrepworkPepfarsaveslives; #prep4blackqueermen; #ondemandprep |
| HIV-related keywords or hashtags | *HIV Clinic; Unsafe sex; POZ; ART; Serosort; The disease; The ick* | #HIVawareness; #HIVprevention; #Queerhealth; #knowyourstatus; #Imstoppinghiv#undetectableequalsun-transmittable; #hivundetectable; #hivpoz; #hivprevention; #uequalu; #uequalsu |
| Medication-related keywords or hashtags | *Descovy; Truvada; Tenemine; Tivicay; Aluvia; AIDS cocktail; Meds; Cabotegravir; Ceftriaxone; Doxycycline; Tenvir; Tenofovir; Duomune; Emtricitabine* | #Truvada; #showyourpill; #Truvadawhore; #Chuvadetrovada; #hivmeds; #truvadaforprep; #preppill |

**Figure 1.** Methodology summary and flowchart. API: application programming interface; PrEP: pre-exposure prophylaxis.





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### Unsupervised Machine Learning

To identify, characterize, and elucidate the experiences, attitudes, and perceived barriers associated with the adoption and adherence to PrEP therapy, we used a form of unsupervised machine learning in the family of topic modeling and natural language processing to identify topics and word groupings relevant to the study objectives. We used the biterm topic model (BTM), which is an unsupervised machine learning approach designed to detect patterns in the data and summarize the entire corpus of text into distinct highly correlated categories [25-30]. BTM can be used to sort short text into highly prevalent themes without the need of predetermined training data and has been previously used for the exploration of other public health topics [25-30]. Groups of social media messages or text containing the same word-related themes are categorized into clusters, and the main themes of those clusters are considered as the topic of the text aggregation, which is then split into a bag of words where a discrete probability distribution for each theme is generated [31].

Using BTM, we identified topic clusters with word groupings, frequencies, and characteristics that appeared to be related to user conversations associated with HIV prevention or PrEP (*signal clusters*) and then extracted social media posts from these topic clusters for manual annotation. For example, signal clusters that contained a high frequency of PrEP-specific keywords for the outputted topic and also included verb word groupings more indicative of user-generated syntax were prioritized and labeled as potential signal clusters. We set a total number of k=20 different clusters (ie, total number of topics for BTM to output), resulting in texts with similar themes put into the same clusters. To find the appropriate k value, we used a topic coherence score to determine the k value. Coherence score is used to measure the performance of a topic model with different number of clusters and can help distinguish between topics that are semantically interpretable and topics that are artifacts of statistical inference. We test 5 different k values (k=10, 20, 30, 40, and 50) for each data set and found that when k=20, we generated the highest coherence score, and this score did not change significantly with an increase in the k value. On the basis of the results generated from BTM, associated social media posts highly correlated with signal clusters were then extracted and reviewed using manual annotation.

Posts were deemed as *signal* posts (ie, relevant social media posts to the study aims) if they were (1) user generated (ie, not posted by organizations or media outlets) and (2) discussed a topic relevant to PrEP therapy access, use, adherence, and associated barriers. Posts related solely to news or media coverage about PrEP, advertisements of PrEP services or treatment, and posts not related to PrEP (eg, such as the use of *prep* for the description of general food preparation) were excluded from further analysis. In addition, based on the number of posts collected from each platform, we used a protocol of using either (1) BTM in combination with manual annotation of posts for platforms where there were greater than 10,000 posts or (2) solely relying on manual annotation of posts for platforms with less than 10,000 total posts. The 10,000-post cutoff was deemed appropriate given previous studies that have relied on manual annotation for similarly sized social media data sets and the relative imprecision of BTM compared with manual annotation when examining smaller sized data sets [32].

### Content Analysis

To classify the content of posts identified as potential *signal* posts following BTM and manual annotation, we used a deductive coding approach based on the socioecological perspective outline (SEPO), which focuses on barriers to PrEP [33-36]. All posts were first reviewed by the first author (QX), and notes were taken on general themes of posts from which an initial code list was created. Following the SEPO [36,37], all detected themes were deductively classified in 3 intervention levels: *Individual and Relationships Domains: Provider Level*, *Individual and Relationships Domains:Patient Level*, and *Community Domains: Health care System Level* (refer to Table 2 for description). Reported categories of barriers to PrEP and other forms of HIV prevention were adopted from SEPO and new subcodes adopted throughout our process of content coding. Subcodes that were not covered under SEPO were inductively added to the codebook under the 3 parent codes based on the conceptual domain and intervention level of the new theme.

To further elucidate potential patient decision-making rationale about the use of PrEP, we also conducted an additional round of deductive coding by adopting the consumer decision-making process model (CDMPM). For CDMPM, we assessed the potential impact on PrEP access and barriers to access by categorizing all signal posts into the 5 stages of the CDMPM decision process (Table 2) [38]. The categorization and inclusion criteria for each of the five stages are as follows: (1) need recognition—post shows the users recognizing their risk of contracting HIV, but have not started looking for a protection method, (2) information search—post shows users have recognized there is a risk of HIV and are looking for information on protection and prevention, (3) evaluation of alternatives—posts comparing the use of PrEP and other alternative prevention methods (eg, condoms), (4) purchase (using)—post reflects users with the intent of using PrEP or have started using PrEP and posts that also show users deciding not to use PrEP, and (5) postusing behavior—posts discussing themes after PrEP use has been initiated (eg, adherence and conversely terminating the use of PrEP for different reasons).

First (QX) and second (MCN) authors coded all posts independently and achieved high intercoder reliability for post signal coding (Cohen κ=93.46). A final coded data set was reviewed by the third (TM) and fourth (HG) authors to assess if any differences in code definitions and application occurred. First through fourth authors reconciled differences and reached consensus on the correct classification.



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**Table 2.** Description of socioecological perspective outline (SEPO) and consumer decision-making process model (CDMPM).

| Model type and levels or stages | Description |
| --- | --- |
| **SEPO** | |
| Individual and relationships domains: provider level | Focused on primary care physicians, HIV and infectious disease specialists, pharmacists, and nurse practitioners |
| Individual and relationships domains: patient level | PrEP[a] patients' and potential patients' attitudes, beliefs, and experiences |
| Community and system domains: health care system level | System-level barriers to PrEP implementation |
| **CDMPM** | |
| Need recognition | Recognition of risk for contracting HIV |
| Information search | Looking for information on HIV protection and prevention |
| Evaluation of alternatives | Comparing the use of PrEP and other alternative prevention methods |
| Purchase (using) | Intent of using PrEP or have started using PrEP or deciding not to use PrEP |
| Postpurchase behavior (postusing behavior) | Discussing themes after PrEP use (satisfied or dissatisfied) |

[a]PrEP: pre-exposure prophylaxis.

### User Metadata Analysis

To further characterize the potential challenges associated with PrEP uptake, access, and adherence specific to minority populations, we also examined publicly available metadata of users associated with signal posts for any potential identifiable minority status. In this study, minority groups included racial and ethnic minorities as well as sexual and gender minorities. This included 5 major racial and ethnic groups: Blacks or African Americans, American Indians and Alaska Natives, Asians, Native Hawaiian or other Pacific Islanders, and Hispanics or Latinos. It also included a broad classification of 5 sexual and gender minorities: lesbian, gay, bisexual, transgender, and queer users. The classification used only publicly available profile data and information from the last 10 posts from the user's account or timeline to assess whether there was sufficient information to identify at least one of the above-mentioned minority classes. These data were collected for purposes of aggregation, and no results contained in this study include individually identifiable information or make any representation to the accuracy of a claimed minority classification of a user.

## Results

### Overview

We collected 522,420 posts over the 60-day study period among all collected retrospective and prospective posts across the 5 social media platforms in this study. Breakdown per platform for the 522,420 posts is as follows: 408,637 (78.22%) tweets, 13,768 (2.63%) YouTube comments, 8728 (1.67%) Tumblr posts, 88,177 (16.71%) Instagram posts, and 3120 (0.6%) Reddit posts. After applying our approach of BTM and manual annotation to confirm signal posts, 785 posts were identified as associated with PrEP-related topics, which comprised posts from 715 unique social media user accounts. The 785 signal posts were identified from Twitter (n=430, 54.8%), Reddit (n=256, 32.6%), Instagram (n=41, 5.2%), Tumblr (n=41, 5.2%), and YouTube (n=17, 2.2%; Table 3). The period covered by this subset of signal posts was from June 4, 2015 (earliest posted on Instagram), to November 23, 2020 (latest posted on Twitter). According to the time duration of signal posts for specific platforms, Instagram had the longest period of signal posts detected (June 4, 2015, to October 30, 2020), and Twitter had the shortest period of coverage (October 14, 2020, to November 23, 2020) because of the prospective nature of the data collection process. Generally, these periods coincide with very early retrospective dates around the time of PrEP therapy introduction (eg, US FDA approval) and more recent conversations about PrEP closer to the study data collection period.


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**Table 3.** Volume and period of coverage of the collected posts and signal posts.

| Platforms | Collected posts | | | | | Signal posts | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Total number | Period of posts | Identified users | Day posts | Day posts, mean (SD) | Total number | Period of posts | Identified users | Day posts | Day posts, mean (SD) |
| Instagram | 88,177 | April 4, 2012, to October 29, 2020. | 23,654 | 28.36 | 8 (98.76) | 41 | June 4, 2015, to October 30, 2020. | 37 | 0.021 | 0 (0.15) |
| Reddit | 3120 | February 28, 2007, to November 25, 2020. | 2772 | 0.62 | 0 (3.17) | 256 | January 22, 2016, to November 10, 2020. | 250 | 0.15 | 0 (0.54) |
| Tumblr | 8728 | August 16, 2010, to November 18, 2020. | 5714 | 2.33 | 0 (7.29) | 41 | August 22, 2015, to June 17, 2020. | 31 | 0.023 | 0 (0.19) |
| Twitter | 408,637 | October 13, 2020, to November 25, 2020. | 207,368 | 9503.19 | 15,537 (6078.02) | 430 | October 14, 2020, to November 23, 2020. | 383 | 10.75 | 2 (29.53) |
| YouTube | 13,758 | May 5, 2010, to November 16, 2020. | 12,185 | 3.58 | 0 (2.09) | 17 | July 26, 2019, to November 1, 2020. | 14 | 0.037 | 0 (0.16) |

### Content Analysis: SEPO

On the basis of our qualitative analysis and deductive coding approach, 39 topics based on the SEPO and CDMPM were derived. A complete breakdown of the stratification of these codes and subcodes for each social media platform is provided in Multimedia Appendix 1. Following the SEPO framework [37], all detected topics were first classified into the 3 parent domains: provider level (13/785, 1.7% posts), patient level (570/785, 72.6% posts), and community level (166/785, 21.2% posts; refer to Table 4 for codes and subcodes and deidentified examples). From the posts identified in the provider domain, which focuses on barriers perceived by users to occur at the health care provider level, discussions focused on themes related to providers' knowledge or lack thereof about PrEP (7/13, 54% posts; A-1-a, A-1-b), provider's attitudes toward PrEP and patients seeking care (5/13, 38% posts; A-2-a), and an instance where a provider unintentionally failed to renew a PrEP prescription (1/13, 8% posts; A-3-a). For example, a group of conversations in this level focused on how primary physicians could not prescribe PrEP because they did not know the correct application or use of the medication.

In the patient domain, which focuses on barriers that are perceived to originate from a patient or prospective patient's attitudes, knowledge, and behavior, the highest number of themes detected related to the SEPO knowledge topic (528/570, 92.6% posts; B-1-[a-h]), which included patients having low awareness of PrEP, lack of knowledge about approved PrEP medications, issues with insurance coverage, and lack of local health resources to access PrEP. In addition, patients also mentioned barriers regarding their attitudes and beliefs shaped by their experiences (157/570, 27.5% posts; B-2-[a-l]), which included subtopics reporting users' apprehension about side effects associated with PrEP, prioritizing another personal health issue over HIV prevention, concerns about contraindication of PrEP with other illicit drugs (eg, recreational drug use), distrust of the medical system, users' self-evaluation as being at low risk for HIV and foregoing PrEP, and a preference to use other HIV prevention measure (eg, using a condom during sexual intercourse). We also observed that patients' experiences related to knowledge and barriers to PrEP therapy varied greatly, such as misinformation on COVID-19 (eg, users stating that they were protected or immune from COVID-19 if they were on PrEP therapy) and use of PrEP that were coded as expressions of adherence, expressions of interest to donate unused PrEP to others, concerns about contraindication with other illicit drug use, and more common experiences of users reporting terminating PrEP because they were experiencing adverse reactions.

The final SEPO level focused on PrEP barriers originating from more structured community-related topics reported by users. The themes primarily focused on issues associated with communication and lack of awareness about PrEP (5/166, 3% posts; C-1-a), general lack of government funding for PrEP programs and its impact on insurance coverage (90/166, 54.2% posts; C-2-a and C-2-b), barriers related to health care referral system, issues of inadequate transportation to clinics (C-3-[a-i]), challenges with prescription filling (48/166, 28.9% posts), and other barriers related to PrEP medication characteristics (eg, route of administration and daily dosing schedule; 21/166, 12.7% posts; C-4-a). Other socially contextual issues were also detected such as the perception of population-specific barriers and stigma to PrEP (54/166, 32.5% posts; C-5-[a-e]), discussion about the need for HIV testing and effectiveness of PrEP therapy


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for injection drug users, and a perceived lack of inclusivity for clinical trials associated with PrEP therapy for certain sexual minority groups. Finally, community concerns included users reporting similar concerns to those observed at the patient level regarding loss of coverage for PrEP patients because of changes in insurance policies or limited access to HIV clinical services because of the COVID-19 pandemic.

**Table 4.** Top 3 topics in 4 ethnic minority groups.

| Ethnic minority groups and top 3 topic code numbers | Topic description | Number of posts (N=162), n (%) | Sexual and gender minorities (N=19), n (%) |
|---|---|---|---|
| **Blacks or African Americans (n=129)** | | | 11 (57.8) |
| B-1-e | Comparing different drugs (Truvada and Descovy) | 39 (24.1) | |
| B-1-b | Sharing PrEP[a] knowledge or experience with other patients | 33 (20.4) | |
| B-1-d | Asking about knowledge related to the use, effectiveness, or side effects of PrEP | 10 (6.2) | |
| **Asians (n=19)** | | | 3 (15.8) |
| B-1-b | Sharing PrEP knowledge or experience with other patients | 11 (6.8) | |
| B-1-e | Comparing different drugs (Truvada and Descovy) | 3 (1.9) | |
| B-2-k | Self-evaluated as low risk | 2 (1.2) | |
| **Hispanics (n=12)** | | | 5 (26.3) |
| B-1-e | Comparing different drugs (Truvada and Descovy) | 5 (3.1) | |
| B-1-b | Sharing PrEP knowledge or experience with other patients | 3 (1.9) | |
| C-5-b | Lack of transinclusive marketing of PrEP | 2 (1.2) | |
| **American Indians and Alaskan Natives (n=2)** | | | 0 (0) |
| B-1-e | Comparing different drugs (Truvada and Descovy) | 1 (0.6) | |
| B-2-a | Side effects, effectiveness, toxicities, and interaction with feminizing hormones | 1 (0.6) | |
| Total (n=162) | | 110 (67.9) | 19 (100) |

[a]PrEP: pre-exposure prophylaxis.

## Content Analysis: CDMPM

In addition to coding user-generated data for SEPO domains, we also assessed the stages of the patient PrEP decision-making processes per the CDMPM. We first removed all signal posts not associated with the patient decision-making process based on our first deductive coding round of SEPO themes and recoded the data for CDMPM categorized stages (eg, posts that discussed HIV and AIDS prevention technology and certain information-seeking categories were removed). Similar to themes generated in the SEPO domains, we observed that users discussed overlapping concerns throughout the patient decision-making process, including information-seeking behavior and how it impacted decisions to seek PrEP therapy (information search stage), users' decisions to use or not use PrEP (purchase or use stage), and what factors led to continued adherence or termination of PrEP therapy (postpurchase behavior level).

Specifically, within this subset of patient-focused data, the most prominent user conversations were found in the CDMPM purchase or use stage for PrEP (407/770, 52.9% posts; Figure 2). Specifically, of the 407 posts, we detected 243 (59.7%) posts where users reflected on their decision to use PrEP or had already started using PrEP and 164 (40.3%) posts where users expressed their intent to not use PrEP. Primarily, patients stated that their decision to ultimately use PrEP was based on their research on the overall effectiveness of its ability to prevent HIV or that they relied on a physician's recommendation about seeking therapy, particularly when the patient knew they were going to engage in high-risk behavior. In contrast, users' common rationale for not using PrEP included concerns about unwanted side effects (also because of observations from other users who reported experiencing adverse side effects), inability to access because of lack of insurance coverage, users believing they were not engaged in high-risk sexual behavior, and users comparing the overall effectiveness of PrEP with condoms (eg, opinions that condoms had greater utility as they prevent both HIV and sexually transmitted diseases or sexually transmitted infections).

The second most prominent CDMPM stage detected from signal posts was at the postpurchase behavior level (209/770, 27.1% posts), which included 14.5% (112/770) posts describing continued use of and adherence to PrEP after the initiation of treatment. Conversely, 12.6% (97/770) of the posts included conversations detailing users reporting termination of PrEP for reasons such as financial issues and lack of affordability, lack of access to HIV and AIDS clinics and other related medical resources, and barriers to continuing PrEP because of other health issues experienced by patients. Health issues experienced by patients that led to PrEP discontinuance included side effects


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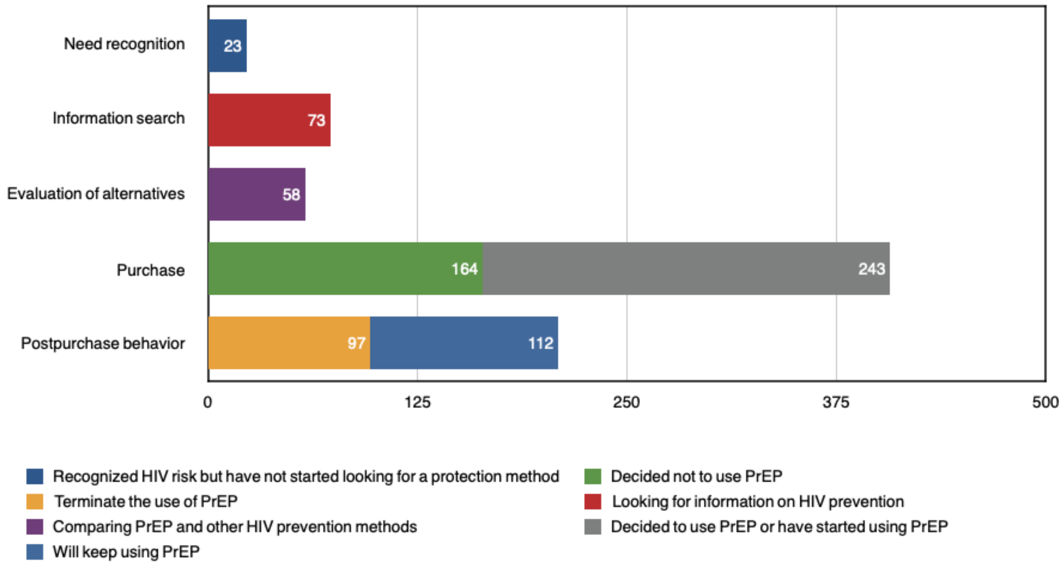
from PrEP therapy (eg, unwanted weight gain, headache, nausea, and loss of appetite), the need and complexity to manage multiple health concerns other than HIV and AIDS, and the presence of other health conditions that interfered with PrEP therapy.

Finally, 9.5% (73/770) posts were categorized as occurring in the CDMPM information search stage and included discussions about information-seeking behavior, where users recognized or became concerned about potential HIV risk and then sought more information on how to protect themselves, including inquiring about PrEP. A total of 7.5% (58/770) of these posts included discussions comparing the use of PrEP with condom use, and 2.9% (23/770) posts were categorized as in the need recognition stage, where users recognized their risk but did not mention any specific measure of protection or prevention action subsequently taken.

**Figure 2.** Number of posts at different stages of the patient decision process. PrEP: pre-exposure prophylaxis.




### User Metadata Analysis

From 785 signal posts confirmed as associated with PrEP, 320 (44.8%) posts had sufficient metadata in publicly available profile or post information to allow for identification of at least one racial or ethnic minority group (127/320, 39.7% posts) or at least one sexual or gender minority group (233/320, 72.8% posts). Among all racial and ethnic minority groups and sexual minority group–related accounts, sexual and gender minorities were the largest group of users (n=233). Their posts covered 32 PrEP-coded topics, with the top topic inquiring about information related to the use, effectiveness, or side effects of PrEP (B-1-d). The second top topic discussed side effects, effectiveness, toxicities, and interaction with feminizing hormones (B-2-a), and the third top topic was associated with users sharing PrEP knowledge or experience with other users (B-1-b).

The largest volume of racial and ethnic user posts (total n=129) were self-identified as Blacks or African Americans (96/129, 74.4%), followed by a much smaller volume of Asians (19/129, 14.7%), Hispanics or Latinos (12/129, 9.3%), and American Indians and Alaskan Natives (2/129, 1.6%). According to our analysis, we did not detect any users self-identified as Native Hawaiian or Other Pacific Islanders. On the basis of a review of codes and subcodes for these racial and ethnic minority user-specific posts, we identified 11 PrEP conversation topics most prevalent among Black or African American users, with the top topic associated with users comparing PrEP-approved treatment options (Table 4; code number B-1-e), the second associated with users discussing their experiences and knowledge about PrEP with their peers (B-1-b), and the third topic including general inquiries about information related to PrEP use. Users self-identified as Asian covered 8 topics, with the top topic related to sharing PrEP knowledge or experiences with other users (B-1-b), the second topic comparing PrEP treatment options (B-1-e), and the third topic discussing how users self-evaluate whether they are at low risk of contracting HIV and AIDS (B-2-k). For users self-identifying as Hispanics or Latinos, 7 topics were detected, with the top topic again comprising discussions comparing PrEP treatment options (B-1-e), the second discussing general knowledge and experiences with PrEP (B-1-b), and the third where users felt there was a lack of transinclusive marketing of PrEP but did not explicitly claim transgender affiliation (C-5-b). Owing to the low volume of users detected as American Indian and Alaskan Native, only 2 topics were detected for this group: comparing PrEP treatment options (B-1-e) and a topic related to concerns about PrEP side effects, effectiveness, toxicities, and interaction with feminizing hormones (B-2-a).

## Discussion

### Principal Findings

In this multiplatform infodemiology study, we analyzed just over a half million social media posts from popular platforms such as Twitter, YouTube, Instagram, Reddit, and Tumblr using a combination of unsupervised machine learning and manual annotation. This resulted in 785 user-generated posts that included conversations about PrEP and other HIV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prevention–related topics confirmed through manual annotation and deductively coded for themes associated with the SEPO specific to PrEP barriers and the CDMPM adapted for PrEP patient decision-making stages. Many of these signal posts (320/785, 40.8%) were identified as a racial or ethnic minority population or sexual minority groups. Most users (233/785, 29.7%) were sexual or gender minority status, followed by Blacks or African Americans.

Of all the SEPO levels reviewed, the patient level had more than three-quarters of the volume of all PrEP-related social media conversations. This indicates that users who belong to the HIV and AIDS community or who may be at higher risk of HIV transmission often associate barriers to PrEP therapy, as influenced by patient knowledge, attitudes, and behaviors toward PrEP, though barriers at the provider and community levels were also detected. The largest volume of data for our CDMPM analysis focused on the purchase or use stage of the PrEP decision-making process, indicating that users actively discuss their intent to use or not use PrEP on social media, which may also be influenced by exposure to different forms of information and overall knowledge, or lack thereof, about the benefits of PrEP therapy.

Importantly, regardless of the platform used or coding framework applied, overlapping topics related to specific barriers experienced by users that may impede PrEP therapy were detected, indicating that these challenges may represent possible priority areas for the future design of HIV prevention interventions and education aimed at promoting PrEP use. In fact, the theme with the largest total volume of posts centered around knowledge about PrEP, including lack of knowledge about already-approved PrEP medications; whether treatment was covered by insurance; and overall user perception regarding the inadequacy of resources, communication, and awareness about PrEP, all occurring at multiple SEPO levels and throughout the CDMPM decision-making processes. For example, users noted that providers and patients both lacked knowledge about the benefits of PrEP therapy.

Beyond knowledge-related topics, users also reported structural barriers to accessing PrEP therapy at different SEPO and CDMPM levels or stages. For example, some users reported that providers lacked sufficient knowledge about PrEP and failed to prescribe it even when it was beneficial for a patient or appropriately indicated for a patient's level of HIV risk. Other examples of barriers included medication insurance coverage issues that impacted access and affordability of PrEP, other external financial and health challenges among these patients, the inability to access HIV and AIDS clinics (also because of disruptions occurring from the COVID-19 pandemic), failure to receive a referral for HIV prevention treatment, and lack of transportation to clinics. This was coupled with different perceptions about perceived risks associated with PrEP therapy that impacted both uptake and adherence, including several posts of users expressing concerns about side effects and other users openly discussing their adverse health experiences. Other reported attitudes and experiences that could further exacerbate these structural barriers included users harboring distrust in the medical system, believing they were at low risk of HIV, and concerns about stigma associated with HIV and PrEP.

Hence, the results of this study, although primarily exploratory, provide additional insights into the specific barriers experienced across the HIV and AIDS PrEP care continuum, as expressed by a diverse audience of social media users. In fact, it appears that many users who identified as sexual minorities are primarily concerned about the effectiveness and potential side effects associated with different PrEP therapies. Sexual minority users were also concerned about issues regarding equitable and diverse representation in clinical trials and marketing of PrEP, topics relevant given that this group is disproportionately impacted by HIV and AIDS [39]. For users associating with select racial and ethnic minority groups, many users were uncertain about the differences between the approved PrEP treatment options, and we also observed that these unique patient communities actively discuss PrEP knowledge and experiences among their digital peers. In addition, African Americans or Blacks, a minority group that accounts for a higher proportion of new HIV diagnoses and those living with HIV compared with other ethnic groups, made up the highest volume of minority web-based users identified in this study, highlighting the disproportionate impact that HIV has on both offline and web-based communities.

Finally, examining the breakdown of PrEP user conversations by specific social media platforms, we found that Twitter yielded the largest absolute volume of signal data, but the signal to noise ratio (ie, the number of posts relevant to PrEP vs nonrelevant content) was relatively high. In contrast, our analysis of Reddit data found that it included a high volume of signal relative to the smaller amount of data collected and had the most diversity of coded topics (including 252 total signal posts that comprised 102 posts under the patient level, 71 at the community level, and 9 at the provider level). The high volume of codes in Reddit posts is also attributable to the long text nature of posts and subreddits reviewed, which can include multiple codes in 1 post. Reddit also had the highest volume of posts associated with users identified as a sexual minority. A full breakdown of the top 3 topics detected on each of the different social media platforms is available in Multimedia Appendix 2. Overall, these results indicate that different groups of users may have distinct and different PrEP-related conversations that occur on platforms that represent different and distinct web-based communities, all of which form a unique communication and peer-to-peer environment discussing relevant HIV and AIDS topics, including PrEP.

Results from this study have the potential to inform and generate additional research questions that examine how social media users discuss their experiences, attitudes, and behaviors regarding PrEP, with an aim of increasing the understanding of diverse voices and perspectives [40,41]. Importantly, the popularity, ubiquity, and relative anonymity of these platforms may represent an important data source to investigate sensitive health topics such as HIV and PrEP, particularly as users become more comfortable with discussing these issues in web-based patient-centric communities. This study additionally adds information to inform risk communication and health literacy objectives by better understanding existing knowledge gaps about PrEP and how to target health communication and promotion to specific web-based, diverse, and at-risk populations


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that may also engage in high-risk behaviors [42,43]. Both of these are important considerations for regulatory decision makers trying to amplify the patient voice and global goals to provide HIV treatment to all those who need it [40].

### Limitations

This study has certain limitations. First, we only collected data from 5 selected social media platforms and limited study keywords to English. This likely biased the study results to native English speakers, excluding minorities for whom English is a second language or those who do not speak English. Hence, the findings are not generalizable to all PrEP social media conversations occurring among web-based users. Our PrEP- and HIV-related keywords and filtered terms were also chosen based on our manual searches conducted directly on the platforms, but they may not have been inclusive of all PrEP-related keywords or other HIV drugs or treatments (eg, bictegravir, emtricitabine, tenofovir alafenamide, abacavir, dolutegravir, and lamivudine) that may nevertheless generate PrEP-related conversations or discussions about HIV prevention behavior. More specifically, this study did not intend to create a comprehensive list of HIV treatment keywords that might occur alongside PrEP-related conversations. Hence, future studies should expand data collection and analysis approaches to different phrases associated with an individuals' HIV-related risk behavior; for example, sharing needles and unsafe or unprotected sex, to obtain a more representative corpus of social media conversations. In addition, among all collected data, we observed imbalanced data sets, specifically the oversampling of collected tweets that could result in bias during the data analysis and content coding phase. To address data set imbalances in multiplatform infodemiology studies, future studies should adopt controls, such as the Synthetic Minority Oversampling Technique, to mitigate potential bias or normalize data in ways that make them more representative of the number of users or imbalance of users on each platform. We also did not cross-validate the veracity of users' race and ethnicity. We determined users' race and ethnicity based on the users' publicly available metadata, public posts, and profile image. Hence, our classification of user's race and ethnicity could be inaccurate because of poor quality data or inaccurate user reporting. Future studies should explore combining multiple data layers from different sources to better validate user's race and ethnicity or use more traditional approaches of data collection (eg, survey instruments and focus groups). This study also did not focus on specific thematic detection of misinformation or inaccurate information regarding PrEP therapy, though these conversations were observed in our data set. Future studies should consider focusing on detection and characterization of specific misinformation or incorrect information that may impact user HIV prevention seeking or HIV prevention behavior, as it specifically occurs on social media platforms. Finally, because of the exploratory nature of this study and the lack of available training data related to PrEP behavior and information seeking, we relied on the use of unsupervised topic modeling using BTM to categorize texts into different groups and selected groups that had keywords relevant to PrEP-related conversations. However, this approach may preclude signal text with a small volume that may be obscured by nonsignal text with higher volume during the topic modeling output phase. To address this limitation, future studies should explore using pretrained natural language processing models (eg, Bidirectional Encoder Representations from Transformers or other forms of supervised machine learning approaches when sufficient training data are available.

### Conclusions

The results from this multiplatform infodemiology study provide additional insights into the challenges faced by diverse web-based patient populations when seeking PrEP therapy. It appears that existing barriers are influenced by a multitude of factors, either they be subjectively based on a user's experiences or more structural to the HIV risk environment and challenges associated with the HIV care continuum. Future research should continue to assess the utility of data derived from social media platforms to help better understand the real-world barriers to PrEP experienced at different intervention levels and in the patient decision-making process, with the ultimate goal of improving uptake and adherence to this critical tool needed to reduce the burden of HIV.

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## Disclaimer

This study reflects the views of the authors and should not be construed to represent FDA's views or policies.

## Authors' Contributions

QX and TKM conceptualized this study. The methodology was designed by QX, JL, and TKM. QX, JL, YH, and MC provided the software. MCN, TM, and HG validated the results of this study. Formal analysis of the study and investigation was performed by QX. Resources for the study were provided by QX, JL, YH, and MC, and data curation was performed by JL, YH, and MC.



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All the authors were involved in the writing of the manuscript and the preparation of the original draft and review and editing of the manuscript. The study was visualized by QX and supervised by TKM. Project administration was performed by QX, and funding acquisition, by TKM. This manuscript has been approved by all authors.

## Conflicts of Interest

QX, MCN, TM, HG, JL, YH, MC, and TKM are employees of the startup company S-3 Research LLC. S-3 Research is a startup funded and currently supported by the National Institutes of Health–National Institute on Drug Abuse through a Small Business Innovation and Research contract for opioid-related social media research and technology commercialization.

Multimedia Appendix 1
Code list and identified topic themes.
[DOCX File , 27 KB - infodemiology_v2i1e35446_app1.docx ]

Multimedia Appendix 2
Breakdown of topics by platform.
[DOCX File , 17 KB - infodemiology_v2i1e35446_app2.docx ]

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## Abbreviations

**BTM:** biterm topic model
**CDMPM:** consumer decision-making process model
**FDA:** Food and Drug Administration
**HHS:** Health and Human Services
**PrEP:** pre-exposure prophylaxis
**SEPO:** socioecological perspective outline


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Original Paper

# Exploring Google Searches for Out-of-Clinic Medication Abortion in the United States During 2020: Infodemiology Approach Using Multiple Samples

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## Abstract

**Background:** As access barriers to in-person abortion care increase due to legal restrictions and COVID-19–related disruptions, individuals may be turning to the internet for information and services on out-of-clinic medication abortions. Google searches allow us to explore timely population-level interest in this topic and assess its implications.

**Objective:** We examined the extent to which people searched for out-of-clinic medication abortions in the United States in 2020 through 3 initial search terms: home abortion, self abortion, and buy abortion pill online.

**Methods:** Using the Google Trends website, we estimated the relative search index (RSI)—a comparative measure of search popularity—for each initial search term and determined trends and its peak value between January 1, 2020, and January 1, 2021. RSI scores also helped to identify the 10 states where these searches were most popular. We developed a master list of top search queries for each of the initial search terms using the Google Trends application programming interface (API). We estimated the relative search volume (RSV)—the search volume of each query relative to other associated terms—for each of the top queries using the Google Health Trends API. We calculated average RSIs and RSVs from multiple samples to account for low-frequency data. Using the Custom Search API, we determined the top webpages presented to people searching for each of the initial search terms, contextualizing the information found when searching them on Google.

**Results:** Searches for *home abortion* had average RSIs that were 3 times higher than self abortion and almost 4 times higher than buy abortion pill online. Interest in home abortion peaked in November 2020, during the third pandemic wave, at a time when providers could dispense medication abortion using telemedicine and by mail. *Home abortion* was most frequently queried by searching for *Planned Parenthood*, *abortion pill*, and *abortion clinic*, presumably denoting varying degrees of clinical support. Consistently lower search popularity for *self abortion* and *buy abortion pill online* reflect less population interest in mostly or completely self-managed out-of-clinic abortions. We observed the highest interest for home abortion and self abortion in states hostile to abortion, suggesting that state restrictions encourage these online searches. Top webpages provided limited evidence-based clinical content on self-management of abortions, and several antiabortion sites presented health-related disinformation.

**Conclusions:** During the pandemic in the United States, there has been considerably more interest in home abortions than in minimally or nonclinically supported self-abortions. While our study was mainly descriptive, showing how infrequent abortion-related search data can be analyzed through multiple resampling, future studies should explore correlations between the keywords denoting interest in out-of-clinic abortion and abortion care measures and test models that allow for improved monitoring and surveillance of abortion concerns in our rapidly evolving policy context.



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*(JMIR Infodemiology 2022;2(1):e33184)* doi:10.2196/33184

**KEYWORDS**

abortion; abortion access; internet; online information; Google searches; infodemiology

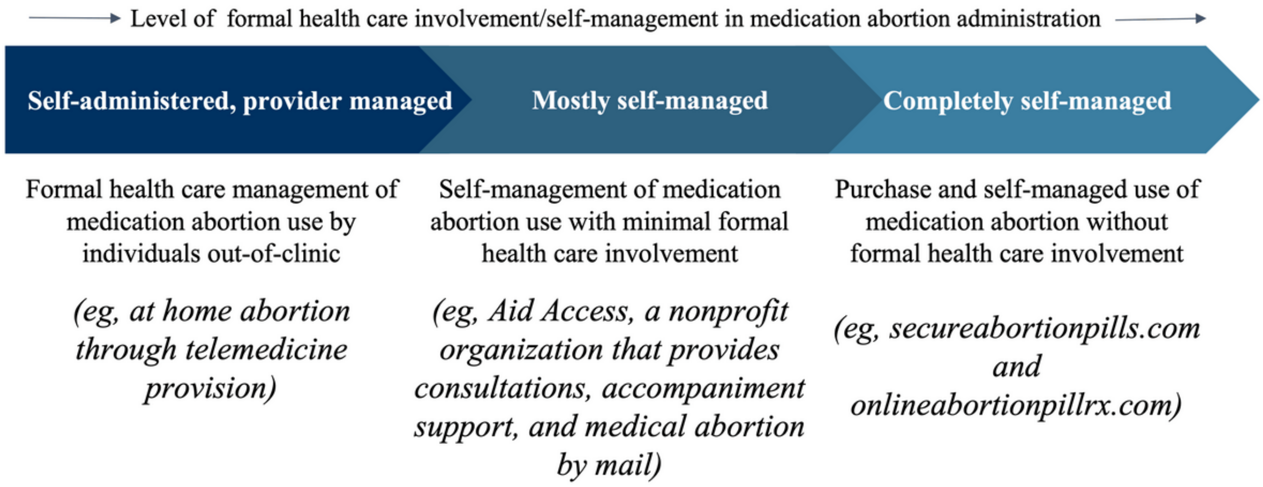
## Introduction

While abortion is a common pregnancy outcome that is currently legal in the United States, laws and policies across states pose substantial challenges to if, when, and how people can access abortions [1,2]. Restrictive laws and policies are multifold. They include gestational age limits, mandated counseling and waiting periods, parental involvement, public funding restrictions, and onerous requirements for abortion clinics and providers to operate and deliver services [2,3]. In addition, several states have imposed restrictions on the provision of abortion via telemedicine, disallowed the mailing of abortion medication to patients, and introduced trigger laws that would make abortion illegal if Roe v. Wade is overturned [2,4].

During the first year of the COVID-19 pandemic, while there was some protection of abortion services instituted in 13 states, additional challenges to access were introduced with states designating abortion as a “non-essential” or “elective” service [5], increased financial and administrative barriers for abortion clinics [6], and clinic closures [7]. Strong advocacy by proabortion groups helped to temporarily lift the national limitation on telemedicine abortion medication in the latter half of 2020 [8], and again in April of 2021 [9]. This has allowed patients to talk with a doctor by video or phone and then receive abortion pills in the mail to manage a home abortion if they live in a state allowing telemedicine abortion [9]. At the same time, people faced constrained access to contraception, with women reporting delayed and inaccessible reproductive health care based upon research in the early months of the pandemic [10]. Shifting policies during COVID-19 and need for health protection against the virus may contribute to greater reliance upon the internet as a source of abortion information and services, ranging from those fully supported by health care providers to fully self-managed abortions [11].

Medication abortion via pills administered at 10 weeks’ gestation or less is considered a safe and effective method for pregnancy termination, both in clinics with provider supervision and when delivered remotely via telemedicine [12,13]. Evidence suggests that many women choose home abortions for privacy, affordability, and convenience [2,13-15]. Others may go outside of the traditional US health care system to get abortions through entirely self-managed abortion [14] or web-based medication abortion services that offer remote provider support [15]. There appears to be a spectrum of formal health care system involvement and self-management for these out-of-clinic abortions, which we outline in a conceptual framework (Figure 1) informed by recent research [16,17].

**Figure 1.** Spectrum of out-of-clinic medication abortion management.




The majority of adults in the United States use the internet to look for health information, most often via Google [18,19]. Web-based searches present a valuable data source for examining health-seeking behaviors and concerns at a population level and the quality of information on websites, thereby advancing the field of infodemiology. Infodemiology is the science of distribution and determinants of information on the internet or in a population, with the aim to inform public health and public policy [20]. We analyzed Google searches to understand health concerns and impactful sources of online health information on out-of-clinic abortions. A study conducted in 2017 showed that there is interest to learn more about “self-abortion” on Google, especially among adolescents and young women facing an unintended pregnancy [21]. We built on recent research using Google Trends that found a high volume of information seeking for *abortion pill* and for *abortion* and wide variations by state policies in the United States in 2018 [22]. Notably, across states a higher volume of abortion pill searches was associated with more concerns about access to contraceptives, higher unplanned pregnancy rates, and fewer abortion facilities. Given the proliferation of telemedicine abortion during the pandemic and an increase in self-managed abortions [23,24], we sought to answer 3 research questions:



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1. During 2020, to what extent did people search for out-of-clinic abortions and when did search interest peak? Did search trends differ in the first quarter (before the pandemic was officially declared by the World Health Organization [WHO] on March 11) compared with the rest of the year when the pandemic surged?
2. When users searched for key initial search terms, what other search queries were users most often also searching for and which queries had the highest relative search volume (RSV)?
3. How did the relative popularity of the initial search terms vary across states?

# Methods

Guided by a literature review [9,10,14-17,21-26] and using an iterative process, we retrieved Google Trends query data on the keywords *home abortion*, *self abortion*, and *buy abortion pill online* as search terms. Each search term was found to be related to the topic *abortion*, while *home abortion* and *buy abortion pill online* were also related to the topic *medical abortion*. Abortion and abortion pill as keyword searches on Google have been shown to correlate with unwanted pregnancies, concerns for contraceptive access, and lack of abortion care facilities [22]. As *home abortion*, *self abortion*, and *buy abortion pill online* contained more than 1 word, we tested these keywords using double quotation marks; however, upon retrieval search data were unavailable or of insufficient quality. We also tested *self-abortion* (with a dash) and ran into similar limitations. While *home abortion* is a broad search term that we saw as encompassing both provider and self-managed abortion, we also explored if the Google Trends website returned results for narrower keywords including *home abortion through telemedicine*, *self induced abortion*, and *self managed abortion*, but search data for these were unavailable.

We followed the core procedures of the simulation protocol described by Zepecki et al [25] and Mavragani and Ochoa [26] where appropriate. To answer the first research question, we retrieved Google Trends data using the Explore function for the period from January 1, 2020, to January 1, 2021, in the United States. This timeframe allowed us to plot weekly data and assess trends and search peaks for the selected keywords. We also compared trends before COVID-19 was declared a pandemic (week including January 1 through week of March 1-7, 2020) with trends observed during the pandemic (week of March 8-14 through week of December 27, 2020-January 2, 2021). We selected the "health" category and the "website" category. Subcategories were not selected when searching for keywords. We examined the relative search index (RSI) for each of our initial search terms. The RSI values reflect the normalized popularity of each initial search term relative to all other Google searches in a given geolocation (in our case, the United States) for January 1, 2020, to January 1, 2021. As search data are normalized and indexed 0-100, where 100 denotes the maximum search interest for a given search term in the time and location selected and 0 denotes no interest, the RSI values for each of the initial search terms selected inform us which terms are relatively more popular as a proportion of all searches on all topics on Google at the chosen time and geographic location. RSI values also show changes in relative popularity over time, allowing us to identify peak interest times. For instance, if we examine the keyword *abortion pill* within a single year in the United States, we might find that it has an RSI of 95 in January and then declines as months go by in that year. This would suggest that the peak interest in that term within the United States was at the beginning of that year.

To answer the second research question, we first used the Google Trends application programming interface (API) to access data to ascertain the top search queries associated with each of our initial search terms and their respective RSI values. Subsequently, we used the Google Health Trends API to ascertain the normalized proportion of searches for a specific query out of the sum of searches for a set of top queries associated with the initial search term. This proportion is known as the RSV [25]. To address the third question, we used the Google Trends website to explore the state-specific RSI values for each of our initial search terms, reflecting normalized regional popularity of each search term compared with other states within the United States for the designated period.

The RSI and RSV values returned by the Google APIs are based on a daily cached random sample of the universe of all Google search data in the specified geolocation. Consequently, any queries with low search volume can sometimes return "no data" even if a new random sample returns valid data. These events produce fluctuations in the top queries retrieved with the Google Trends and Health Trends APIs across samples [27]. Following an approach used by Pew Research Center scholars [28], we adapted our methodology to create nonmissing average measures for RSI and RSV values, calculated from resampled results for each initial search term. Specifically, from the Google Trends webpage, we pulled 30 unique data samples for *home abortion*, *self abortion*, and *buy abortion pill online* and estimated the nonmissing average RSI over time and by state. We used a similar resampling approach to compile data from the Google Trends API and Health Trends API. To alleviate concerns about idiosyncratic data extractions on a given date, half of the 30 samples were pulled between April 1 and 21 and half between June 4 and 18, 2021.

Finally, to help contextualize the search interest in out-of-clinic abortions, we used the Custom Search API [25]. This API allowed us to obtain the top 10 webpages linked to each of the 3 initial search terms determined by Google's search engine optimization algorithm as of April 4, 2021. A previous study suggested that these webpages receive at least 92% of the search traffic [29]. Webpage probabilities, or the likelihood that a user would click-through that webpage search result on Google, were assigned based on research by Chitika Insights [29].

# Results

## Search Traffic Over Time and Top Queries

Figure 2 compares the average RSI values over time for *home abortion*, *self abortion*, and *buy abortion pill online*. As shown, *home abortion* was the most popular of the 3 initial search terms explored. *Home abortion* had an average popularity search index relative to all other searches in the United States (RSI) of 30 in



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2020 compared with almost 10 for *self abortion* and 8 for *buy abortion pill online*. Searches for *home abortion* remained higher throughout the year compared with those for the 2 other search terms we explored, and peaked in November. By contrast, searches for *self abortion* and *buy abortion pill online* peaked in January and February of 2020, prior to the official onset of the COVID-19 pandemic, although there was less variability in these searches over time and these peaks do not reflect significantly greater relative interest compared with other weeks in 2020.

There were many top ranked queries associated with *home abortion*, including *abortion at home*, *at home abortion(s)*, *abortion pill*, *abortion remedies*, *abortion clinic*, *home remedies for abortion*, *pregnancy symptoms*, *how to have an at home abortion*, *how to do an at home abortion*, *how to do an abortion at home*, *Planned Parenthood*, and *abortion clinic near me*. Relative to all these top queries, *Planned Parenthood* had the highest RSV, followed by *abortion pill* and *abortion clinic* (Figure 3). In comparison, specific queries on *abortion at home*, *home abortion remedies*, and *how to do an abortion at home* or *how to have an abortion at home* were popular but had lower search volumes.

*Self induced abortion* was the only consistent top query for *self abortion*. Similarly, *buy abortion pill online* was associated with only 1 query, *buy abortion kit online*.

**Figure 2.** Nonmissing mean RSI (relative search index) values for *home abortion*, *self abortion*, and *buy abortion pill online* for January 1, 2020, to January 1, 2021. [a]Mean RSI calculated based on 30 unique data samples for January 01, 2020, to January 01, 2021, pulled from the Google Trends website for "health" queries only between April 01, 2021, and June 18, 2021. Nonmissing means presented with associated standard deviations.

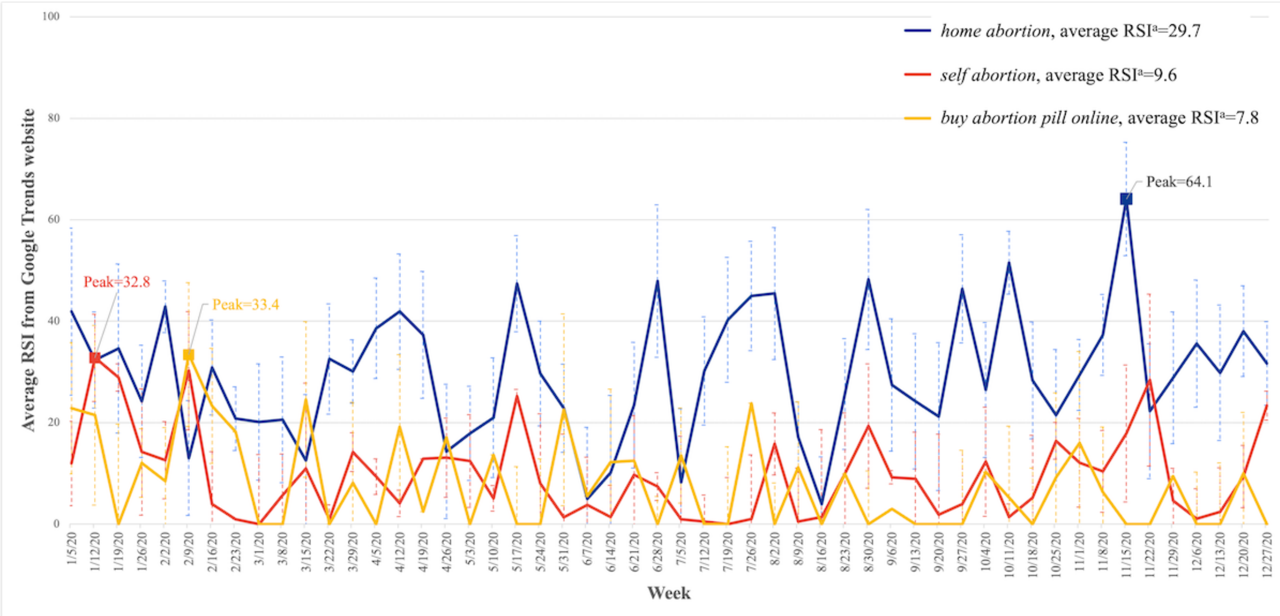
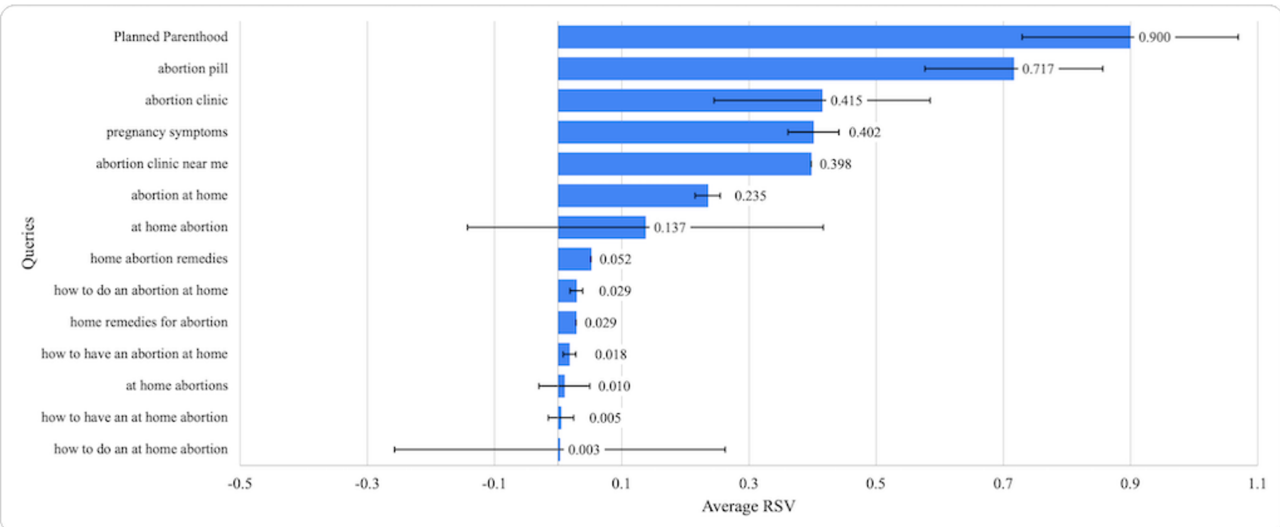



**Figure 3.** Nonmissing mean RSVs (relative search volumes) for top ranked queries associated with *home abortion* in the United States for January 1, 2020, to January 1, 2021. Nonmissing averages presented with associated standard deviations.





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### Search Traffic Across States

As shown in Table 1, among the 10 states with highest average RSI for *home abortion*, the majority were those where abortion was severely restricted (5/10) or restricted (3/10). Except for Pennsylvania, none of the top states with abortion restrictions were located in the Northeast. Conversely, New York and Connecticut, 2 states in the Northeast where abortion was accessible, also topped the list with highest searches for *home abortion*. Similarly, the majority of states with high average RSI for *self abortion* were severely restricted (2/10) or restricted (4/10) and some states where abortion is accessible, such as Massachusetts, New Jersey, Vermont, and Illinois, also topped the list for *self abortion* searches. There was no overlap in high-search states for these 2 initial search queries, suggesting differences in state-level interest in *home abortion* and *self abortion* searches. Google did not provide results for top states with the highest RSI for *buy abortion pill online*.

**Table 1.** Top 10 US states with the highest search traffic for home abortion and self abortion in 2020.

| Rank | *Home abortion* | | | *Self abortion* | | |
|---|---|---|---|---|---|---|
| | State | Average RSI[a] (SD) | Abortion access | State | Average RSI (SD) | Abortion access |
| 1 | Indiana | 0.7 (0.33) | Severely restricted | Alabama | 0.61 (0.44) | Severely restricted |
| 2 | Arizona | 0.69 (0.33) | Restricted | Virginia | 0.5 (0.38) | Restricted |
| 3 | New York | 0.65 (0.35) | Accessible | Florida | 0.4 (0.25) | Restricted |
| 4 | Pennsylvania | 0.65 (0.36) | Restricted | Massachusetts | 0.39 (0.33) | Accessible |
| 5 | Connecticut | 0.64 (0.38) | Accessible | Georgia | 0.30 (0.25) | Severely restricted |
| 6 | Missouri | 0.63 (0.41) | Severely restricted | New Jersey | 0.29 (0.33) | Accessible |
| 7 | Iowa | 0.62 (0.42) | Restricted | North Carolina | 0.26 (0.29) | Restricted |
| 8 | Kentucky | 0.62 (0.37) | Severely restricted | Illinois | 0.23 (0.21) | Accessible |
| 9 | Ohio | 0.62 (0.29) | Severely restricted | Pennsylvania | 0.22 (0.26) | Restricted |
| 10 | Arkansas | 0.61 (0.39) | Severely restricted | Vermont | 0.20 (0.42) | Accessible |

[a]RSI: relative search index.

### Top Webpages for *home abortion, self abortion,* and *buy abortion pill online* Searches

To better provide contextual evidence for our results, we took a snapshot of the top 10 webpages presented to users searching for *home abortion, self abortion,* and *buy abortion pill online* in the United States as of April 2021 (Multimedia Appendix 1). Regarding *home abortion,* only 2 of the top ranked webpages focused on health education, 1 from Healthline, a health blog that cautions against abortion home remedies while recommending that women consider physician-prescribed medication abortion at home; the other, an antiabortion blog from a Wisconsin clinic that focuses on the abortion process and on ways of reversing medication abortion. These 2 sites ranked first and ninth, respectively. A Wikipedia overview article on self-induced abortion ranked eighth. Several webpages focused on potential access expansions to home abortions under the Biden administration and to mail-order abortion pills approved in the United Kingdom during the pandemic. Webpages covering news and scholarly articles were more common than webpages from clinical settings.

For *self abortion,* webpages from the Guttmacher Institute (a proabortion advocacy organization) ranked first and third, followed by several academic publications.

As many as 4 out of 10 top webpages for *buy abortion pill online* were sponsored by prochoice groups such as Planned Parenthood, Vox, Ms. Magazine, and Plan C; these webpages openly discuss where and how to get abortion pills online. In contrast, 4/10 webpages presented antiabortion content, 2 managed by Crisis Pregnancy Centers that dissuade people from buying the abortion pill; 1 from a Florida county promoting a referendum to declare itself a "Pro-Life Sanctuary"; and 1 from a business blog cautioning potential online pill buyers from ending in jail because they are doing an illegal activity. Notably, the top webpage from the National Pharmaceutical Provider Association does not include any content on medication abortion. Images of top webpages for *buy abortion pill online* that were links to internal website search results providing no relevant content for medication abortion are presented in Multimedia Appendix 2 (webpages ranked 1, 7, and 10). The search query used for each of these internal searches included emojis or special characters or both.

## Discussion

### Principal Findings and Comparison With Prior Work

The use of medication abortion has been increasing steadily in the United States since its introduction in 2000, accounting for just 6% of all induced abortions in 2001 and almost 40% in 2017 [12]. Such steady growth in uptake of medication abortion coupled with increased access barriers to abortion, including recent disruptions related to COVID-19, may have accelerated the use of out-of-clinic-abortion services in the United States in 2020 [23,24]. We aimed to describe, in near–real-time, population interest in out-of-clinic abortion information and services during the pandemic on Google.

In 2020, *home abortion* was the most popular search term among those we explored. As shown by the multiple associated queries,


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this search term reflects interest from searchers in out-of-clinic abortion care. We cannot know the precise type of out-of-clinic abortion information or services being sought by consumers searching *home abortion*. However, we do know that there were more searches for *home abortion*—which could encompass any abortion happening at home regardless of clinical support—than for *self abortion*, a term that we believe implies an interest in self-management of abortion, and *buy abortion pill online*, a term that implies an interest in self-procurement of medication abortion.

Of the multiple top queries for *home abortion*, *Planned Parenthood* received the highest search traffic relative to other search queries for this keyword (based on RSV), followed by *abortion pill*. The higher search traffic may be associated with the high ranking of the Planned Parenthood website on Google. A previous study indicated that Planned Parenthood was the top webpage for medication abortion searches on Google and the site that provides the most accurate information on medication abortion [30]. Additionally, the higher RSV for Planned Parenthood in relation to *home abortion* searches may reflect an interest in out-of-clinic abortion involving a provider that can give oversight, medications, and support for an abortion at home and the role of Planned Parenthood as a recognized abortion provider offering telemedicine abortion services both prior to and during the pandemic [31]. In this model, clinicians remotely prescribe medication abortions by collaborating with Planned Parenthood centers that do not have on-site abortion providers. The patient visits their laboratories, undergoes ultrasound, and receives medications from their local Planned Parenthood Clinic.

Until 2020, the US Food and Drug Administration (US FDA) required certified providers to dispense mifepristone, 1 of the 2 drugs in the abortion regimen most commonly prescribed, in clinics or hospitals [9]. However, a federal district court ruled in July 2020 that the US FDA was required to lift this restriction and allow remote distribution of mifepristone via telemedicine during the pandemic. We note that searches for *home abortion* peaked in November of 2020, during the third wave of the COVID-19 pandemic and national allowance of telemedicine provision of medication abortion [8,9].

Novel platforms such as AidAccess and the Plan C Campaign are facilitating the online provision of abortion pills by offering information, support for, and access to medications for self-managed abortion [9,24]. Our results for *self abortion* and *buy abortion pill online*, searches that denote minimal provider support or fully online self-managed abortion care, showed that searches for *self abortion* were slightly more popular, but data for both were sparse. Our findings indicate relatively low population interest in these search queries for Google searchers in general, and compared with *home abortion*. Minimally supported or totally self-managed medication abortion with the 2-drug regimen of mifepristone and misoprostol is difficult to implement in the United States, even in states considered supportive of abortion rights, because ordering the drugs online through direct order without a prescription is considered illegal and many foreign clinics or pharmacies do not ship to the United States. By contrast, clinically supported home abortions may overcome multiple legal, economic, and cultural barriers because they may be more private, convenient, affordable, and less stigmatizing than in-clinic abortions. Aiken et al [24], using AidAccess data spanning January 2019 through April 2020, found an increase in the rate of requests for self-managed medication abortion in the United States [24]. Nonetheless, past research estimated that 7% of women in the United States would attempt to self-manage an abortion during their lifetime [14]. Notably, we found that searches for these 2 queries in 2020 peaked before the pandemic, in contrast to searches for home abortion that peaked during a third wave of COVID-19, during a time when telemedicine provision of medication abortion was allowed.

Previous studies have shown that legal restrictions to abortion do not reduce desire or intention to seek abortion care, but may push abortion seekers to virtual sources of information and services [15,24]. In light of such findings, our study provides important contextual evidence about the differences in relative queries across states with varying social attitudes and legal positions on abortion. *Home abortion* searches were predominantly most popular in states with restricted abortion access such as Arizona, Missouri, Arkansas, Indiana, and Kentucky. Arizona, Missouri, and Arkansas are 3 of the 5 states that prohibit the use of telemedicine for abortion while Indiana prohibits prescription of medication abortions without a prior in-person patient examination [9,31]. In 2020, Kentucky and Arizona enacted laws requiring physical presence of prescribing clinicians, hence effectively blocking the use of telemedicine [9]. Furthermore, several of the states with highest search traffic for *home abortion* attempted to limit abortion access during the COVID-19 outbreak by deeming abortion “non-essential” [32].

We saw the highest search traffic for *self abortion* among different states than for *home abortion*. Although *self abortion* traffic was mostly concentrated in Southern states where abortion is more restricted, traffic also came from 4 states, predominantly located in the Northeast, that make abortion accessible via telemedicine and by allowing nonphysician-certified clinicians to authorize the medication abortion [33]. Previous research suggested that barriers to clinic access are present even in states with more supportive abortion policies [15]. In these states, barriers to abortion include cost, difficulties taking time away from work or arranging childcare, abortion stigma, and the need to keep an abortion secret for fear of negative consequences [15].

As people turn to the internet for information and resources on out-of-clinic abortion, they can face challenges to informed reproductive choice and abortion access. Consistent with previous research on abortion webpages [30], we found that the top webpages listed in our snapshots provided limited evidence-based clinical content on self-management of abortions, particularly abortions without clinical provider supervision. The webpages linked to *buy abortion pills online* were neither relevant nor helpful. In fact, some pages offered no content related to abortion (self-managed or otherwise) and their appearance as top search results could be related to efforts to leverage search algorithm optimizations to appear higher on search results either through spam or erroneous linking. Furthermore, several sites presented disinformation about abortion, the pill, and other aspects of sexual and reproductive


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health, a finding that aligns with past research on the contents of abortion search results on Google [30,34,35]. Multiple legal, financial, cultural, and logistical barriers to abortion care underscore the need to support consumer access to accurate webpages that provide high-quality information and resources.

### Limitations

Our study faced several limitations. Although we researched 3 keywords for out-of-clinic abortions and their associated top queries, it is not an exhaustive list of every term searched. For instance, we considered *telemedicine abortion* and *telehealth abortion*, but Google did not give results for these search queries. Moreover, we were not able to identify the number of unique users or their individual characteristics, nor the reasons that prompt individuals to search for out-of-clinic abortion. Additionally, this research did not compare searches in 2020 for out-of-clinic abortion terms with previous years. Rather, we chose to scope our study to pre- and post-pandemic US searches within 2020. Nonetheless, additional sensitivity analyses comparing searches in 2020 with those in 2018 and 2019 showed similar search trends for *home abortion* and *self abortion*. Further research should be done to exhaustively explore differences in searches over time, in consideration of the impacts of changes in the volume of all Google searches over time on the frequency of searches for abortion-related terms. For example, time-series heatmaps and other visual representations of key terms by geographic region could be useful in future research and as general tools for understanding these trends.

We also cannot assume that online searches for out-of-clinic abortion reflect intention to use or current use of this type of abortion care. Google data allow us to assess relative population-level search interest and concerns about key topics and search queries in near or real-time. However, Google Trends only shows data for popular queries, so search queries with low volume appear as "0." The Google Health Trends API does not give RSV below a certain threshold (unknown to us). Following prior research, we addressed this limitation by implementing a resampling approach over several months. We treated each of 30 data extractions from the Google Trends and Health Trends API as an independent sample and calculated average measures (RSI score and RSV score with nonmissing averages). We believe this is a valid way to account for inherent sampling fluctuations created by Google's own mechanisms that intentionally obfuscate precise search activity at any one point in time [36]. We urge other researchers to consider the resampling approach in future analyses of infrequent Google search data.

Additionally, although we chose our initial search queries carefully, with consideration of relevant literature and search interest, further research should explore other search queries related to self-management of abortion to establish user interest for other relevant queries. As for top webpages that searchers of out-of-clinic abortion are shown on Google, we took a snapshot of these based on a 1-day retrieval of data; these listings and rankings are likely to fluctuate over time. Future research should examine top webpages and their rankings by frequent resampling over time and do a thorough content analysis to gain further insights into the content and quality of webpages providing information on abortion self-management to people searching on Google.

### Conclusions

Our analysis provided meaningful insights into population-level interest in out-of-clinic medication abortions in the United States during the first year of the pandemic. Our findings demonstrate greater interest in home abortions, which presumably have varying degrees of clinical support than in minimally or nonclinically supported self-induced abortions. While our study was mainly descriptive, showing ways in which infrequent abortion-related search data can be analyzed, future studies should explore correlations between the keywords denoting interest in out-of-clinic abortion and abortion care measures and test models that allow for improved monitoring and surveillance of abortion concerns in our rapidly evolving policy context.


## Acknowledgments

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## Conflicts of Interest

None declared.

Multimedia Appendix 1

A snapshot of top webpage results for *home abortion*, *self abortion*, and *buy abortion pill online* searches in the United States as of April 4, 2021.

[DOCX File , 25 KB - infodemiology_v2i1e33184_app1.docx ]

Multimedia Appendix 2

Images of top webpages for *buy abortion pill kit online* presenting internal site search results.

[DOCX File , 1904 KB - infodemiology_v2i1e33184_app2.docx ]



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## Abbreviations

**API:** application programming interface
**US FDA:** US Food and Drug Administration
**RSI:** relative search index
**RSV:** relative search volume
**WHO:** World Health Organization

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Original Paper

# COVID-19 and Tweets About Quitting Cigarette Smoking: Topic Model Analysis of Twitter Posts 2018-2020

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## Abstract

**Background:** The risk of infection and severity of illness by SARS-CoV-2 infection is elevated for people who smoke cigarettes and may motivate quitting. Organic public conversations on Twitter about quitting smoking could provide insight into quitting motivations or behaviors associated with the pandemic.

**Objective:** This study explored key topics of conversation about quitting cigarette smoking and examined their trajectory during 2018-2020.

**Methods:** Topic model analysis with latent Dirichlet allocation (LDA) identified themes in US tweets with the term "quit smoking." The model was trained on posts from 2018 and was then applied to tweets posted in 2019 and 2020. Analysis of variance and follow-up pairwise tests were used to compare the daily frequency of tweets within and across years by quarter.

**Results:** The mean numbers of daily tweets on quitting smoking in 2018, 2019, and 2020 were 133 (SD 36.2), 145 (SD 69.4), and 127 (SD 32.6), respectively. Six topics were extracted: (1) need to quit, (2) personal experiences, (3) electronic cigarettes (e-cigarettes), (4) advice/success, (5) quitting as a component of general health behavior change, and (6) clinics/services. Overall, the pandemic was not associated with changes in posts about quitting; instead, New Year's resolutions and the 2019 e-cigarette or vaping use–associated lung injury (EVALI) epidemic were more plausible explanations for observed changes within and across years. Fewer second-quarter posts in 2020 for the topic e-cigarettes may reflect lower pandemic-related quitting interest, whereas fourth-quarter increases in 2020 for other topics pointed to a late-year upswing.

**Conclusions:** Twitter posts suggest that the pandemic did not generate greater interest in quitting smoking, but possibly a decrease in motivation when the rate of infections was increasing in the second quarter of 2020. Public health authorities may wish to craft messages for specific Twitter audiences (eg, using hashtags) to motivate quitting during pandemics.

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**KEYWORDS**

COVID-19; machine learning; pandemic; quit smoking; topic model analysis; Twitter; social media; smoking cessation; latent Dirichlet allocation; tweet; public health

## Introduction

### Background

Researchers and health authorities (eg, Centers for Disease Control and Prevention) are increasingly using Twitter, a social media platform with over 35 million daily active users in the United States [1], to achieve public health goals. These include disseminating health information and surveillance or prediction of health-related behaviors [2-5]. Tobacco researchers have also investigated Twitter postings (tweets) to identify and monitor attitudes or behaviors of people who smoke cigarettes or other tobacco products [6-11]. The aim of this study was to examine key topics of public conversations about quitting cigarette smoking during the COVID-19 pandemic. This could help



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determine whether public health action(s) to address smoking or quitting during a pandemic may be warranted.

There are several reasons why the COVID-19 pandemic may have influenced cigarette smoking behavior. Perceiving oneself at heightened risk for disease due to smoking can trigger attempts to quit that lead to abstinence [12,13]. COVID-19 has caused more than 6 million deaths worldwide [14], and is understood to be a respiratory disease for which the risk of infection and severity of illness are significantly elevated for cigarette smokers (due to preexisting damage to the respiratory system) [15,16]. Rates of quitting smoking would be expected to increase during the pandemic, at least to the extent that people who smoke are aware of their elevated risk. Yet, analyses from the North American Quitline Consortium found a 27% reduction in calls to quitlines in 2020 for cessation counseling compared to those in 2019 [17]. The largest decreases occurred in the second (–39%) and third (–30%) quarters of 2020, paralleling the onset and unfolding of the pandemic. These data suggest that people who might otherwise have quit continued smoking instead (ie, postponed or canceled plans to quit). However, given the very low reach of quitlines [18,19], it is unclear whether smokers who intended to call quitlines for cessation assistance are representative of the overall population of people who smoke.

Although perceiving oneself at higher risk of infection or illness might increase the motivation to quit smoking for some individuals, for many individuals the pandemic may have had the opposite effect. Several studies have documented increased anxiety or depression linked to the pandemic [20-27], and for many who smoke, negative affect or stress is a trigger of cravings and/or smoking [28-31]. At its peak, the pandemic had, and continues to have, multiple stressful sequelae (eg, on employment, income, social interactions, health care, child care) [32], which may have led to cigarette smoking as a stress-relief strategy. Moreover, lockdowns that necessitated working from home could have obviated workplace smoking restrictions that had previously limited consumption. Using cigarettes to cope with stress, or the absence of restrictions on smoking, may partly explain findings from data collected by the Alcohol and Tobacco Tax and Trade Bureau of the US Department of Treasury. Analyses of these data indicated that sales of cigarettes to retail and wholesale outlets increased during 2020, a reversal from annual decreases since 2015 [33].

Studies that have directly asked smokers about their smoking patterns or quitting behaviors during the pandemic have been inconclusive, with some reporting increases, decreases, or both. One cross-sectional study of 366 mostly dual users of cigarettes and electronic cigarettes (e-cigarettes) conducted early in the pandemic in the United States (April 2020) found that approximately half reported no change in their motivation to quit due to COVID-19, with approximately one-third reporting an increase. Approximately one-fifth of the sample reported trying to quit because of COVID-19 [34].

An online survey (also conducted early in the pandemic) of 6800 cigarette smokers from 5 countries found that although 41% and 37% of US and UK smokers, respectively, said that they considered quitting, only 27% (US smokers) and 21% (UK smokers) reported actually making a quit attempt [35]; however, since the respondents were asked only about recent quit attempts, quitting for reasons other than COVID-19 could not be ruled out [35]. A qualitative study conducted in April-May 2020 of 44 individuals who used either cigarettes or electronic nicotine delivery systems found increased consumption to be more common, but also noted a decrease among "social" users [36].

Overall, while several studies have suggested that smoking intensity increased during the pandemic [37-42], there have been exceptions [43,44]. Methodological differences across studies likely account for varying results in terms of design (eg, longitudinal vs cross-sectional), sample size, measures used, geographic location, sociodemographic differences (eg, age, gender), or other factors (eg, exposure to news media coverage of the pandemic that could exacerbate stress reactions [45]).

### Current Focus

We propose that a topic model analysis of tweets related to quitting cigarette smoking in 2020 and prior years could illuminate how the pandemic influenced thoughts about, plans, or attempts to quit. Since Twitter posts are user-generated, analyses of postings represent an organic and real-time approach compared to investigator-initiated surveys, which involve lags in development, administration to respondents, and data collection and analysis. The frequency of tweets can also be examined over many days, weeks, or even years to gain insights into motivations and trends. Other appealing features of Twitter include its use by approximately one quarter of US adults, with similar proportions of white, Black, or Hispanic users [46-48].

Prior work also suggests links between talking about tobacco-related topics on Twitter and subsequent tobacco use behaviors [49]. Additionally, Twitter conversations are sensitive to ongoing events and are useful for monitoring health-related trends [2]. As such, tracking the trajectory (frequency) of key topics of conversations pertaining to quitting cigarette smoking during and prior to the pandemic could offer insights about its relationship to quitting behaviors. Findings from this research could potentially provide early warning signs for public health interventions to address adverse effects of the pandemic using Twitter or other social media platforms.

## *Methods*

### Overview

We used a latent Dirichlet allocation (LDA) model to identify dominant topics among Twitter postings that included the phrase "quit smoking." LDA, a form of unsupervised machine learning used to classify documents [50], assumes that each document (in this case a tweet) may belong to more than one topic. Words from tweets are randomly placed into topics but are systematically moved to different topics so that "fit" can be iteratively tested. After a number of iterations, "topics" emerge consisting of a combination of words with associated "weights." The combination of words provides insight into the theme of a topic. Tweets with the highest probability of belonging to a particular topic are considered to be most representative of that topic.



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By using LDA to identify topics associated with the term "quit smoking" and examining their frequency in 2018, 2019, and 2020, we aimed to (1) identify the most important themes in natural discussions about quitting cigarettes, and (2) their changes in frequency in 2020 in the context of the pandemic.

### Ethics Approval

Institutional review board approval was not required as our data collection involved aggregate analysis of visible public data without linking of personal identifiers. Twitter's user consent agreement also includes the possibility of tweets being used in research.

### Data Collection

All (100%) daily tweets containing the phrase "quit smoking" posted between January 1, 2018, and December 31, 2020, were collected using Social Studio, an online social media engagement platform owned by Salesforce. This resulted in a total of 201,181 tweets.

Tweets were geographically limited to US accounts to increase generalizability to the US population and because of differences among countries as to when public health measures were implemented to reduce the pandemic's spread.

Only tweets containing the phrase "quit smoking" were collected. We had originally employed an expansive list of search terms to capture quitting smoking, but this resulted in poorer topic modeling due to the colloquial nature of tweets (eg, using the search phrase "stop smoking" was often used pejoratively in replies to tweets unrelated to tobacco use).

Retweets, quote tweets, and identical tweets were removed from the data set to reduce spam from bots associated with products and website promotion or activity. To reduce noise related to cannabis use, tweets containing the words "weed," "blunt," "crack," "roach," "baked," "dabs," "marijuana," "bong," "mary jane," "maryjane," and "pot" were removed [51].

To improve model performance, all tweets were converted to lower case and URLs were removed. Tweets were converted into lists of individual words (ie, tokenization). Individual words were then tagged with their part of speech (eg, "verb" or "noun") and shortened to their stem. This conversion of words such as "coughing" or "coughed" to simply "cough" prevents misclassification due to tense or plurality. Words that contained only digits were removed because they do not provide meaningful information to a topic model. Stop words; words such as "the," "to," or "and"; as well as words less than two characters long were removed to prevent inclusion of noninformative words in the topic model. Two-word phrases that occurred in at least 20 tweets were combined into one "word" so that commonly related words would be placed in a topic together.

### Topic Selection

For topic modeling, we used the gensim library for Python, which provides an LDA model creation function and has a sizeable documentation library and large feature set. Model parameters such as the document-topic distributions (α) and topic-word distributions (η) can also be automatically determined.

A (bigram) model was first trained on tweets from 2018 and then applied to tweets posted in 2019 and 2020. We used the 2018 tweets as the training set to identify topics related to cessation that would not be influenced by COVID-19–related topics and that would not be present in our comparison data set (2019).

To determine the total number of topics in the 2018 data, the model was run for 10 passes and 200 iterations. For the first iteration, the total number of topics was set to 2 and the model's coherence statistic was noted. This process was repeated progressively for up to 50 topics, and the resulting coherence scores were graphed to enable selection of the optimal number of topics. The LDA model also indicated the proportionate distribution among final topics for each tweet (eg, a tweet could have a proportion of 0.75 for one topic and 0.25 for a second topic if the tweet broached both topics). Final topics were labeled by two authors (JLW and MM) based on the most influential words for that topic and by examining representative tweets. For each final topic, proportions were summed to derive the total number of tweets belonging to that topic.

### Statistical Analysis

For each topic, we analyzed mean daily tweets by quarters because rates of infection in the second quarter of 2020 had begun to rise more steeply compared to those in the previous 3 months (first quarter) of the year [52]. Analysis of variance and follow-up pairwise comparisons (with Bonferroni correction) compared mean numbers of daily tweets among quarters within each year. We also compared, by quarter, pairwise differences across years (eg, January-March for 2020, 2019, and 2018). As a measure of the sensitivity of topics to the pandemic, we examined the proportion of each topic's tweets in 2020 (by quarter) that mentioned "coronavirus" or "covid."

## *Results*

### Overview of Topics Identified and Trends Over Time

The average daily number of tweets related to quitting smoking in 2018, 2019, and 2020 were 133 (SD 36.2), 145 (SD 69.4), and 127 (SD 32.6), respectively. Ten topics were initially identified as optimal. Of these, four were clearly spam or advertisements and were eliminated, resulting in six final topics that were selected for analyses: (1) *need to quit*, (2) *personal experiences*, (3) *e-cigarettes*, (4) *advice/success*, (5) *quitting as a component of general health behavior change*, and (6) *clinics/services*. The number of quit smoking–related tweets, by topic and quarter, are provided in Table 1. Examples of tweets from each topic appear in Table 2.



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**Table 1.** Number and percent of "quit smoking" tweets by topic and year for each quarter.

| Topic | 2018 | | 2019 | | 2020 | |
|---|---|---|---|---|---|---|
| | N | n (%) | N | n (%) | N | n (%) |
| **Need to quit** | | | | | | |
| January-March | 13,839 | 1654 (11.95) | 13,709 | 1382 (10.08) | 13,732 | 1311 (9.55) |
| April-June | 11,971 | 1503 (12.56) | 10,696 | 1146 (10.71) | 10,605 | 1121 (10.57) |
| July-September | 11,206 | 1466 (13.08) | 15,178 | 1402 (9.24) | 10,608 | 1083 (10.21) |
| October-December | 11,456 | 1262 (11.02) | 13,433 | 1202 (8.95) | 11,683 | 1191 (10.19) |
| **Personal experiences** | | | | | | |
| January-March | 13,839 | 3610 (26.09) | 13,709 | 3646 (26.60) | 13,732 | 3641 (26.52) |
| April-June | 11,971 | 3185 (26.61) | 10,696 | 2887 (26.99) | 10,605 | 2895 (27.30) |
| July-September | 11,206 | 2934 (26.18) | 15,178 | 3624 (23.88) | 10,608 | 3001 (28.29) |
| October-December | 11,456 | 2898 (25.30) | 13,433 | 2887 (21.49) | 11,683 | 3313 (28.36) |
| **Electronic cigarettes** | | | | | | |
| January-March | 13,839 | 2447 (17.68) | 13,709 | 2586 (18.86) | 13,732 | 2671 (19.45) |
| April-June | 11,971 | 2006 (16.76) | 10,696 | 1896 (17.73) | 10,605 | 1617 (15.25) |
| July-September | 11,206 | 1729 (15.44) | 15,178 | 4222 (27.82) | 10,608 | 1594 (15.03) |
| October-December | 11,456 | 2012 (17.56) | 13,433 | 3483 (25.93) | 11,683 | 1573 (13.46) |
| **Advice/success** | | | | | | |
| January-March | 13,839 | 1767 (12.77) | 13,709 | 1857 (13.55) | 13,732 | 2108 (15.35) |
| April-June | 11,971 | 1569 (13.11) | 10,696 | 1560 (14.58) | 10,605 | 1651 (15.57) |
| July-September | 11,206 | 1549 (13.82) | 15,178 | 2186 (14.40) | 10,608 | 1619 (15.26) |
| October-December | 11,456 | 1548 (13.51) | 13,433 | 2000 (14.89) | 11,683 | 1837 (15.72) |
| **Health changes** | | | | | | |
| January-March | 13,839 | 2761 (19.95) | 13,709 | 2860 (20.86) | 13,732 | 2759 (20.09) |
| April-June | 11,971 | 2577 (21.53) | 10,696 | 2291 (21.42) | 10,605 | 2317 (21.85) |
| July-September | 11,206 | 2426 (21.65) | 15,178 | 2728 (17.97) | 10,608 | 2319 (21.86) |
| October-December | 11,456 | 2476 (21.61) | 13,433 | 2464 (18.34) | 11,683 | 2485 (21.27) |
| **Clinics/services** | | | | | | |
| January-March | 13,839 | 1600 (11.56) | 13,709 | 1378 (10.05) | 13,732 | 1242 (9.04) |
| April-June | 11,971 | 1131 (9.45) | 10,696 | 917 (8.57) | 10,605 | 1004 (9.47) |
| July-September | 11,206 | 1101 (9.83) | 15,178 | 1015 (6.69) | 10,608 | 991 (9.34) |
| October-December | 11,456 | 1259 (10.99) | 13,433 | 1085 (8.08) | 11,683 | 1284 (10.99) |


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**Table 2.** Topics and representative tweets.

| Topic | Key words | Sample tweets |
|---|---|---|
| Need to quit | need, really, gotta, cigarette, wanna, help, like, know, stop, friend, pregnant, sad, job, real, die, hard, soon, damn, win, cigs | "I need to quit smoking. tobacco is a demon it's so addictive I gotta stop. I threw out my cigarettes just now. I want them tho." "I need to quit smoking man. This shit has taken away my life. But there isn't shit to do in Lorain besides rolling up with your friends." |
| Personal experiences | cigarette, year, day, since, time, year_ago, last, try, month, week, buy, still, gonna, decide, hard, life, cold_turkey, ago, smell, feel | "I quit smoking right around this time of year, 10 years ago (passover). After the first year the cravings stopped, pretty much completely. Yet all of a sudden, a minute ago I got the strongest urge, even visualized lighting up. I guess it never does go all the way away?" "I've decided to quit smoking. For good. Hopefully. I hadn't smoked since Saturday. I bought a pack tonight. Got home. Opened the pack. Pulled out a cig. And was about to light it when I stopped. I ran to the trash can, threw the lighter, cig and the whole pack away." |
| E-cigarettes | help, vaping, people, use, want, vape, tobacco, start, nicotine, flavor, product, try, may, health, find, juul, offer, adult, learn, good | "I know of hundreds of adults that have quit smoking cigarettes in favor of candy flavored ejuice. I find it hard to believe that children are buying this in a large scale, and sounds like a parental and education problem rather than a candy flavor problem. this creates false fear" "With vaping, you take away most of the harmful parts of tobacco. I'll admit the science is not fully developed, esp on negative consequences, but it seems clear that vaping helps people quit smoking and is safer than cigarettes." |
| Advice/success | would, help, say, never, use, life, people, year, tell, wish, love, work, give, change, mom, doctor, easy, addiction, still, nicotine | "I can tell you how to quit smoking and it won't suck as much. Get the patches use the highest dosage for 21 days that's how long it'll take to break the hand-to-mouth habit after 21 days get a lesser dosage after 21 days of. step down again. It works" "Had some bad days in 2018. made big changes! down 40lbs, quit smoking > 3 mths, walking 5 mi. a day. and yes, the other stuff too- but much longer! thank you! you could've been mean, but all choose not to! thankful for the ass kicking I needed and the silver lining I found!" |
| Quitting as a component of general health behavior change | get, good, want, like, think, year_ago, drinking, drink, cigarette, eat, feel, start, work, life, try, job, people, stop, since, never | "Life is good. My daughter is smart, healthy, witty, & beautiful. I have a stable job that I'm good at & don't hate. I'm about to trade in my 2010 Malibu & get my own place. My credit score is bomb. I quit smoking cigarettes almost a year ago. I'm super blessed." "So far this year I have stopped eating fried food, started getting up earlier, started eating more vegetarian/vegan food types, and quit smoking cigarettes. I intend to constantly peak in 2018." |
| Clinics/services | free, help, get, call, time, support, good, today, stop, need, health, reason, ready, visit, plan, book, therapy, service, contact, register | "Pregnant and ready to quit smoking? our baby & me - tobacco free program can help! enroll today to start your quit journey and start earning free diapers and baby gear! Call to schedule your first appointment. #pregnancy #smoking #smokefree #baby #free #health" "Happy National Non-Smoking Week! #mlhu is hosting a quit smoking workshop in #ldnont Thursday, January 25. participants will receive free nicotine patches & educational material. To see if you're eligible and to register, please call #nnsw #nnsw2018" |

## Need to Quit

Tweets for which *need to quit* was the dominant topic expressed a desire or need to quit smoking cigarettes in the present or near future (eg, "I'm going to really try to stop smoking after this weekend"; see Table 2 for additional examples of tweets from each topic). In 2020, the mean daily frequency of tweets about the need to quit smoking (Figure 1) was higher in the first quarter (mean 14.4, SD 3.6) compared to the second (mean 12.3, SD 2.6; $P$=.001), third (mean 11.8, SD 2.7; $P$=.001), and fourth (mean 12.9, SD 3.5; $P$=.009) quarters; the last 3 quarters of 2020 did not differ significantly from each other.

The frequency of tweets about the need to quit was significantly higher for the first 3 quarters of 2018 compared with those at the same periods in 2020 (mean 18.4 vs 14.4, $P$=.001; 16.5 vs 12.3, $P$=.001; 15.9 vs 11.8, $P$=.001). From October to December, however, there were no significant differences across all 3 years in daily tweets about the need to quit. The only significant difference between 2019 and 2020 was observed for the 3rd quarter (mean 15.2 vs 11.8, respectively; $P$=.001).


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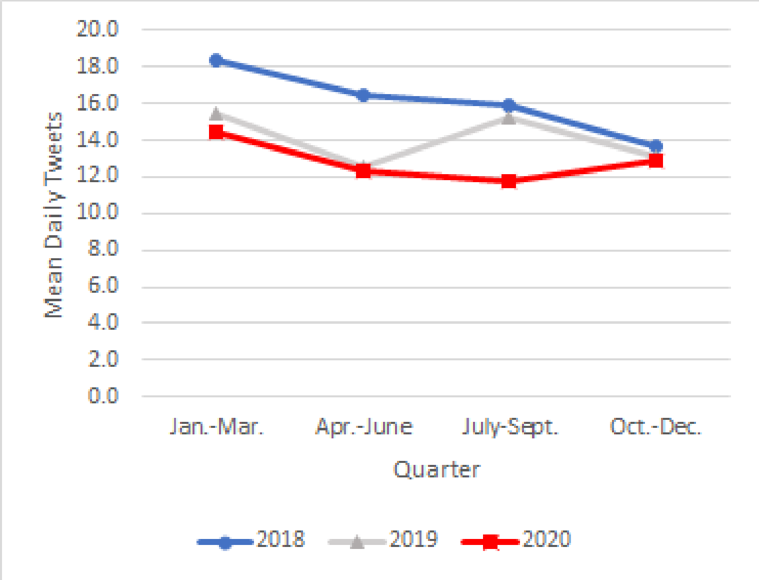
**Figure 1.** Mean daily tweets about need to quit by year and quarter.

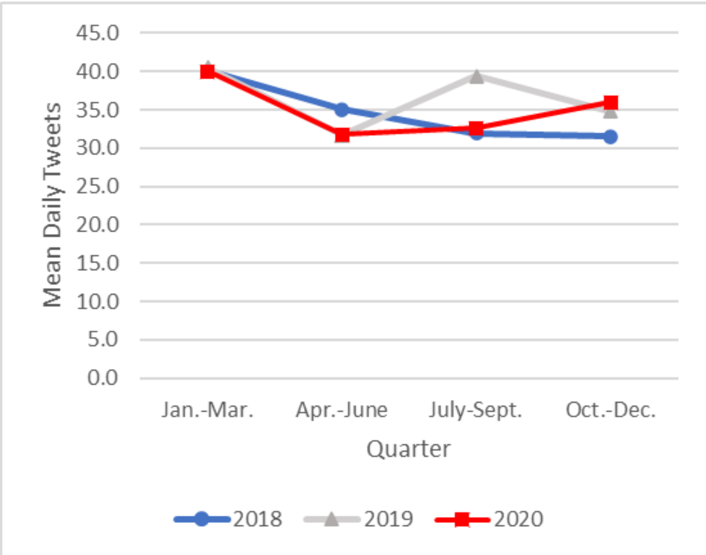



## Personal Experiences

Tweets for which *personal experiences* was the dominant topic expressed personal actions or difficulties in attempting to quit or positive effects of having quit (eg, "I'm trying to stop smoking but I'm dying to smoke"). In 2020, the mean daily frequency of tweets about personal experiences with quitting (Figure 2) was higher in the first quarter (mean 40.0, SD 11.3) compared to the second (mean 31.8, SD 6.9; *P*=.001), third (mean 32.6, SD 6.2; *P*=.001), and fourth (mean 36.0, SD 10.5; *P*=.02) quarters. Of the 4 quarters in 2020, the frequency of the last quarter's tweets was the second highest and significantly greater than that for the second quarter of 2020 (*P*=.01), suggesting an uptick in frequency late in 2020. The mean number of daily tweets in the last quarter of 2020 (mean 36.0, SD 10.5) was also significantly greater than that for the same quarter in 2018 (mean 31.5, SD 8.7; *P*=.005), but not compared to that in 2019 (mean 34.8, SD 9.5; *P*=.99).

A substantial spike in tweets about personal experiences with quitting was observed in 2019 during the third quarter, coincident with the e-cigarette or vaping product use–associated lung injury (EVALI) epidemic. The mean number of daily tweets during the third quarter in 2019 was significantly higher (mean 39.4, SD 18.5) than that in the third quarter of 2018 (mean 31.9, SD 6.6; *P*=.001) or in 2020 (mean 32.6, SD 6.2; *P*=.001).

**Figure 2.** Mean daily tweets about personal experiences by year and quarter.




## E-cigarettes

Tweets for which *e-cigarettes* was the dominant topic referred to e-cigarettes in the context of quitting smoking (eg, "…finally decided to buy a JUUL to quit smoking cigarettes, but I paid $50 for a starter kit with only two pods…four were advertised online.. not good"). In the first quarter of 2020, the mean number of daily tweets about e-cigarettes (Figure 3) was significantly higher (mean 29.3, SD 14.6) compared with those in the second (mean 17.8, SD 6.2; *P*=.001), third (mean 17.3, SD 4.8; *P*=.001),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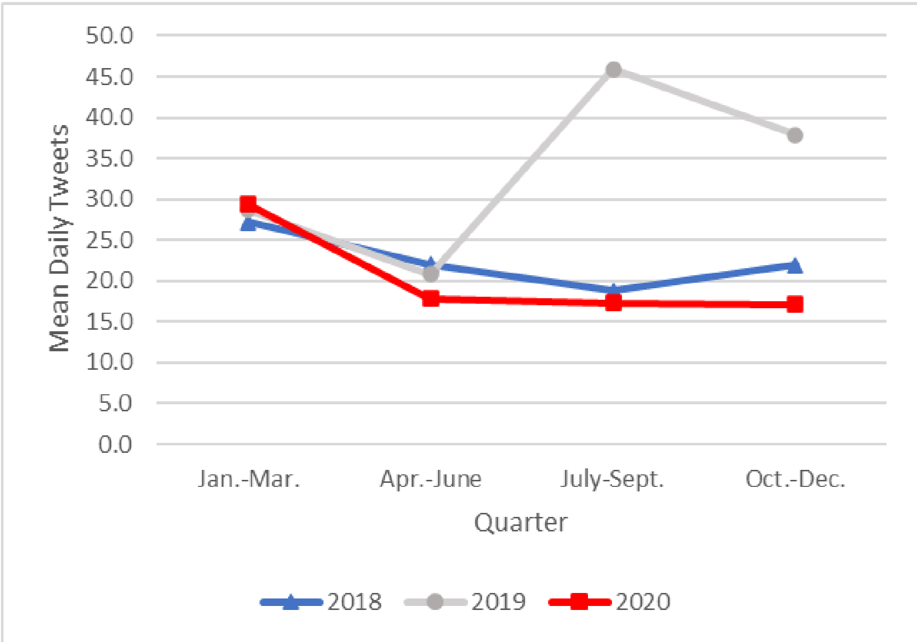
and fourth (mean 17.1, SD 6.5; *P*=.001) quarters of 2020. For these last 3 quarters in 2020, the mean daily number of tweets about e-cigarettes did not differ significantly from each other. Cross-year comparisons indicated that the mean number of fourth-quarter tweets in 2020 was significantly lower (mean 17.1, SD 6.5) than those in the same period in 2019 (mean 37.9, SD 15.3; *P*=.001) and 2018 (mean 21.9, SD 11.6; *P*=.02).

The pattern of tweets about e-cigarettes across quarters in 2018 was similar to that of 2020 (a drop in frequency of tweets after the first quarter, and similar levels in subsequent quarters). In 2019, there was a substantial spike in the third quarter (mean 45.9, SD 61.2) compared to the first (*P*=.003) and second (*P*=.001) quarters that likely reflected heightened awareness and discussion about the role of e-cigarettes in causing EVALI. This heightened frequency of tweets in the third quarter of 2019 continued into its final quarter (mean 37.9, SD 15.3).

**Figure 3.** Mean daily tweets about electronic cigarettes by year and quarter.




## Advice/Success

Tweets for which *advice/success* was the dominant topic expressed personal success in having quit smoking and/or provided encouragement or advice for quitting (eg, "That's when you get help for your addiction to quit smoking…"). The mean number of daily tweets with quitting advice/success stories (Figure 4) was significantly higher in the first quarter of 2020 (mean 23.2, SD 7.1) compared with those in the second (mean 18.1, SD 5.3; *P*=.001), third (mean 17.6, SD 3.7; *P*=.001), and fourth (mean 20.0, SD 5.4; *P*=.001) quarters. First-quarter tweets in 2020 were also significantly higher compared with those in the same period in 2019 (mean 20.6, SD 6.1; *P*=.03) and 2018 (mean 19.6, SD 6.3; *P*=.001). Fourth-quarter tweets in 2020 (mean 20.0, SD 5.4) were significantly higher compared with those in the same period in 2018 (mean 16.8, SD 8.9; *P*=.008), but did not differ from those of 2019 (mean 21.7, SD 6.0; *P*=.26).

In 2019, the third quarter's mean daily number of tweets with quitting advice/success stories was significantly elevated (mean 23.8, SD 18.3) compared with that of the previous quarter (mean 17.1, SD 4.5; *P*=.001). This heightened level of tweets in the third quarter of 2019 continued into its final quarter (mean 21.7, SD 6.0).


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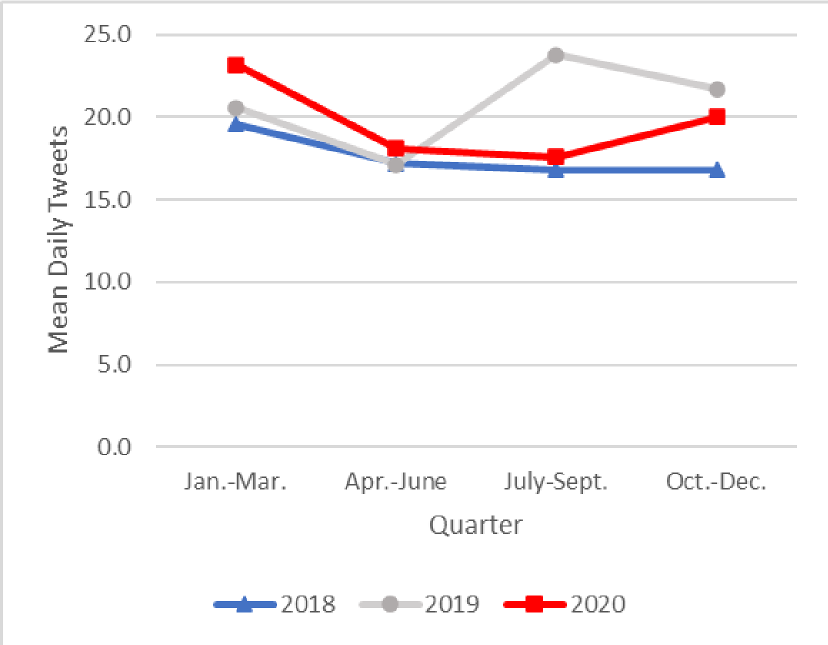
**Figure 4.** Mean daily tweets about advice/success by year and quarter.




## Quitting as a Component of General Health Behavior Change

Tweets for which *quitting as a component of health behavior change* referenced health behavior change in general that also included quitting smoking, for example:

> *Remembering how important it is to have self control has: 1. Helped me quit smoking cigarettes 2. Realize the control alcohol had over me when I was weak 3. Made me a better friend 4. Be optimisitic about my overall self worth 5. Be a better worker at my job.*

In 2020, the mean daily frequency of tweets about quitting in the context of health behavior change (Figure 5) was significantly higher in the first quarter (mean 30.3, SD 7.9) compared with those in the second (mean 25.5, SD 5.4; *P*=.001), third (mean 25.2, SD 5.4; *P*=.001), and fourth (mean 27.0, SD 6.2; *P*=.003) quarters.

The mean number of daily tweets was also lower in the second quarter of 2020 (mean 25.5, SD 5.4) compared with that in the same period in 2018 (mean 28.3, SD 6.6; *P*=.002), although not compared with that in 2019 (mean 25.2, SD 5.1; *P*=.99). The frequency of tweets about quitting in the context of general health behavior change was lower in the third quarter of 2020 (mean 25.2, SD 5.4) compared with that in the same period in 2019 (mean 29.7, SD 13.3; *P*=.002), but not compared to 2018 (mean 26.4, SD 4.9; *P*=.99).



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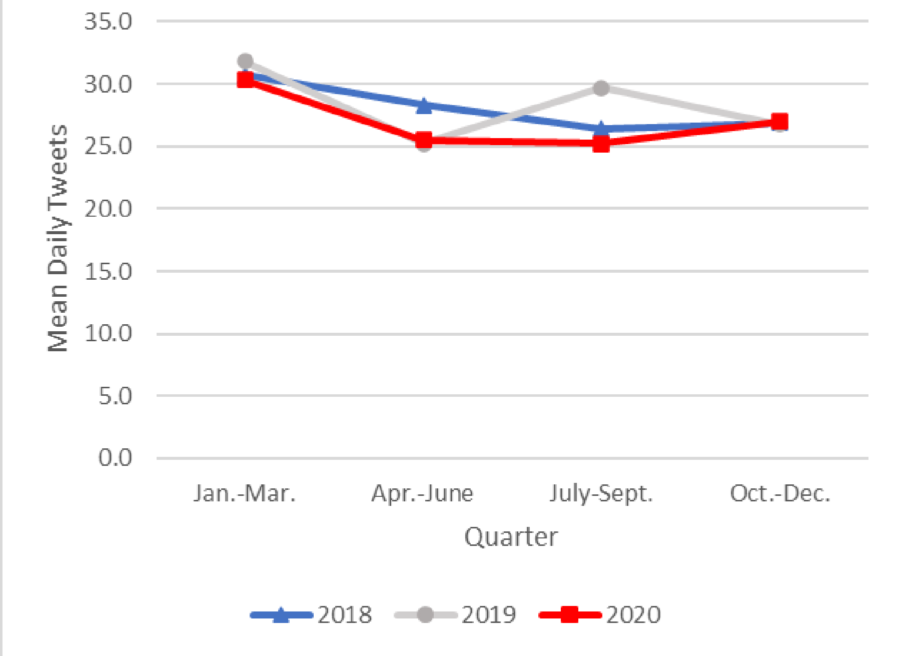
**Figure 5.** Mean daily tweets about quitting as a component of general health behavior change by year and quarter.




## Clinics/Services

Tweets for which *clinics/services* was the dominant topic offered help for quitting by clinics, companies, or support services, for example:

> *Quit smoking for the first 7 days of the month and you could win $500! Why is the first week so important? Because if you are successful for the first week, you're 9x more likely to quit for good. And that's amazing!*

The general pattern for frequency of tweets about support services for quitting was similar across quarters for all 3 years: higher in the first quarter, followed by a decrease in the second quarter that was maintained in the third quarter, followed by modest increases in the last quarter of the year (Figure 6).

For 2020, the frequency of daily tweets about support services for quitting was higher in the first quarter (mean 13.6, SD 5.1) compared with those in the second (mean 11.0, SD 3.6; *P*=.002) and third (mean 10.8, SD 3.7; *P*=.001) quarters, but not compared with that of the fourth quarter (mean 14.0, SD 6.5, *P*=.99) of 2020. In the last quarter of 2020, however, the increase in tweets for support services was significantly greater compared with those in the previous two quarters of 2020 (both *P*=.001). The mean frequency of tweets about support services for the first quarter of 2020 was significantly lower (mean 13.6, SD 5.1) than that of the first quarter of 2018 (mean 17.8, SD 7.4; *P*=.001).



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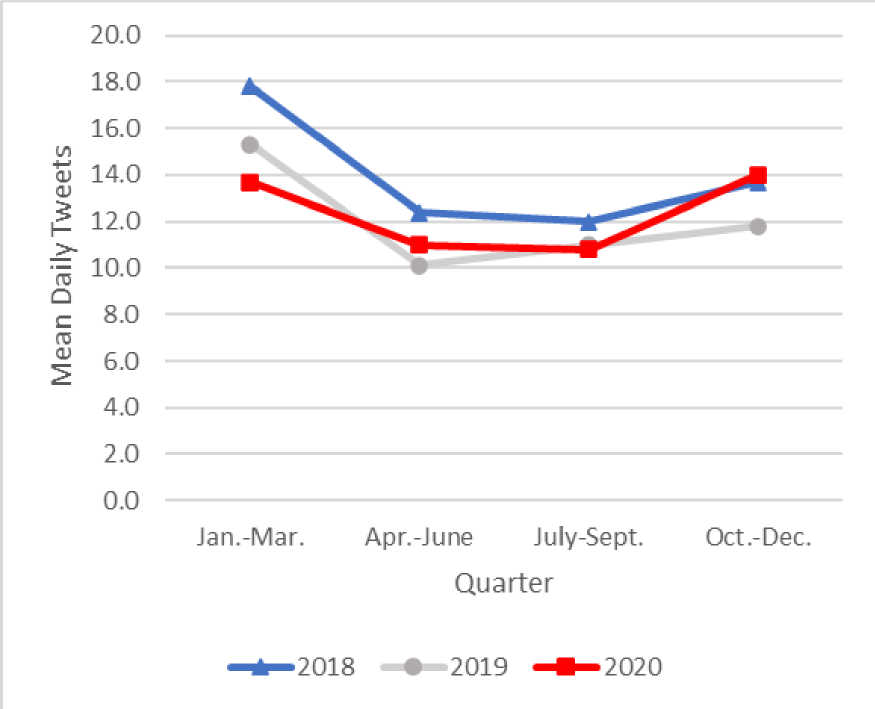
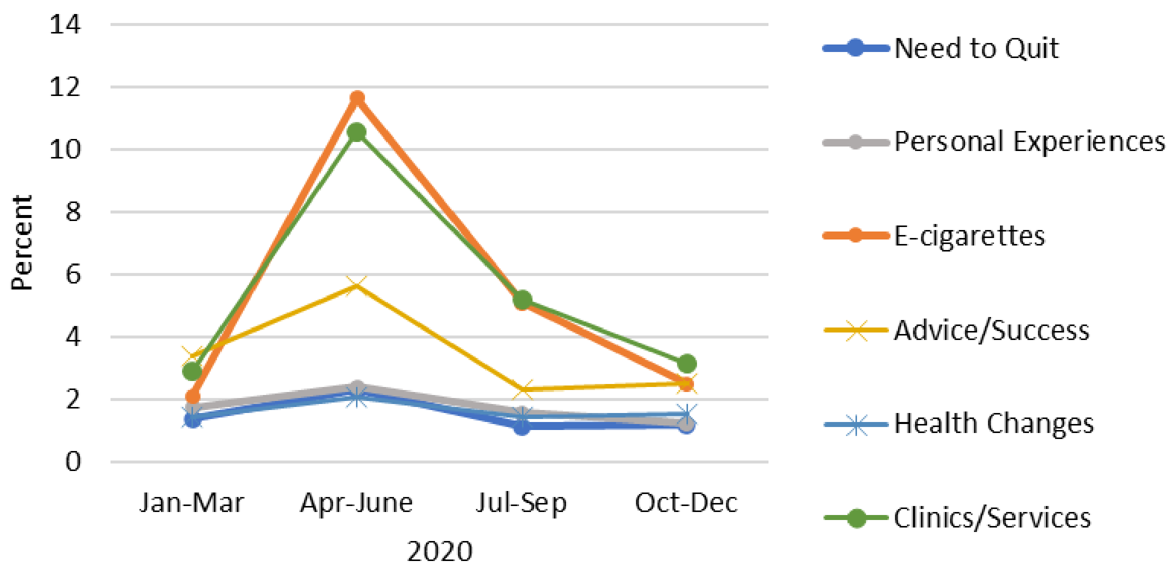
**Figure 6.** Mean daily tweets about clinics/services by year and quarter.




## Proportion of Tweets on Each Topic Including "Coronavirus" or "Covid"

In 2020, for all topics, there were observable increases in the second quarter in the proportion of tweets for each topic that mentioned "coronavirus" or "covid" (Figure 7). The largest absolute increase was observed for e-cigarettes; in the second quarter of 2020, the proportion of tweets about e-cigarettes in the context of quitting smoking that included "coronavirus" or "covid" increased from 2.1% to 11.7%. By the third quarter, however, the proportion had returned to close to first-quarter levels. This pattern was evident for all topics but was the greatest for *e-cigarettes*, *clinics/services*, and *advice/success*.

**Figure 7.** Percentage of tweets for each topic in 2020 that mentioned "coronavirus" or "covid," by quarter.



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## Discussion

### Principal Findings

This study used topic model analysis to observe if and/or how conversations, attitudes, or behavior related to quitting cigarettes changed before and during the pandemic. Six topics were identified by our topic model analysis, all of which would appear to be valid indicators of attitudes, plans, or behaviors regarding quitting cigarettes. Topics were (1) *need to quit*, (2) *personal experiences*, (3) *e-cigarettes*, (4) *advice/success*, (5) *quitting as a component of general health behavior change*, and (6) *clinics/services*. Moreover, our topics were sensitive to the effects of the pandemic, judging from increases in the second quarter of 2020 in the proportion of tweets on each topic that included the terms "coronavirus" or "covid." In addition, we observed a striking increase in 2019 in tweets related to e-cigarettes and quitting that coincided with the EVALI outbreak, illustrating how external events can generate relevant and potentially valuable information in real time.

For all topics for 2018, 2019, and 2020, mean daily frequencies of posts were generally the highest in the first quarter of the year compared with those in the second and third quarters. However, the size of the reduction in frequency of posts from the first to the second quarter did not differ in 2020 from those in the two previous years; this suggests (for all 3 years) an effect of New Years' resolutions having either been achieved by the second quarter or the dissipation of motivation to quit after failed New Year's quit attempts. Moreover, for the second quarter of 2020, when COVID-19 infection rates were rising sharply, for all topics, there were no significant differences in mean daily frequency of tweets in 2020 compared with those in the same period in 2019.

For 2020, a quadratic shape was evident for all topics (except *e-cigarettes*) because of an uptick in posts from the third to the fourth quarter. Reasons for this are not clear but could include the following: (1) smokers realizing a need to quit (perhaps after having postponed such plans earlier in the year), (2) feeling less stress following positive news about vaccine effectiveness in November that resumed interest in quitting, and/or (3) social media or other quit-smoking campaigns such as the nationwide Great American Smokeout in November. Whatever the reason, these results suggest there may have been pent-up demand toward the end of 2020 for cessation services that public health programs might have been able to address.

Only our results for *e-cigarettes* suggest the possibility of somewhat less interest in 2020 in quitting cigarettes that might be pandemic-related. E-cigarettes have become a popular tool for quitting cigarette smoking according to recent research [53-55], with the proportion of people switching to e-cigarettes to quit smoking (35%) similar to that of using any evidence-based treatment [55]. In 2020, in both the second quarter (when COVID-19 cases were surging in the United States) and in the last quarter, tweets about e-cigarettes were significantly lower compared with those in 2018. This suggested diminished interest in 2020 in either using e-cigarettes for quitting, or (by proxy) for quitting in general. These results comport with research from quitlines suggesting diminished interest in 2020 in quitting cigarettes [17], and with data showing increased cigarette sales in 2020 [33].

### Limitations

Our analyses did not permit examination of whether the patterns we observed differed by sociodemographic or other user characteristics, as these are not made available by Twitter for confidentiality and privacy reasons. However, according to research conducted by the Pew Foundation in 2019, the median age of Twitter users is younger (47 years) than that of the US population [56]. Twitter users are also more educated and earn higher incomes [56]. Although variables such as gender or age can be inferred from tweets using specialized algorithms, our primary interest was attempting to understand how discussions about quitting changed during the pandemic on a platform used by millions of US residents.

Crises that occurred during the pandemic related to systemic racism and the political climate may have diverted individuals' propensity to tweet about the topics we identified. This may have been particularly true for younger individuals who at the same time may be less likely to take concerns about COVID-19 or quitting smoking as seriously as older individuals.

It is also not clear to what extent quit smoking–related tweets were posted by nonsmokers; however, it seems unlikely that nonsmokers would tweet about their need to quit, or about e-cigarettes, in the context of quitting smoking.

Our analyses did not control for possible yearly changes in the number of Twitter users. A decrease from 2019 to 2020 in the number of Twitter users, or in overall tweets, could potentially be a reason for the reduction in the frequency of posts for some topics in 2020 compared to the same period in 2019 (and in some cases compared to 2018); however, the number of "monetizable daily active" Twitter users has been increasing annually, including the years covered by our analyses [57]. Moreover, the fact that the number of "quit smoking" tweets by quarter for some topics *increased* in 2020 argues against our results being due simply to decreases in the number of Twitter users in 2020.

### Future Research

Future research that recruits a nationally representative sample of Twitter users who smoke and who allow their Twitter handles to be followed could help determine how generalizable the results obtained from an analysis of tweets are to the general population of people who smoke. Additionally, while there is evidence for the validity of tweets in predicting health-related behaviors [2], future research could assess relationships between the frequency of quit smoking–related tweets and actual behavioral changes. Including perceptions of risk, and individual and social contextual characteristics in such research could help identify for whom a pandemic or other shared event increases or decreases quitting. Such knowledge could then be used to help public health authorities craft messages for specific audiences (eg, using hashtags) to motivate more quitting. Applying our topic model solution to tweets on an ongoing basis can also provide cancer prevention and other institutions with real-time data on how nationwide campaigns or policies may affect cigarette quitting–related thoughts and behaviors.



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## Conclusions

Overall, based on the frequencies of posts related to quitting smoking in 2020, the COVID-19 pandemic had limited associations with conversations about quitting or plans to quit. Differences in frequencies across years appeared to be more easily explained by other events such as (after) effects of New Years' resolutions or the EVALI epidemic. Results for *e-cigarettes* (which are now widely used as a quitting tool) suggest the possibility that the pandemic may have somewhat decreased motivation (or attempts) to quit, but only during the second quarter of 2020 when infection rates were rising rapidly.

## Acknowledgments

This study was funded by the American Cancer Society.

## Conflicts of Interest

None declared.

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## Abbreviations

**e-cigarette:** electronic cigarette
**EVALI:** e-cigarette or vaping product use–associated lung injury
**LDA:** latent Dirichlet allocation


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Original Paper

# Factors Affecting Physicians' Credibility on Twitter When Sharing Health Information: Online Experimental Study

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## Abstract

**Background:** Largely absent from research on how users appraise the credibility of professionals as sources for the information they find on social media is work investigating factors shaping credibility within a specific profession, such as physicians.

**Objective:** We address debates about how physicians can show their credibility on social media depending on whether they employ a formal or casual appearance in their profile picture. Using prominence-interpretation theory, we posit that formal appearance will affect perceived credibility based on users' social context—specifically, whether they have a regular health care provider.

**Methods:** For this experiment, we recruited 205 social media users using Amazon Mechanical Turk. We asked participants if they had a regular health care provider and then randomly assigned them to read 1 of 3 Twitter posts that varied only in the profile picture of the physician offering health advice. Next, we tasked participants with assessing the credibility of the physician and their likelihood of engaging with the tweet and the physician on Twitter. We used path analysis to assess whether participants having a regular health care provider impacted how the profile picture affected their ratings of the physician's credibility and their likelihood to engage with the tweet and physician on Twitter.

**Results:** We found that the profile picture of a physician posting health advice in either formal or casual attire did not elicit significant differences in credibility, with ratings comparable to those having no profile image. Among participants assigned the formal appearance condition, those with a regular provider rated the physician higher on a credibility than those without, which led to stronger intentions to engage with the tweet and physician.

**Conclusions:** The findings add to existing research by showing how the social context of information seeking on social media shapes the credibility of a given professional. Practical implications for professionals engaging with the public on social media and combating false information include moving past debates about casual versus formal appearances and toward identifying ways to segment audiences based on factors like their backgrounds (eg, experiences with health care providers).

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**KEYWORDS**

source credibility; user engagement; social media; health communication; misinformation; Twitter

## Introduction

### Background

Policy makers, journalists, researchers, and industry leaders have promoted social media as a catalyst for revolutionizing health care by extending the reach of health advice from physicians [1-7]. Notwithstanding the persistence of digital divides in who has internet access and uses social media [8,9], the focus appears well-placed given that internet users turn to social media for health advice [4,10,11] and that many report improvements in their health as a result [2-6,12]. However, there is little research to date investigating what impacts



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physicians' credibility as a source of health advice on social media, with most research focusing on only comparing the credibility of physicians versus other sources [10]. The credibility of a source refers to the degree to which the information it supplies is believable [13]. Understanding variations in credibility among physicians on social media is important given the need to combat misinformation there. This is particularly important during public health emergencies like the COVID-19 pandemic [14].

Best practices for how professionals can cue their credibility on social media are unclear [15-18]. This is because on social media platforms for health advice like Twitter, the norm is to present yourself as an approachable peer, while in professional settings, the norm is distinguishing yourself from the lay public to signify you are an authority. For physicians, the competing norms fuel philosophical debates over how to leverage social media to strengthen their connections with the public while also presenting themselves in a way that adheres to medical ethics [19-21]. As a practical matter, the presentation norms prescribe contrasting strategies for populating one's own social media account, like whether one should post casual or formal pictures of themselves [19-22]. No study to date has compared how the 2 strategies shape the credibility of a physician sharing health advice on social media.

Thus, we conducted an experiment addressing how a casual and formal appearance may shape a physician's credibility on Twitter when sharing health advice through a tweet. We investigated the complexity in this process by examining how the importance of a casual and formal appearance for physician credibility depends on whether a user has a regular health care provider. Moreover, we examined how the effects of appearance on credibility in turn affect the likelihood that a user engages with the tweet. Findings contribute to theorizing how social context influences credibility judgments during information seeking through amplifying cues (eg, formal appearance), as well as discussions about online presentation strategies and ways physicians can aid in inoculating against falsehoods (ie, misinformation and disinformation) on social media. Moreover, as health professionals turn to the internet to provide care during the COVID-19 pandemic [23], knowing the factors that signal a physician's credibility and inoculating against falsehoods on online media have become more critical.

## Prior Work

The social media ecosystem creates a decentralized information environment where access to information is mediated by nontraditional authorities (eg, friends, family, influential social media users), which consequently spurs questions about source credibility. Social media users are tasked with determining source credibility, which raises concerns that they may engage with or spread false information. Thus, there is a need to research how social media users determine source credibility and how legitimate sources like physicians can leverage findings to share validated information.

### *Credibility on Social Media*

To form impressions about the veracity of information shared by a source, individuals use 3 features of the source to determine its credibility [13]: competence, trustworthiness, and goodwill. Competence refers to the source's ability or qualifications to know the truth regarding a matter. The source's trustworthiness represents the motivation to be truthful or biased on a matter. Goodwill is the extent that the source has the individual's best interest at heart.

On social media, users can glean these 3 features constituting credibility by looking for authority cues. The presence of credentials, such as a badge, organizational affiliation and other external links, or a professional title, on a social media profile acts as an authority cue that users rely on to determine whether the source is credible [10,24]. For example, one study found that a Twitter profile sharing information about gonorrhea with cues connecting it to the Center for Disease Control and Prevention resulted in stronger perceptions of competence, trustworthiness, and goodwill than when the profile contained cues signaling the information came from a peer or stranger [25].

### *Physician Credibility*

Few studies have examined variation in credibility ratings on social media within a single type of authority operating as a source. For physicians, researchers have studied how 2 different presentation styles—casual versus formal attire—cue their credibility within in-person settings. Patients generally prefer physicians to wear formal attire, like a white coat, rather than casual attire during clinic visits [26], but attire has no significant effect on the credibility ratings of a physician's treatment recommendations [27].

Although a casual or formal appearance may not matter for cueing physician credibility within in-person settings, the issue becomes more complex within social media and spurs deliberation. The American Medical Association advises physicians to separate their "personal and professional content online" [20]. Profile images where the physician is wearing formal dress (eg, white lab coat, stethoscope) is one way to achieve this since professional symbols like these that indicate the profession [28] crystallize the separation between the public and a profession [29].

Pragmatically, however, this is difficult. This is because the strategies for appearance on social media and a profession can clash, which can diminish an authority's credibility on social media [16,18,22]. Thus, identifying which strategy is best for cueing a physician's credibility on social media is critical to improving the reach of factual health advice and inoculating against falsehoods.

## Conceptual Framework and Hypotheses

### *Hypothesis 1: When Reading a Tweet Sharing Health Advice, Credibility Ratings (Competence, Trustworthiness, and Goodwill) Will Be Higher for Physicians Dressed in Formal Wear Than for Those in Casual Wear Within Their Profile Picture*

Figure 1 summarizes our hypotheses. D'Angelo and Van Der Heide [22] found that participants rated a profile from a physician more favorably when the physician was wearing a white lab coat and a stethoscope than when the physician dressed



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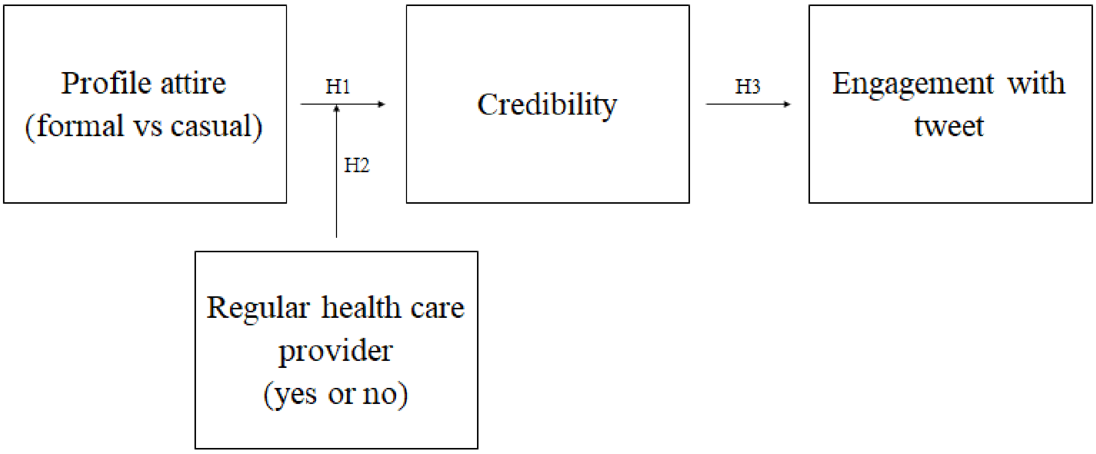
casually. The significant differences in favorability held regardless of whether the profile was on Facebook or a platform with more formal presentation norms, like WebMD (based on our own analysis of their descriptives). They did not examine how a casual and formal appearance shaped credibility ratings in the context of physicians offering health advice on social media, which we investigate in this study. Because studies examining other professionals besides physicians show a formal appearance on social media promotes higher credibility ratings than does a casual appearance [16,30,31], there is a possibility that the findings from D'Angelo and Van Der Heide [22] extend to other contexts.

**Figure 1.** Summary of hypotheses. H: hypothesis.




### *Hypothesis 2: When Reading a Tweet Sharing Health Advice From a Physician Dressed in Formal Wear Within Their Profile Picture, Credibility Ratings (Competence, Trustworthiness, and Goodwill) Will Be Higher Among Users With a Regular Provider Than Among Those Without One*

An approach missing from debates about whether physicians should use a formal appearance on social media is to consider when formal appearance may be effective. Prominence-interpretation theory [32] claims users' past experiences can shape their interpretation of cues online and, in turn, their credibility ratings. For social media users with previous exposure to symbols that are emblematic of physicians, formal wear may be more critical for credibility.

Indirect support for this expectation comes from research on patient preferences for physician attire during a clinic visit. A systematic review of studies sampling patients found that patients express fewer preferences when asked following a clinical visit versus when asked only to imagine experiencing one while they sat in a clinical setting [26]. Patients in the latter case were more likely to prefer formal attire, such as a white lab coat. This is indirect support because in both cases, patients would have been exposed to symbols emblematic of physicians (either during the clinic visit or while waiting). Among these patients, only those asked to imagine an interaction with physicians—akin to the imagined or parasocial interaction that occurs within technology-mediated communication [33,34]—tended to prefer formal attire.

To distinguish between individuals with and without exposure to professional symbols, we asked whether they have a regular health care provider, defined as a physician or other health care professional (eg, nurse, nurse practitioner, physician assistant). The regular provider need not be a physician for this process because the lay public often refers to their regular provider as "doctor" regardless of the type of provider [35,36]. Since professional symbols representing physicians (eg, white coat) are likely more accessible among those with a regular provider than those without, we expected formal attire would be more important for cueing credibility among those with a regular provider than among those without one.

### *Hypothesis 3: As Ratings of Physician Credibility (Competence, Trustworthiness, and Goodwill) Increase, Intentions To Engage With The Physician on Twitter and the Tweet Sharing Health Advice Will Strengthen*

Last, we examined how credibility ratings of a physician sharing health advice through a tweet would influence the intentions to engage with the tweet. As Figure 1 shows, the direct predictor of engagement within this model is level of credibility. Because we outlined how appearance in a profile picture and having a regular provider affect credibility, these 2 operate as indirect predictors of engagement. Credible sources are more likely to persuade others by changing their attitudes and behavior [37], with prior research showing the credibility of a source on social media to be associated with the strength of the resulting attitudes and behavioral intentions [38-41].

## Methods

### Ethics Approval

This study was approved by the University of Wisconsin-Milwaukee's Institutional Review Board (review number 18.045).

### Experimental Design

We conducted a 2 (has regular provider: yes vs no) × 3 (profile attire: no profile image vs casual vs formal) between-subject online experiment to test our hypotheses. Along with enquiring about other demographic variables, we asked participants to



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report whether they had a regular provider and then randomly assigned them to read 1 of 3 tweets varying only the attire of the physician displayed in the profile image. We then asked them to assess the credibility of the physician and the likelihood that they would engage with the tweet and the physician on Twitter.

### Recruitment

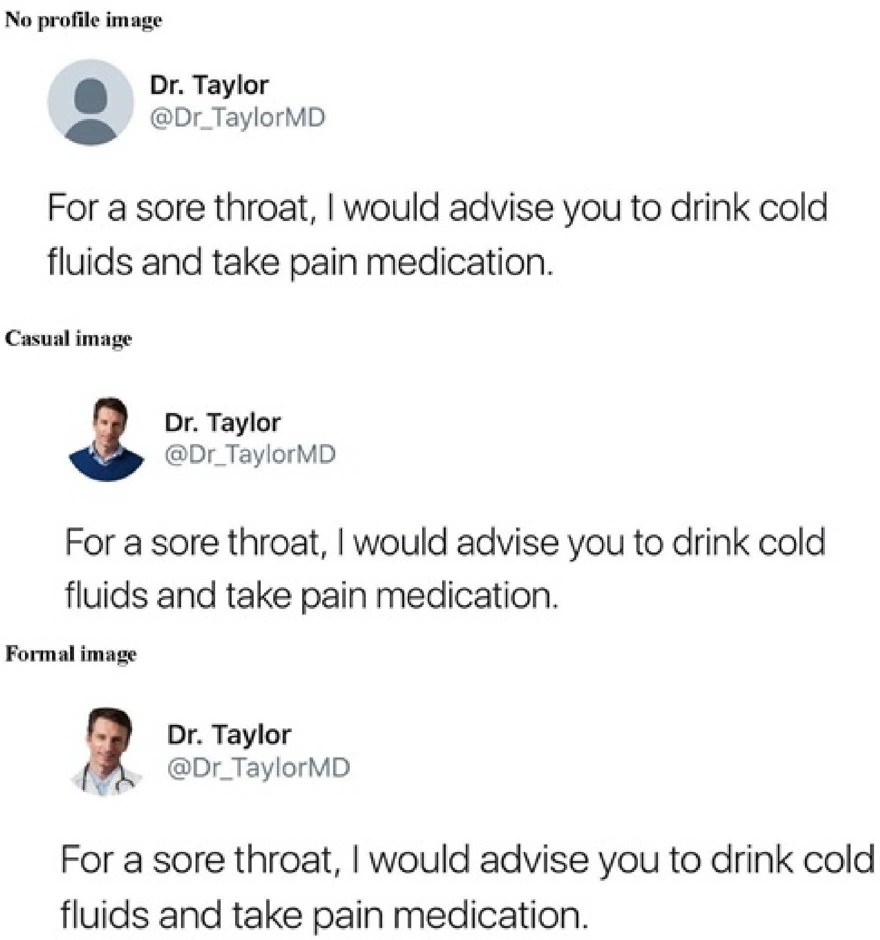
On October 9 and 10 in 2018, we recruited social media users living in the USA from Amazon Mechanical Turk (MTurk) with at least a 95% approval rate. Compared to other convenience samples (eg, college students) used in research to study source credibility and health behaviors, respondents from MTurk tend to be more demographically diverse [42]. Notably, they are more likely to read instructions more carefully than are other convenience samples [43] and therefore may be more attuned to differences in presentation styles. Respondents from MTurk are also more likely to report poorer health overall [44], suggesting they may be more in need of accessing health advice.

We analyzed data from the 205 respondents who passed a series of questions designed to assess the quality of their responses. A power analysis using G*Power software showed this sample size would provide enough power (>0.80) to detect an effect size (0.40) on par with studies comparing the credibility of physicians versus peers on social media [10] with an α level of .05. Of the 205 respondents, approximately 78.% (160/205) identified as White, 7.3% (15/205) as Black, (16/205) 7.8% as Latino, and 6.8% (14/205) as another race or ethnicity. Approximately 43.9% (90/205) reported they were female. The mean age was 36, with the youngest participant reporting an age of 20 years and the oldest reporting an age of 69 years. When asked to rate their overall physical health on a 5-point Likert scale (1=poor, 5=excellent) [45], most (40%, 82/205) selected the “good” option.

### Profile Attire

Figure 2 shows the 3 tweets used in this study, each of which refer to the physician as “Dr.” We designed the content of the tweets that remained consistent across conditions to represent what the average user on Twitter is likely to see. For the tweet, we created a text post that stated, “For a sore throat, I would advise you drink cold fluids and take pain medication.” The text of the post is based on previous research [46] and shares health advice regarding a sore throat, which is a common symptom people experience [47]. Thus, we designed the tweet to present empirically supported information. We selected a male physician, as female physicians are more likely to use Twitter to network with same-gender colleagues and mentors as opposed to sharing medical advice because they are motivated to use the platform to improve their mobility within the profession [48,49]. Moreover, we chose a picture of a physician who appeared to be White and under the age of 55 as most professionals in this field fall within this racial category and age range in the United States [50,51].

**Figure 2.** Profile attire conditions.





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The formal and casual conditions used an image of the same male, which we manipulated to alter only his attire and thereby control for confounding variables like attractiveness. In the casual condition, he wore a blue sweater and collared shirt without a tie, while in the formal condition, he wore a white lab coat and a stethoscope, which are symbols associated with the medical professional [28].

Our design incorporated a third condition, the no-profile condition, which contained no profile image of the physician. If there was a nonsignificant difference in the effects of the casual and formal conditions on credibility ratings, the no-profile condition would offer a useful baseline to guide interpretation. A nonsignificant difference would suggest the dress styles exert comparable effects, but perhaps also that the styles do not add significantly to the cues conveying who the source is (eg, the "Dr." title), which could also affect credibility ratings. Because of the widespread diffusion of medical symbols through media channels [52], it may be that only the cues conveying who the source is are necessary to establishing credibility, and thus images conveying dress style are redundant and exert negligible effects. Such information would also be useful for quelling debates about physicians' self-presentation on social media by indicating that the 2 styles in practice produce comparable credibility ratings.

### Regular Provider

We used a question that is commonly used in self-reports to identify whether participants had a regular provider [53]: "Not including psychiatrists and other mental health professionals, is there a particular doctor, nurse, or other health professional you see most often?" The measure is dichotomous (1=yes, 0=no).

### Measures

#### *Credibility Ratings of Physician*

A scale from McCroskey and Teven [13] measures the 3 features that compose a source's credibility: competence, goodwill, and trustworthiness. Each feature is measured with six 7-point semantic differential questions, totaling 18 survey items.

#### *Engagement*

Using 7-point Likert questions, we asked participants their intentions to engage with the tweet [54,55], specifically asking how likely they would be to like the tweet, retweet the tweet, share the tweet, and follow the physician.

### Statistical Analysis

The analysis was conducted using Stata 16 (StataCorp). We began with a preliminary analysis, which readers can find in Multimedia Appendix 1. For the preliminary analysis, we conducted randomization checks to ensure that the number of participants with and without a regular provider was neither associated with demographics nor the profile attire conditions. We ended this phase by conducting exploratory factor analyses of the credibility and engagement items to assess their factor structure and calculate factor scores because how people construct credibility can vary [56] and thereby produce changes in factor structure based on situational context [22]. For the main analysis, summarized here in the main text, we estimated 2 path models to test our hypotheses, one with an interaction between profile attire and having a regular provider (testing hypothesis 2) and another without the interaction (testing hypothesis 1 and hypothesis 3). We estimated the path models using the "sem" command and 5000 bootstrap samples. Statistical significance is based on 2-tailed tests and an $\alpha$ level set at .05.

## Results

### Hypothesis Testing

The estimates for the first path model testing hypotheses are depicted in Table 1. The path estimates for the casual and formal attire conditions summarize the predicted levels of the 2 credibility factors for respondents in these conditions relative to levels for respondents in the no-profile condition. Thus, to assess whether credibility ratings were higher for physicians with a formal appearance than those with a casual appearance and thereby test hypothesis 1, a Wald test was used to determine whether the path estimate for the formal condition was significantly greater in magnitude than was the corresponding one for the casual condition. For neither the goodwill ($\chi^2_1$=0.18, N=205; *P*=.67) nor the competence or trustworthiness factor scores ($\chi^2_1$=1.95; N=205; *P*=.16), were the path estimates significantly different. A 1-way multivariate analysis of variances comparing the means for the 2 credibility factor scores between participants in the casual and formal conditions produced the same conclusion ($F_2$=1.09, N=132; *P*=.34; Wilks' $\Lambda$=0.984). The conclusions did not change when we removed the paths estimating the relationships between having a regular provider and the 2 credibility factor scores. These findings fail to support hypothesis 1, suggesting that neither type of appearance is more effective than the other for cueing the credibility of physicians on Twitter.


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**Table 1.** Path model estimating the effects of profile attire on engagement without conditional effects of having a regular provider.

| Path | Coefficient, *b* | *z* score | *P* value[a] |
|---|---|---|---|
| Casual → competence/trustworthiness | 0.239 | 1.40 | .16 |
| Formal → competence/trustworthiness | 0.001 | 0.01 | .99 |
| Regular provider → competence/trustworthiness | 0.139 | 1.00 | .32 |
| Casual → goodwill | –0.154 | –0.91 | .37 |
| Formal → goodwill | –0.226 | –1.35 | .18 |
| Regular provider → goodwill | 0.159 | 1.15 | .25 |
| Competence /trustworthiness → engagement | 0.030 | 0.38 | .71 |
| Goodwill → engagement | 0.382 | 4.80 | <.001 |

[a]Two-tailed test.

A comparison of the credibility ratings in these conditions to those in the no-profile condition sheds additional insight into this finding. Table 1 shows that compared to participants in the no-profile condition, those in the casual (b=0.239; *P*=.16) and formal (b=0.001; *P*=.99) conditions did not rate the physician's competence or trustworthiness differently. A similar pattern emerged for ratings of the physician's goodwill (casual: b=–0.154 and *P*=.36; formal: b=–0.226, *P*=.18). Thus, not only is neither type of appearance more effective than the other for cueing the credibility of physicians on Twitter, but also neither style adds significantly to the baseline credibility established from a source with "Dr." in the title.

Table 1 also shows results from a test of hypothesis 3, which is that credibility ratings will be positively associated with intentions to engage with the tweet. Only goodwill ratings had a significant association, with higher ratings associated with stronger intentions (b=0.382; *P*<.001). Since the goodwill and competence or trustworthiness factors are strongly correlated, we assessed multicollinearity in the equation-predicting engagement. Multicollinearity could explain why only the goodwill factor was significantly associated with engagement. We calculated the variance inflation factor for both, and each was below the 2.50 recommended threshold [57]. This suggests multicollinearity in the engagement equation is not an issue and that only goodwill is significantly associated with engagement. The findings partially support hypothesis 3.

To test hypothesis 2, we estimated a second path model, summarized in Table 2. Hypothesis 2 states that the relative effectiveness of a formal appearance on credibility ratings is contingent on users' experience with professional symbols, which we operationalized as whether they have a regular provider. Table 2 shows a significant interaction in the equation estimating goodwill ratings between the formal condition and having a regular provider (b=0.690; *P*<.05). To better understand this finding, Figure 3 plots the marginal effect of having a regular provider on predicted goodwill ratings by condition, with 95% CIs. A marginal effect crossing the zero threshold (denoted by a horizontal dashed line) indicates no significant difference in goodwill ratings between those with and without a regular provider. Marginal effects above the threshold represent significantly higher goodwill ratings for those with a regular provider relative to those without, while marginal effects below the threshold represent significantly lower ratings. Figure 3 shows that among participants in the formal condition, those reporting they had a regular provider had significantly higher goodwill ratings than those who said they did not have a regular provider. Goodwill ratings did not significantly differ by whether participants had a regular provider in the other 2 conditions. The results support hypothesis 2 and indicate formal attire in a Twitter profile picture can cue credibility for physicians among users with a regular provider.

Given that earlier we showed goodwill ratings were positively associated with intention to engage with the tweet, we explored indirect effects to assess whether this significant interaction translated into measurable differences in intentions to engage with the tweet between participants with and without a regular provider. Among participants in the formal condition, those with a regular provider had significantly stronger intentions to engage with the tweet than did those who did not (effect 0.265; SE 0.119; 95% CI 0.032-0.499).



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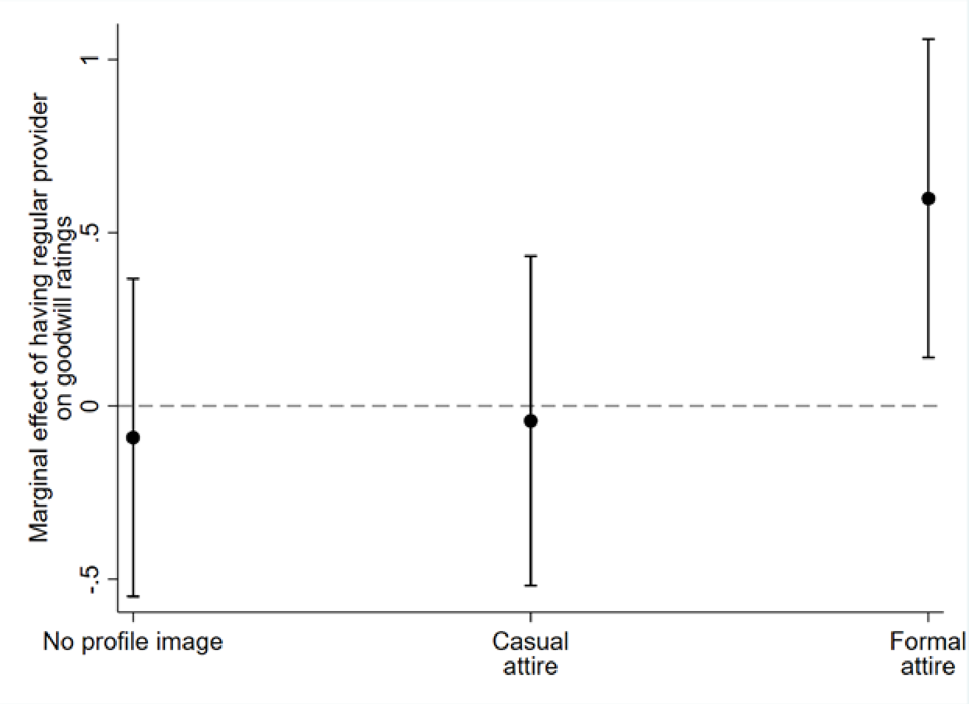
**Table 2.** The estimates for the path model summarizing effects of profile attire on engagement with conditional effects of having a regular provider.

| Path | Coefficient, *b* | *z* score | *P* value[a] |
|---|---|---|---|
| Casual → competence/trustworthiness | 0.194 | 0.85 | .40 |
| Formal → competence/trustworthiness | –0.032 | –0.13 | .89 |
| Regular provider × casual → competence/ trustworthiness | 0.086 | 0.28 | .78 |
| Regular provider × formal → competence/ trustworthiness | 0.063 | 0.18 | .86 |
| Regular provider → competence/trustworthiness | 0.090 | 0.33 | .74 |
| Casual → goodwill | –0.184 | –0.69 | .49 |
| Formal → goodwill | –0.597 | –2.45 | .01[b] |
| Regular provider × casual → goodwill | 0.049 | 0.16 | .88 |
| Regular provider × formal → goodwill | 0.690 | 2.48 | .01[b] |
| Regular provider → goodwill | –0.091 | –0.42 | .68 |
| Competence/trustworthiness → engagement | 0.030 | 0.46 | .65 |
| Goodwill → engagement | 0.382 | 5.02 | <.001[b] |

[a]Two-tailed test.

[b]*P*<.05.

**Figure 3.** The marginal effect of having a regular provider by profile attire condition, with 95% CIs.




## Discussion

### Principal Findings

The growing concern over misinformation and disinformation regarding health information [58,59] on social media raises the need to understand the factors that cue the credibility of authorities. For authorities like physicians and other professionals, a formal appearance potentially clashes with the casual norms on social media platforms like Twitter and thereby risks lowering their credibility. Alternatively, a formal appearance can bolster credibility, helping users evaluate the veracity of the information shared by the physician.

In our study, findings from the experiment varying whether a physician sharing health advice on Twitter wore formal or casual attire in a profile image showed no significant differences in credibility ratings, and, further, these ratings were not significantly different from a condition without a profile image. However, among participants who were shown a physician with formal attire, those reporting that they have a regular provider gave the physician higher credibility ratings than did individuals without one, which in turn led to stronger intentions to engage



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with the tweet. This pathway operated through a specific credibility rating, goodwill, indicating the importance of this credibility factor for engaging with health advice on social media. The findings are important for advancing theories of source credibility on social media and practitioners interested in combating false information, both of which are critical endeavors to curb the spread of widespread disease (eg, during the global COVID-19 pandemic).

On average, whether a physician used a formal appearance displaying symbols in their profile picture that are emblematic of their profession (eg, white lab coat, stethoscope) had little bearing on their credibility ratings, with ratings comparable to a physician with no profile picture. A physician with a casual appearance likewise had similar credibility ratings as one with no profile picture. In all conditions, the physician was labeled "Dr.," indicating the contribution of visual symbols in a profile picture did not significantly add to the credibility stemming solely from the physician's title. The finding implies that debates about how physicians should present themselves on Twitter [19-21] have little practical relevance, at least with respect to decisions about one's profile image.

We found a key qualifier to the effects of appearance, whereby having a regular provider amplified the effect of a formal appearance on a physician's credibility ratings, specifically leading to higher goodwill scores compared to those without a regular provider. This finding aligns with prominence-interpretation theory [32] by showing how users' experiences modulate the relationship between cues and credibility. The result is a demonstration of how context alters the meaning assigned to cues, which in turn results in disparate credibility judgments of the same professional. We therefore echo others in recommending efforts to segment users based on their backgrounds to promote engagement with social media content [7].

The conditional effects we found for formal appearance produced significant differences in intentions to engage with the tweet and the physician posting it. Specifically, a formal appearance shaped intentions to engage among participants with a regular provider through altering ratings of only the goodwill and not the combined competence-trustworthiness factor. Like another study analyzing impressions of physicians on social media [22], an exploratory factor analysis of the items measuring credibility ratings suggested that the items represented 2 instead of 3 factors. However, whereas this other study found that the trustworthy items aligned with the goodwill items, we found they aligned with the competence items. The different factor structure may be because of the different social media platforms under investigation (Twitter vs Facebook and WebMD), samples (MTurk workers vs college students), or gender of the physician (male vs female) but could also be attributable to the different task contexts [32]. The context for our study was to decide whether to engage with a tweet sharing health advice, which may strengthen the link between perceptions of competence and trustworthiness. Conversely, participants in the other study were only asked to judge the profiles of physicians, which might not have associated competence and trustworthiness to the same degree. In line with this interpretation is research from 2 different lines. The first shows people can vary in how they construct credibility depending on context [56]. The second shows the extent that a person's perceived competence and a term related to goodwill—benevolence—inform perceptions of the individual's trustworthiness and is also contingent on context [60].

### Limitations and Future Research

We were unable to evaluate how the gender of the physician may moderate findings because we only examined tweets by a male physician. Previous studies reported few differences by physicians' gender in patient preferences for attire [26]. One study [22] found that a female physician wearing a white lab coat with a stethoscope on her Facebook profile image received higher favorability ratings (a measure that included credibility ratings, among other ratings) than did one wearing a short-sleeved casual shirt. This aligns with our finding showing credibility ratings were higher in the formal than in the casual attire condition. We therefore suspect the conditional importance of formal attire we found will be comparable for tweets by a female physician, but future research should conduct a direct test. Moreover, additional factors, like the perceived age and race of the physician, may likewise shape findings, which future research may examine.

### Conclusions

Although this study was conducted before the discovery and spread of COVID-19 across the globe, the findings are still relevant. Many people turned to the internet to learn information about the virus and government responses [61,62]. Social distancing and stay-at-home orders to curb the spread of the virus led to a dramatic drop in in-person clinic visits [63]. These changes amplified the need to understand how best to disseminate health advice over the internet. Our findings suggest that, on average, a formal and casual appearance influence physician credibility comparably. However, for those with a regular provider, formal dress can raise physician credibility. Indeed, during the rapid uptake of telehealth during the pandemic [63], patients were asking their physicians whether they were wearing their white lab coat [64]. After COVID-19 is controlled, the need to understand how best to support communication between patients and their providers over the internet will remain, along with the need to combat false information about diseases and mitigation strategies. Segmentation strategies [7] will also be key because users' backgrounds provide relevant contexts shaping how they interpret cues and engage with content. By understanding the factors influencing credibility within a specific authority, this study is one critical step toward those efforts.

## Conflicts of Interest

None declared.



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Multimedia Appendix 1
Supplementary material.
[DOCX File , 22 KB - infodemiology_v2i1e34525_app1.docx ]

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## Abbreviations

**MTurk:** Amazon Mechanical Turk


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Original Paper

# Identifying Frames of the COVID-19 Infodemic: Thematic Analysis of Misinformation Stories Across Media

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## Abstract

**Background:** The word "infodemic" refers to the deluge of false information about an event, and it is a global challenge for today's society. The sheer volume of misinformation circulating during the COVID-19 pandemic has been harmful to people around the world. Therefore, it is important to study different aspects of misinformation related to the pandemic.

**Objective:** This paper aimed to identify the main subthemes related to COVID-19 misinformation on various platforms, from traditional outlets to social media. This paper aimed to place these subthemes into categories, track the changes, and explore patterns in prevalence, over time, across different platforms and contexts.

**Methods:** From a theoretical perspective, this research was rooted in framing theory; it also employed thematic analysis to identify the main themes and subthemes related to COVID-19 misinformation. The data were collected from 8 fact-checking websites that formed a sample of 127 pieces of false COVID-19 news published from January 1, 2020 to March 30, 2020.

**Results:** The findings revealed 4 main themes (attribution, impact, protection and solutions, and politics) and 19 unique subthemes within those themes related to COVID-19 misinformation. Governmental and political organizations (institutional level) and administrators and politicians (individual level) were the 2 most frequent subthemes, followed by origination and source, home remedies, fake statistics, treatments, drugs, and pseudoscience, among others. Results indicate that the prevalence of misinformation subthemes had altered over time between January 2020 and March 2020. For instance, false stories about the origin and source of the virus were frequent initially (January). Misinformation regarding home remedies became a prominent subtheme in the middle (February), while false information related to government organizations and politicians became popular later (March). Although conspiracy theory web pages and social media outlets were the primary sources of misinformation, surprisingly, results revealed trusted platforms such as official government outlets and news organizations were also avenues for creating COVID-19 misinformation.

**Conclusions:** The identified themes in this study reflect some of the information attitudes and behaviors, such as denial, uncertainty, consequences, and solution-seeking, that provided rich information grounds to create different types of misinformation during the COVID-19 pandemic. Some themes also indicate that the application of effective communication strategies and the creation of timely content were used to persuade human minds with false stories in different phases of the crisis. The findings of this study can be beneficial for communication officers, information professionals, and policy makers to combat misinformation in future global health crises or related events.

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**KEYWORDS**

COVID-19; pandemic; misinformation; fake news; framing theory; social media; infodemic; thematic analysis; theme; social media; pattern; prevalence

# Introduction

## Background

The contagious SARS-CoV-2 virus caused a global pandemic that has influenced many aspects of people's lives across the world since early 2020. Due to the global scale of the pandemic, different stakeholders created and circulated an abundance of true and false information through various channels to fill the uncertainty in this crisis. Unfortunately, the sheer volume of false or fake information was such a severe problem during the pandemic that the World Health Organization (WHO) announced that battling misinformation was as challenging as fighting the virus itself [1]. Information disorder is defined with different terminologies such as misinformation, disinformation, and malinformation [2]. Disinformation is created to harm people with the aim of gaining money, political manipulation, and hurtful social and psychological consequences, while misinformation refers to sharing false information unintentionally [3]. The velocity of misinformation was one major issue to handle in the case of COVID-19. For instance, according to a Pew Research Center survey, around half (48%) of respondents had encountered false stories about the COVID-19 pandemic [4].

Therefore, research on false information specifically pertaining to COVID-19 is necessary because it will help to gain deeper insights into this issue and to manage similar crises more efficiently in the future. One main step toward this goal is to identify and classify COVID-19 misinformation stories that provide the necessary contextual data to understand the current ecosystem of unhealthy information. Several previous studies have reported COVID-19 misinformation, yet they are limited to a specific medium such as Facebook [5], Twitter [6,7], or YouTube [8]. Some earlier research includes only narrow samples [9,10] and theoretical frameworks [11,12]. Hence, it is important to explore the motivations and sources of false information and to discover its progress and prevalence on different platforms over time. Additionally, it is unclear how COVID-19 misinformation is framed and presented to the public on different platforms. Thus, this study targeted a comprehensive sample of false stories reported by fact-checking websites.

To fill these gaps in the literature, this study aimed to apply arguments from framing theory and thematic analysis to identify the main subthemes related to COVID-19 misinformation on a wide range of platforms from traditional outlets to social media. Another objective of this study was to explore the changes in the prevalence of misinformation subthemes over time.

## Literature Review

### *Theoretical Framework*

Framing, as a concept, refers to attempts to include and highlight specific aspects of a reality related to a phenomenon while excluding or minimizing other elements of it [13]. Framing refers to selecting some aspects of an issue to make them more noticeable in communication [14]. Framing is useful at both the macro and micro levels. Macro-level framing emphasizes the reflection, motivations, and goals of message senders [14], while micro-level effects focus on the ways message receivers see, understand, and act on messages [15]. Framing theory has been applied in a wide range of academic fields such as psychology, sociology, communication studies, and information science [16].

Framing studies can be divided into 2 broad levels: content research and effects research. Content research aims to analyze the messages to identify and categorize existing frames, while effects research investigates the most influential frames to achieve a targeted result, such as changing the attitudes or behaviors of audiences [17]. Effects research also analyzes frames that exist within communicated messages (possibly identifying or categorizing frames).

Framing theory asserts that how messages are framed and presented to the public can have different impacts on public opinion, behavior, and actions. A slight change in how a message is framed can sometimes have a significant impact on public opinion [18]. For instance, Tahamtan et al [19] showed that people used various hashtags on Twitter to frame their opinion about COVID-19. They, for instance, showed that the "conflict" frame, despite its low frequency, had received high attention among Twitter users. Therefore, it is important to study how COVID-19 misinformation is framed and presented to the public. In this study, we used framing as a theoretical framework to investigate how misinformation about COVID-19 has been framed on various platforms.

### *COVID-19 and Misinformation Consequences*

Recent studies on disseminating misinformation about the COVID-19 pandemic [20] through online media have illuminated both the means through which false information is spread and the implications that such information has on the public's response to national and global health crises.

The dissemination of false health information, specifically on social media, can negatively affect peoples' perceptions, beliefs, decisions, and actions [21]. For instance, past studies indicate that misinformation regarding vaccine safety can manipulate public opinion about vaccines and negatively affect immunization rates [22].

Through creating the dual-inheritance model of conspiracy theories, Mulukom [23] found that periods of public unease and uncertainty about public issues such as COVID-19 create conditions upon which those who are underinformed, lack trust, feel uncertain, and threatened are more likely to propel conspiracy theories. However, misinformation statements may receive different amounts of attention from the public. For instance, Enders et al [24] showed that general misinformation about COVID-19 received more attention than more specific misinformation such as the "the treatment and transmissibility" of COVID-19.



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Right after the COVID-19 pandemic started in early 2020, due to public uncertainity about the virus and widespread misinformation, several studies investigated misinformation related to this health crisis from various perspectives. For instance, Flew [25] demonstrated that mistrusting the news could lead to a catastrophic societal unfolding during COVID-19. Laato et al [26] discovered that the higher degree to which someone trusts online media and information, the more likely they are to share unverified information about COVID-19.

A study by Li and Scott [27] investigated how fake news was spread after a well-known Chinese soccer player, Wu Lei, contracted COVID-19. According to this study, news (and consequently, fake news) about famous people tends to receive high attention from the public. This study found that social media such as Weibo and WeChat and self-media (ie, user-generated content) tend to worsen the spread of false information about COVID-19. Kouzy et al [28] also showed that COVID-19–related misinformation statements were mostly distributed by individual or group accounts and unverified Twitter accounts.

Past studies have investigated various aspects of COVID-19 misinformation across different countries. For instance, Kim et al [29] maintained that, in the early stages of COVID-19, being exposed to general information about the pandemic made people realize they need further information, while exposure to misinformation would make individuals realize they need to obtain less information about the pandemic, which consequently has negative consequences on people. This study also indicated that there are cultural differences in how people in different countries interpret and respond to misinformation during a global pandemic. Soto-Vásquez et al [30] studied the correction of misinformation regarding COVID-19 in families and communities in the United States and Mexico. The study found that, while there is a general reservation to dispel misinformation that appears on social media, family and friends are more likely to correct misinformation through text messages and everyday conversations. Through exploration of online religious misinformation in the Middle East and North Africa, Alimardani and Elswah [9] identified how new parameters for religion that have been created through the internet would create distinct regional and religious types of false information. Meese et al [31] investigated the deep-rooted societal unease with mobile infrastructure and technology and its connection to the rise in conspiracy theories that suggest COVID-19 and 5G are related in Australia, the United States, and the United Kingdom. Apuke and Omar [32] created a predictive model to determine that altruism, instant news sharing, socialization, and self-promotion are the main factors behind COVID-19 misinformation dissemination on social media in Nigeria. Notably, entertainment was not found to have any connection to the propagation of fake news about COVID-19 on social media.

The literature review showed that past studies on COVID-19 misinformation are limited to specific contexts such as religious misinformation [9], geographical areas [29], or platforms such as Twitter [7]. These studies may not represent all aspects of COVID-19 misinformation. Only one study has examined misinformation through fact-checking resources, but this study only used Spanish fact-checking resources [33]. Therefore, this study aimed to fill the gap in the literature by examining misinformation related to COVID-19 on various fact-checking websites.

### *Framing Misinformation on COVID-19*

A few studies have investigated the framing of COVID-19 misinformation. For instance, by investigating 4 conspiracy theories about COVID-19, Bolsen et al [21] found that encountering fake messages about COVID-19 was detrimental to how the public had framed health messages; this could lead to this global pandemic not being taken seriously. Bolsen et al [21] indicated that exposure to framed messages regarding the origins of COVID-19 can have a powerful effect on people's beliefs about the cause of the global pandemic. Moreover, beliefs about the origin of the virus had strong "downstream effects" on respondents' willingness to penalize China when they believed it may have been created by the Chinese government. Conversely, results indicated that those who believed the virus originated naturally, from zoonotic transmission, were more supportive of additional funding for biomedical research to identify harmful coronaviruses. This study also indicated that exposure to a conspiracy theory about the virus's origin, in isolation or in competition, resulted in a "conspiracy effect," which led individuals to be less likely to view actions such as wearing face masks, washing hands, and maintaining social distancing as important for alleviating the effects of the pandemic [21].

Using framing analysis of misleading YouTube videos about COVID-19, Rooke [34] found that risk amplification for their online audiences was the main goal of far-right misleading information sources. Using a narrative research design, with in-depth interviews with 19 individuals in Western Kenya, Chamegere [35] investigated which misinformation and conspiracy theories about COVID-19 were rising in Kenya. He also examined how people framed their opinions about those conspiracy theories. Results indicated that people framed their opinions about COVID-19 misinformation as follows: COVID-19 is "no worse than normal flu," "a biological weapon," "a political tool theory," "a religious conspiracy theory," and "an isolation theory." Brennen et al [36] examined the most common visual frames related to COVID-19 misinformation. They identified 6 frames, including authoritative agency (claims about actions of public authorities), intolerance (expressions of racism, xenophobia, and sexism), virulence (claims that the virus is not real), medical efficacy (claims that treatments exist for the virus), prophecy (claims that the virus has previously been predicted), and satire (humorous content).

This literature shows that, although some past studies have explored COVID-19 misinformation, how misinformation stories have been framed on different platforms and at different time periods is understudied. Only a few studies have reported results regarding how misinformation has been framed, but they are limited to specific areas or contexts such as the study by Chamegere [35] in Western Kenya. The current study fills the gap in the literature by studying the major misinformation stories that were covered by 6 fact-checking websites, meaning this study is not isolated to any specific area or context.


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# Methods

## Data Collection and Analysis

Identifying misinformation on the social web is a challenge for researchers. For this study, false information cases that were reported by fact-checking websites were selected and analyzed. Fact checking refers to the process in which journalists, experts, and nonprofit organizations use different sources and methods to systematically evaluate the validity of a claim and examine whether it is factual [37]. This approach is less biased because fact-checking websites not only are maintained by professional journalists and experts but also use rigorous procedures to identify and report false and misleading information. In addition, these websites monitor traditional and social media platforms that cover diverse information channels where users get their daily information. Therefore, the quality and methods used to identify false stories in this study were checked by journalists and professionals, rather than by the authors of this paper. Between January 2020 and March 2020, 8 different fact-checking websites (listed in Table 1) were monitored, and 2 researchers checked these websites manually to find and extract COVID-19 misinformation stories. Finally, 127 pieces of false news related to COVID-19 were found and collected.

**Table 1.** List of fact-checking organizations that was used for data collection.

| Name | Managed by | URLs |
|---|---|---|
| Factcheck | University of Pennsylvania | Factcheck.org |
| The Fact Checker | Washington Post | washingtonpost.com/news/fact-checker |
| Media Bias/Fact Check | Independent Media | mediabiasfactcheck.com |
| PolitiFact | Poynter Institute | politifact.com |
| Snopes | Snopes Media Group | snopes.com |
| TruthOrFiction | Whats True Incorporated | truthorfiction.com |
| RealClearPolitics | RealClear Media Group | realclearpolitics.com |

In the next step, thematic analysis was applied to all 127 false stories. Thematic analysis was used because it helps to discover aspects, similarities, and differences within the false information stories [38]. Thematic analysis is a common methodology for identifying main themes in framing studies [17].

First, researchers read the full stories, multiple times and separately, to identify occurring patterns in the data sets. The original false news was referred to in order to maintain a better understanding of the data. A deductive approach was utilized in a meeting, and researchers brainstormed about the existing themes using available resources, mainly news and reports. In addition, inductive analysis was applied in this study. Each researcher individually developed their own themes with clear descriptions for each subtheme and theme by reading the misleading stories fully. NVivo, a qualitative data analysis tool, was used to sort, organize, manage, and analyze the qualitative data. Researchers reviewed the themes that they assigned to the data independently. Cohen kappa was used to evaluate intercoder reliability [39]. The agreements between 2 coders ranged from .8112 to 1 across all identified subtheme and themes. The Fleiss guidelines considers Cohen kappa values above .75 to indicate strong agreement levels. [40].

## Ethical Considerations

All data used in this project are secondary data from fact-checked websites that are accessible to the public on the web. This study did not use and analyze any personal or individual information.

# Results

## Themes and Subthemes

Following approaches from extant literature [41], the researchers first identified 4 main themes from the 127 pieces of news that were analyzed: attribution, impact, protection and solutions, and politics. Within these themes, 19 subthemes emerged. They are summarized in Table 2 and described in the following sections.


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**Table 2.** Identified COVID-19 misinformation themes, subthemes, and frequencies in the studied sample.

| Themes and subthemes | Examples | Frequency |
|---|---|---|
| **Attribution theme** | | |
| Origination and source | 5G, lab-created | 20 |
| Pseudoscience | Scientists believe; COVID-19 comes from bats; Charles Lieber. | 11 |
| Origination date of the virus | Lysol knew; coronavirus is not actually new. | 11 |
| Biological weapon and war | Virus was created as a bioweapon. | 5 |
| Religious | Sent by God to punish homosexuals and environmentalists. | 4 |
| **Impact theme** | | |
| Fake statistics | 65 million deaths | 14 |
| Not severe and exaggerations | Media is exaggerating the risks of COVID-19; coronavirus is the least deadly virus. | 9 |
| Racist issues | Africans are genetically resistant to coronavirus. | 4 |
| Health costs | The United States is charging over $3.00 to test for COVID-19. | 3 |
| **Protection and solutions theme** | | |
| Travel and transportation | The United States would suspend "all travel from Europe" for the next 30 days, excluding the United Kingdom. | 7 |
| Stopping or containing the virus spread | The number of COVID-19 cases in the United States, as of February 27, was decreasing. | 6 |
| Quarantine | Trump will mandate 2-week in-home quarantine for the nation. | 4 |
| Home remedies | Chlorine dioxide; vinegar, garlic water; warm water | 16 |
| Treatments and drugs | Saline; hydroxychloroquine | 12 |
| Diagnosis and testing | Hold your breath without coughing; diabetic monitors and complimentary testing kits for the coronavirus | 7 |
| Virus killers | Virus is killed at 26/27 degrees. | 5 |
| Personal protective equipment | Hand sanitizer will do nothing for the coronavirus; face masks should only be worn by medical professionals. | 4 |
| **Politics theme** | | |
| Governmental and political organizations | Democrat party, Chinese Communist Party; US Department of Homeland Security, Chinese Government; Spanish Army, US Army; CDC[a] | 38 |
| Administrators and politicians | Donald Trump, Nancy Pelosi | 24 |

[a]CDC: Centers for Disease Control and Prevention.

## *Attribution Theme*

### Origination and Source

Any inaccurate or unproven information related to the source of the virus was classified in this category. Some internet users blamed governments of some countries, such as Canada, China, and the United States, for producing the COVID-19 virus:

> *Canada is the source of the 2019 coronavirus outbreak in China.*
>
> *The US was interested in the bioweapon and the deal to transfer the virus accidentally released it in Wuhan.*
>
> *Government lab sent pathogens to the Wuhan facility prior to the coronavirus outbreak in China.*

Another type of false information about the root of COVID-19 argues that the virus was created in a lab by humans:

> *There was an accidental leak of lab-created coronavirus.*
>
> *The new coronavirus contains HIV insertions and shows signs of being created in a lab.*

Certain products have also been stated to be the root of the virus. For instance, it was said that:

> *COVID-19 was found in toilet paper, and a strain of the dead virus breeds rapidly in tissue fiber.*
>
> *The virus is an American product par excellence, according to the registry of inventions submitted in 2015.*

Some other statements claim that famous figures are the root of the virus, such as professors or celebrities. For instance, it was stated that:

> *Harvard professor Charles Lieber has been arrested for creating the coronavirus.*



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A related misinformation story about artists claimed that:

> *Sam Hyde is responsible for the spread of the new coronavirus.*

Other falsely claimed sources of COVID-19 are related to technology, such as 5G:

> *5G has damaged people's immune systems.*

### Pseudoscience

Another type of misleading information pertained to unproven scientific facts and claims related to different aspects of COVID-19. Some argued that there are existing scientific solutions such as patents or medications for the virus:

> *There is a patent for the virus, and a vaccine is already available.*

Some focused on the misinterpretation of scientific findings, for example:

> *Scientists believe that coronavirus may have come from bats in a Chinese research facility.*

### Origination Date of the Virus

There were some incorrect claims that COVID-19 was a known virus before 2019:

> *Clorox bottle claimed it could kill 2019 coronavirus before it was developed, proving that the virus was developed prior to the outbreak.*
>
> *Lysol knew about coronavirus before it was common knowledge or spreading in humans.*

Some of this false information argued that medications for the virus were available before the pandemic, for instance:

> *There is medication for the coronavirus that proves that the novel coronavirus is not actually new and has been known about for years.*

Another example indicated that the Centers for Disease Control and Prevention (CDC) was aware of the virus:

> *The CDC had "advanced knowledge" of the COVID-19 outbreak in November 2019.*

### Biological Weapon and War

This category consists of statements that falsely claimed COVID-19 was created as a biological weapon by the Chinese or US governments to possibly pursue their political or economic goals against other countries. For instance, a false claim related to the United States was:

> *The coronavirus is part of the American biological war against Russia and China.*
>
> *A spokesman for the Chinese foreign ministry claimed that the coronavirus did not originate in a Wuhan market, but rather was weaponized deliberately by US troops taking part in an athletic competition in that city last year.*

Some statements, also related to the Chinese government, have shown:

> *A picture depicting a railroad tanker car with the 'COVID19' labeling indicating the transportation of the virus across the country.*
>
> *Rumor claiming that the virus was created by the Chinese Government as a bioweapon to be released on the people of China.*

### Religious

Some misleading information about COVID-19 is related to several religious issues. Some of these stories focus on religious leaders. An example includes a fabricated story about Pope Francis:

> *Pope Francis and two of his aides have tested positive for the novel coronavirus.*

Some piece of news connected the pandemic to Saint Corona:

> *Saint Corona is the patron saint of epidemics.*

Another subtheme in this category was religious myths, such as:

> *Covid was sent by God to punish homosexuals and environmentalists.*

## *Impact Theme*

### Fake Statistics

As shown in Table 2, some stories focused on fake predictions about various aspects of COVID-19. For instance, a piece of news claimed that:

> *Health experts predicted the new coronavirus could kill 65 million people.*

Another example was the false news about the forecast done by Gates foundation:

> *The Gates foundation and others have predicted up to 65 million deaths from the coronavirus.*

Additionally, some fabricated statistics circulating the internet referred to increasing and decreasing COVID-19 cases and deaths, such as:

> *The coronavirus will kill Ukraine in days, according to the expert Olyaksandr Teplyuk.*
>
> *The number of COVID-19 cases in the US, as of Feb. 27, was decreasing.*

### Not Severe and Exaggerations

These statements claimed that COVID-19 and the pandemic are not as severe of a problem as others are claiming, for instance:

> *The coronavirus is the least deadly virus.*
>
> *Novel coronavirus (COVID-19) is no more dangerous than the common cold.*
>
> *Sweden declines treatment for coronavirus because virus is safe, and they have not closed borders.*

Particularly, some stories claimed that consequences of the pandemic are not serious issues (including the economic impact and deaths). For instance, it was falsely claimed that:



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> *The global economic impact of the shutdown – could be for nothing.*
>
> *In terms of the global population, COVID-19 mortality figures are insignificant, and indicates natural process.*

Some statements tried to provide evidence by citing sources such as a photograph that shows the role of media and journalists in exaggerating the risks of the virus, for example:

> *A photograph proves the media is exaggerating the risks of COVID-19 by showing a reporter in personal protective equipment.*

### Racist Issues

This category is about blaming the Chinese, as a nationality or ethnicity, for causing and spreading the COVID-19 virus. Some false statements attributed the root of the virus to the Chinese Communist Party, for instance:

> *The Chinese Communist Party will admit that there was an accidental leak of lab-created coronavirus.*

Other false statements or claims in this category included:

> *The 1918 influenza pandemic was called the "Spanish Flu" because it emanated from Spain, so the Chinese should be fine with the US referring to COVID19 as the "Chinese virus" or "coronavirus may have come from bats in a Chinese research facility".*

### Health Costs

This subtheme consists of false claims related to COVID-19 costs, such as the decision of authorities to waive copayments. For instance, it was claimed that:

> *Industry leaders agreed to waive all copayments.*

This subtheme also contains information about the COVID-19 testing costs. For instance, it was stated that:

> *The US is charging over $3,000 to test for COVID-19.*

Another example is a false claim noting that:

> *There are free diabetic monitors and complimentary testing kits for the coronavirus for diabetics using insulin.*

## *Protection and Solutions Theme*

### Travel and Transportation

This category covers any false news related to human travel, as well as transportation and travel restrictions, and their consequences (see Table 2 for more information), for example:

> *The U.S. would suspend "all travel from Europe" for the next 30 days, excluding the U.K.*

The positive or negative consequences of false claims about travel and restriction include impacting trade and cargo, saving lives, contracting the virus, and protecting populations, for instance:

> *The Coronavirus will be the end of globalization with states and countries closing borders in order to protect their population.*

Another example is:

> *Wish.com ships all products from Wuhan, China, and Wish.com products might cause you to contract coronavirus.*

### Stopping or Containing the Virus Spread

This category consists of incorrect claims about stopping and decreasing the spread of viruses. Some statements falsely claimed that the virus has been contained, such as:

> *COVID-19 has been contained.*
>
> *Chinese officials were seeking approval from the Supreme People's Court to start the mass killing of 20,000 people infected with the coronavirus in an attempt to contain.*

Some statements claimed that the number of COVID-19 cases is decreasing, such as: "The number of COVID-19 cases in the US, as of Feb. 27, was decreasing."

Other false claims in this category were related to the actions taken by officials to prevent or slow down the spread of COVID-19. For instance, it was stated that:

> *Images show the Spanish Army in the process of locking the country down to prevent the spread of coronavirus strain COVID-19.*
>
> *Belgium's health minister banned "non-essential sexual activities" in groups of three or more due to coronavirus.*

Another example was related to the warm temperatures that would help to get rid of the virus, such as:

> *The coronavirus will go away in April, as temperatures warm.*

### Quarantine

This issue reflects misinformation related to all aspects of quarantine. There are some pieces of news about the "immediacy" of quarantine, for example:

> *A text message sent in mid-March from the White House stating there would be a national lockdown or quarantine within 48 hours.*

Another aspect of focuses on the "mandatory" aspect of quarantine, for instance:

> *The Stafford Act, which will mandate a mandatory two-week in-home quarantine for the nation.*

Additionally, this subtheme points to the consequences of the quarantine such as looting. For instance, it was claimed that:

> *There has been an increase in looting in San Francisco since the city entered a shelter-in-place order in March 2020.*

### Home Remedies

Home remedies include false and unproven information to cure or prevent COVID-19. The home remedies include drinking liquids such as garlic water, chlorine dioxide, and vinegar to kill the virus. It also included false information about the impact



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of hot air and water in killing the virus. For instance, it was claimed that:

> *Using a hair dryer to breathe in hot air can cure COVID-19 and stop its spread.*
>
> *Gargling with saltwater or vinegar "eliminate" the COVID-19 coronavirus from the throat of an infected person's system.*

### Treatment and Drugs

This category includes issues related to false claims about the treatment of, and drugs used, to cure the COVID-19 disease. Some of the claims in this subtheme referred to the availability of immediate treatments for the disease. For example, a statement falsely claimed that:

> *There are two drugs, as of March 19, (chloroquine and remedesivir) that show promise as therapies for COVID-19 and have been approved and are available for immediate delivery.*

Another aspect is related to the unproven claims about existing drugs used to treat COVID-19. For instance, some internet users shared that:

> *Russian doctors have found a way to treat the virus.3 drugs that are also used to fight HIV, Hepatitis C and MS (Multiple Sclerosis) are recommended.*

Specifically, there were some stories referring to the use of traditional medicine in treating COVID-19, for example:

> *China was able to control the pandemic without a vaccine by using traditional and low-cost medicine.*

### Diagnosis and Testing

This subtheme includes incorrect information about the methods for the diagnosis of COVID-19 and misleading information about different aspects of testing. One aspect of this subtheme relates to methods for self-diagnosis and self-tests. One example for self-testing is:

> *If you can hold your breath without coughing, discomfort, stiffness, or tightness, your lungs do not suffer from fibrosis and therefore you have no COVID-19 infection.*

Some false information focused on testing methods for specific diseases, for instance, "There are free diabetic monitors and complimentary testing kits for the coronavirus for diabetics using insulin."

Another issue in this category relates to the availability of testing methods in the early days of the pandemic that claimed:

> *There is no shortage of coronavirus tests in the US.*

Also, there was a false story that discusses the interference of politicians to make the testing more difficult:

> *The Obama administration officials made regulations that have made it difficult to make testing for the coronavirus available.*

### Virus Killers

This category includes false information about the ways the virus can be killed, including heat and saline. Some false claims argued that the virus is not heat resistant. For instance, it was stated that:

> *The virus is not heat-resistant and will be killed by a temperature of just 26/27 degrees.*
>
> *Coronavirus dies at 26-27 degrees (Celsius). Spring heat will overcome the coronavirus, and you also need to often drink hot drinks and spend more time in the sun.*

On the other hand, some stories claimed the opposite, such as:

> *The virus is heat resistant and will be killed by a temperature of just 26/27 degrees.*

Some claims also referred to saline as a substance for killing the virus, such as:

> *Coronavirus can be killed in 4 days by using saline.*

### Personal Protective Equipment

This category includes false information about personal protective equipment such as masks and sanitizers. For example, it was claimed that:

> *Face masks should only be worn by medical professionals.*

Another type of misleading information in this category is related to the ineffectiveness of washing hands, such as:

> *Hygienist criticizes measures to protect against COVID-19 and states "Washing your hands is useless."*
>
> *Hand sanitizer will do nothing for the coronavirus.*

## *Politics Theme*

### Governmental and Political Organizations

This theme includes false information that internet users have created and disseminated about authorities at the organizational levels, including governments, governmental agencies, political parties, health care institutions, and military forces. The false information in this category contained rumors related to the role of governmental and political organizations about different aspects of COVID-19 such as economic impacts, the virus' roots, and border crossings.

For instance, a false piece of information about the US Department of Homeland Security claimed:

> *The US Department of homeland security said that they fear illegal border crossings may increase the spread of the novel coronavirus.*

Another example about the US government attempting to control economic impacts was indicated in a post that has garnered more than 5000 shares and stated that:

> *All US Citizens are Entitled to $700 USD per week to stay at home to avoid the spread of COVID-19 novel Coronavirus, starting from March 17, 2020.*

Another post indicated:

> *The Government grant pay is accessible to all no matter employment status.*



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Some stories focused on political and governmental institutions as the root cause of the virus. As an example, social media users created a rumor "claiming that the virus was created by the Chinese Government."

An example related to health organizations claimed "The CDC had 'advanced knowledge'" of the COVID-19 outbreak in November 2019."

Some false news was related to the engagement of military forces in creating the virus, for instance:

> *US military brought the virus to Wuhan.*

Another aspect of this context regards using the power of the army as a strategy to control the pandemic, for example: "Images show the Spanish Army in the process of locking the country down to prevent the spread of coronavirus strain COVID-19."

### Administrators and Politicians

This category includes any rumor and misinformation related to administrators and politicians or rumors created by them at the individual level. These include politicians receiving personal benefits from the disease (eg, stock market manipulation) and politicians' decisions about the virus (eg, travel restrictions, quarantine, regulations, funding the National Institutes of Health and CDC, national security council, scientists).

For instance, it was claimed that:

> *Nancy Pelosi was caught trying to include abortion funding in the bill to combat coronavirus.*

> *Donald Trump owns stock in and stands to benefit from the use of testing machines produced by Thermo Fisher Scientific Corporation.*

Another example in this category is the fake information created by Donald Trump that was published on the Web through his speeches and official Twitter account. For example, he claimed that:

> *Antiviral therapies will be available in no time.*

This highlights his strategy to manage the pandemic in a short time. Another similar example is his claim about the effort of Google in developing an application for screening the virus:

> *Google is working on a screening website that large numbers of Americans can soon use to see if they should be tested for the coronavirus.*

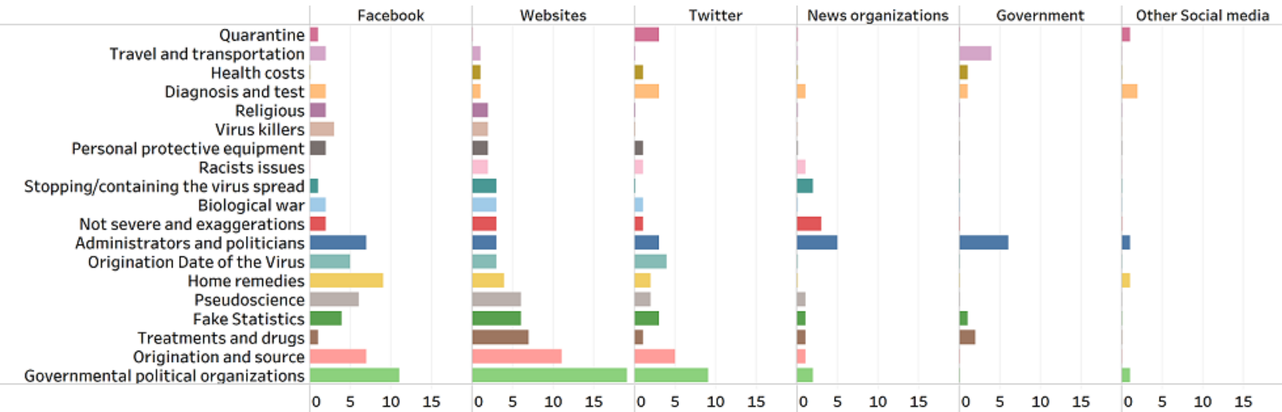
## Subthemes and Themes and Media Platforms

After completing thematic analysis, the platform(s) from which the stories had originated were re-checked to identify on which platforms each piece of news was primarily shared. In some cases, stories started from different platforms at the same time; when this occurred, more than one media platform was coded for these cases. It is possible that a story started in one medium and spread across others later, but we only considered the platforms on which the piece of news originated because it was difficult to track secondary media dissemination. Through checking the reported articles in the fact-checking websites, we identified the key platforms. The stories are mainly shared through websites such as *InfoWars* that are maintained by conspiracy theorists (n=79). Facebook was the second platform on which misleading information was created (n=69). In our sample, Twitter was the third-leading avenue by which people created misleading information (n=40). Another place where misinformation stories originated was mainstream media (n=18). This included some tabloid outlets and some official news agencies such as *Newsweek*, *CNBC*, and *Yahoo! News*. Other sources of misleading information were official government avenues, such as formal websites, press conferences, and briefings. White House channels were one of the examples for this category (n=18).

Due to the low frequency of YouTube, instant messaging, and Reddit in our sample, we merged them into a category labeled as *other* social media (n=5).

As Figure 1 shows, the frequency of misinformation has differed across platforms. "Governmental and political organizations" (9/40, 23%) and "Origination and source" (5/40, 13%) were 2 subthemes with high frequency on Twitter and websites (19/79, 24% and 11/79, 14%, respectively). "Administrators and politicians" was the popular subtheme on Facebook (7/69, 10%), mainstream media (6/18, 33%), and governmental outlets (6/15, 40%). "Home remedies" (9/69, 13%), "Travel and transportation" (4/15, 27%), and "Not severe and exaggerations" (3/18, 17%) were the second most popular subthemes on Facebook, governmental sources, and mainstream media, respectively.

**Figure 1.** Distribution of COVID-19 misinformation frames across different platforms.





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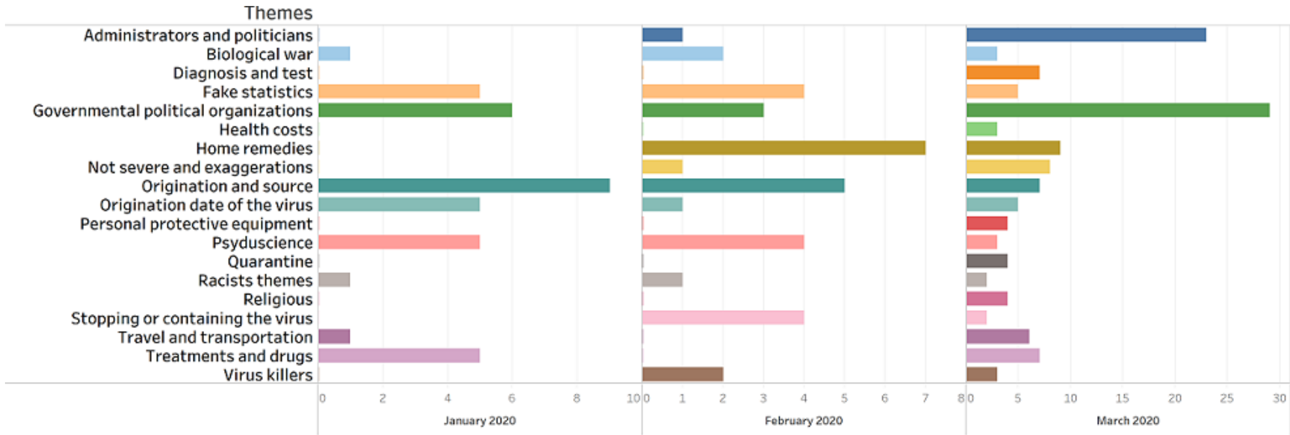
### Subthemes and Time

This section explains the frequency of subthemes over time, from January 1, 2020 to March 30, 2020. Each month was split into 3 periods. Figure 2 shows that the subthemes were mentioned only 39 times in January, 35 times in February, and 135 times in March. Mid-March had the highest frequency (79/207, 38.2%) followed by late January (37/207, 17.9%) and early March (33/207, 15.9%). The high frequency of false information in March, specifically mid-March, is possibly because the COVID-19 disease was declared as a pandemic by the WHO on March 11, 2020 [42].

**Figure 2.** The prevalence of COVID-19 misinformation between January 2020 and March 2020.




"Origination and source" (9/38, 24%) and "Governmental and political organizations" (6/38, 16%) were the 2 subthemes with the highest frequency in January. In February, again, "Origination and source" had the highest frequency (5/35, 14%), followed by "Fake statistics," "Pseudoscience," and "Stopping or containing the virus spread," each with a frequency of 4 (4/35, 11%). In March, "Governmental and political organizations" (29/134, 21.6%), "Administrators and politicians" (23/134, 17.2%), and "Home remedies" (7/134, 5.2%) had the highest frequencies.

Most of the subthemes, such as "Administrators and politicians" and "Home remedies," had increased from January 2020 to March 2020. However, a few subthemes, such as "Treatments and drugs" and "Origination date of the virus," experienced a decrease in February. For instance, "Treatments and drugs" was mentioned 5 times in January, decreasing to 0 in February, then increasing to 7 in March. The frequency of "Administrators and politics" was 0 in January, increasing slightly to 1 in February, with a significant increase to 23 in March.

## Discussion

### Principal Findings

Misinformation and disinformation are extremely complex and contextual concepts with various layers and levels. Therefore, it is not easy for people to distinguish credible information from fake or false news, especially in the case of an overly complicated crisis, such as the ongoing global pandemic. Even for people with information literacy skills, it is still not an easy task to avoid misinformation and disinformation, as the complexity of this issue is increasing constantly. Developing a more widespread awareness of influential misinformation categories could help people to be more informed and prepared when facing misinformation.

For example, as Table 2 indicates, "Government organizations" and "Administrators and politicians" were the top 2 subthemes in the results, which aligns with findings from a previous study [12]. There are 3 probable reasons for this. First, any news about this group will attract more attention from users as this group's decisions have a tremendous impact on society. Second, it is extremely difficult for ordinary people to directly access this group to verify the validity of the information. Therefore, there is a paradoxical circumstance here: "Governmental and political organizations" and "Administrators and politicians" are more visible and less accessible at the same time. This paradox creates a fertile ground to produce misinformation related to this group more than ever. Finally, they are easy targets to blame for their poor decision-making and their incapability to deal with the crisis.

The third most frequent subtheme was "Origination and source" of the virus. This subtheme's high frequency comes from the fact that any information about the origin of an unknown phenomenon has a higher chance of attracting peoples' attention. Knowledge regarding a certain phenomenon helps people to lower their levels of uncertainty. In the case of the current pandemic, the level of uncertainty about the origin of the virus is extremely high for everyone, even for experts, and people seek explanations about the mysterious source of this unknown disease. They need to make sense of what is going on around the world, and any information about the source can lower their uncertainty level. Therefore, information on this aspect of the pandemic, regardless of its credibility and validity, will naturally be incredibly interesting for most people, and they pay consequently more attention to it. With consideration to media framing, these subthemes are indicative of information sources "declaring the underlying causes and likely consequences," as suggested by extant research [43]. This is also an exemplification of early arguments by Iyengar and Simo [44] about attributing blame for a societal issue.

The fourth category was "Home remedies," probably because, during this disastrous time, people desperately seek solutions, especially easy solutions, and home remedies sound like



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promising options for many. Therefore, any information about home remedies has a higher level of attractiveness and will inevitably create another rich ground for misinformation creation and dissemination. Here, a distinction between thematic versus episodic framing emerges, as many of the shared home remedies are a result of a specific case or example, or episodic framing [45].

The fifth category was "Fake statistics." The reason behind its popularity is the power of statistics to more precisely and correctly show false stories. This communication strategy helps to represent incorrect information more evidentially and to persuade minds as a result [46]. The capacity of figures to exaggerate any situation may be another reason for the creation of fake statistics. For example, the number of people affected by the disease, or the economic consequences of the pandemic, can be easily summarized into statistics that cannot be verified by people; however, it can attract attention. Moreover, browsing numbers and figures is often much easier for people than reading long stories.

The next 4 categories, including "Treatment and drugs," "Pseudoscience," "Not severe and exaggerations," and "Origination date of the virus," have a shared element that can potentially accelerate the dissemination of misinformation. The shared element among these 4 categories is a form of denial for people, that the new disease is not a big problem and there is nothing serious about it. One of the reasons for this denial is related to an orchestrated strategy to show that organizations and decision-makers are not responsible for managing crises, and it is a known application of false information in crisis communication [47]. Another aspect of the denial is pertinent to the abuse and misinterpretation of research and scientific discoveries. This can be another tactic of misinformation to manipulate public opinion, which has been reported in previous research about misinformation and climate change [48]. These types of misinformation may attract attention because people are looking for relief and comfort in crisis, and this kind of news will be very appealing; thus, they pay more attention to it.

In the quarantine subtheme, the claims were not false after March 15, 2020 when the WHO declared the disease as a pandemic and countries opted for mandatory lockdowns. This shows that a false claim may not be false anymore at another time. Context matters in discussing false information.

When considering the broader themes under which each of the above subthemes were classified, this study found that the "Protections and solutions" theme included the largest number of subthemes (8 subthemes), followed by the "Attribution" theme with 5 subthemes. The "Impact" theme included 4 subthemes, and the "Politics" theme included only 2 subthemes. Therefore, although the subthemes that reoccurred the most (government and political organizations as well as administrators and politicians) were within the "politics" theme, the theme with the largest number of subthemes was related to how individuals and our society can find solutions related to the pandemic.

Results of this study revealed the role of different platforms in circulating misinformation. Findings show that "hoax or conspiracy theorist news websites" were the primary sources of creating false information about COVID-19. This agrees with the results of a similar study about a specific false story [10,41]. In our sample, Facebook and Twitter were the 2 main social media sources of misinformation, which aligns with quantitative studies about the sources of false information about COVID-19 and previous health crises. Surprisingly, this study shows that trusted media, such as news agencies and official government platforms, were also sources of false stories in the pandemic, which is in line with a survey study in different countries [49].

The COVID-19 pandemic had different stages based on which misinformation subthemes were prevalent at the time. For instance, before March 11, 2020, it was known as an epidemic, while on March 11, 2020, it was declared as a pandemic by the WHO. At this stage, the globe experienced new challenges such as the mask mandate, quarantine, and panic about the shortage of products [19,50]. The type of misinformation could vary by the different stages of a pandemic. For instance, during the initial phase of a pandemic, when there is a lack of trust between politicians and the public [51] and there are high levels of uncertainty in society about the origins of the virus, nonverified information about the origins of the virus is more likely to be disseminated and possibly adopted by the public.

The results of this study indicate that "Origination and source" of the virus was one of the prevalent subthemes in the early phase of the pandemic, which is not surprising because right after the pandemic started, people around the world started exploring to learn more about the origins and causes of the virus. During this time, conspiracy theorists were rapidly spreading their ideas on social media, marketing their thoughts to the public, and shaping public opinion. "Origination and source" was still popular in February. These findings further support the findings of the study by Evanega et al [52]. Some conspiracy theories related to "Origination and source" were as follows: the relationship between 5G technologies and COVID-19, Gates' plan to develop a vaccine using microchips, and bat soup as a source of the virus.

In February, "Home remedies" became a prominent subtheme for creating misinformation stories as COVID-19 went to another phase, that is, the public started taking it more seriously. As a result, people were searching for easy ways to cure the disease. In March, "Governmental and political organizations," "Administrators and politicians," and "Home remedies" were among the popular topics. These subthemes became more important because the actions and policies of governmental organizations to manage the pandemic were increasingly important to the public, and misinformation in these areas could attract more attention. In this period, the US presidential election was approaching, and people were more interested in information around political parties and COVID-19 issues that created a situation for misinformation. Additionally, as mentioned, March 11, 2020 was when the WHO declared the COVID-19 disease a global pandemic [42]. These subthemes had a common point, indicating that politicians tried to offer immediate and unproven solutions to stop, cure, or kill the virus. For example, the former president of the United States talked about hydroxychloroquine and chloroquine as treatments of COVID-19 on March 19, 2021, while there was no scientific evidence to prove this claim.


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In summary, from a framing perspective, the results clearly suggest that there is a concerning amount of inaccurate information being disseminated across a variety of platforms concerning COVID-19. Results from this study clearly support the framing theory's arguments about message themes and public opinion, as argued in previous research [18]. For example, the "Governmental and political organizations" subtheme that emerged as the top subtheme is reflective of a society that distrusts science and those in positions who strive for truth-telling in an era of misinformation, such as the CDC, Dr. Anthony Fauci, and others. Specifically, the findings identified that the analyzed stories most frequently included misinformation about politics. The "Origination and source" subtheme raises questions about attribution of responsibility. In a different context, scholars have argued that a correct understanding of the cause of an issue is the key to success in promoting mitigative behaviors [53]. The false information identified across several subthemes in this study raises concern about individuals and their interest in, or ability to, act responsibly during the pandemic because of a lack of factual information. Subthemes such as "Fake statistics" and "Origination date of the virus" present information in a way that might diminish individuals' willingness to engage in responsible behaviors to combat the virus, which is also reflective of findings in unrelated framing studies that examined how message themes impact public opinion, behaviors, and actions [54-56]. These are important considerations as we aim to inform and educate individuals, and we continue to combat misinformation that can have detrimental effects on health and society.

## Conclusions

This study identified a wide range of subthemes and elements that are potentially significant for better understanding of information behavior patterns in this context (ie, pandemics). This study discovered that misinformation about authorities at the "organizational levels" (ie, rumors about the role of governmental and political organizations in issues such as economic impact and the source of the virus) and misinformation related to (or created by) administrators and politicians at the "individual levels" (ie, politicians receiving personal benefits from the disease) were more frequent than other types of misinformation.

The results also indicated that misinformation type and prevalence could vary by the different stages of a pandemic over time. These results could provide some insights for policy makers as well as communication and information officers to gain a better understanding of different phases of a crisis and take appropriate and timely actions. The actions could involve combating misinformation and designing better strategies to create correct content beforehand to help the public. Effective policies and practices focusing on this aim can minimize the harmful effects of this phenomenon. A global movement with local initiatives is necessary to increase public awareness of this problem and educate more people across the world in information literacy. Policymakers should engage in more evidence-based decision-making practices. Also, information service providers should offer more effective tools and techniques for their users to evaluate the authenticity and credibility of information sources.

Misinformation type and prevalence could vary by different platforms. This study confirms that web and social media platforms are the primary sources of misinformation, which is not unexpected. Surprisingly, though, results revealed trusted outlets of information such as government channels and known news agencies were platforms for creating COVID-19 misinformation as well.

In summary, regardless of its name, whether it is called disinformation, misinformation, fake news, or malinformation, this phenomenon is a form of "information disorder" and is a major threat to the global information landscape. It is a complex phenomenon, and there is no single way to fight it.

## Practical Implications

The catastrophic consequences of misinformation and disinformation on people's lives are more disastrous than ever, especially during the current COVID-19 pandemic. The global crisis is much vaster than a smaller-scale health crisis and has numerous economic, social, and environmental aspects. Therefore, the results of this study can potentially present a range of practical implications for both policy makers and practitioners. At the policy level, policy makers can use the results to develop more effective policies to support dissemination of more trustworthy sources of information in society. At the practice level, practitioners can use the results to provide more effective and reliable services. For example, information professionals across the GLAM (Galleries, Libraries, Archives, and Museums) sector can identify the areas they need to focus on to enhance public awareness about the necessity of access to credible information in dealing with a challenging time like a global pandemic. Moreover, they can provide wider and more accessible learning opportunities for the public to empower people with higher levels of information literacy and media literacy skills. Furthermore, information system designers can use the results to identify the areas that require increased focus to help users find the most authentic and trustworthy sources of information. In addition, as this study found that web and social media platforms are the primary sources of misinformation, it is increasingly important for such platforms to issue information dispute warnings by flagging information that may be questionable or inaccurate. Finally, as individuals, members of society need to be vigilant and act as responsible media consumers to the best of their abilities. Until changes are incorporated at both the societal and individual level, there exists a risk of perpetuating the "information disorder" that has increasingly threatened the global information landscape.

## Limitations and Future Directions

This study has some limitations that should be noted. There are different private challenges such as closed Facebook pages, instant messaging applications, and emails that misinformation created and circulated. However, the content of these channels is not accessible for the fact-checking organizations to monitor systemically and, thus, are not part of the studied sample in this paper. Additionally, the time frame of this study was limited to


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a 3-month window, and it may not reflect the entire picture of false stories about COVID-19. Although fact-checking organizations aim to help provide factual data about misinformation in different contexts, they have some biases [57,58].

Further research is required to explore and reflect on each element with more qualitative and interpretive approaches. For example, conducting qualitative studies on these elements enables us to understand the actual impact of misinformation and disinformation on various aspects of everyday life during the pandemic. For instance, it can be explored to what extent dissemination of misinformation about the COVID-19 vaccination caused hesitation for various groups of people to delay their vaccination, and how this dilemma affected their real lives. In other words, what we need in further studies is a sample of real stories of real people to understand the actual influence of misinformation on various aspects of their life, ranging from their personal health and well-being to their financial and family issues. These real stories will shed light on some of the less-explored aspects of the damaging impacts of misinformation on people. Finally, some categories of misinformation could have a higher level of influence or impact on public perception, which should be investigated in future studies.

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## Conflicts of Interest

None declared.

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## Abbreviations

**CDC:** Centers for Disease Control and Prevention
**GLAM:** Galleries, Libraries, Archives, and Museums
**WHO:** World Health Organization

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Original Paper

# Themes Surrounding COVID-19 and Its Infodemic: Qualitative Analysis of the COVID-19 Discussion on the Multidisciplinary Healthcare Information for All Health Forum

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## Abstract

**Background:** Healthcare Information for All (HIFA) is a multidisciplinary global campaign consisting of more than 20,000 members worldwide committed to improving the availability and use of health care information in low- and middle-income countries (LMICs). During the COVID-19 pandemic, online HIFA forums saw a tremendous amount of discussion regarding the lack of information about COVID-19, the spread of misinformation, and the pandemic's impact on different communities.

**Objective:** This study aims to analyze the themes and perspectives shared in the COVID-19 discussion on English HIFA forums.

**Methods:** Over a period of 8 months, a qualitative thematic content analysis of the COVID-19 discussion on English HIFA forums was conducted. In total, 865 posts between January 24 and October 31, 2020, from 246 unique study participants were included and analyzed.

**Results:** In total, 6 major themes were identified: infodemic, health system, digital health literacy, economic consequences, marginalized peoples, and mental health. The geographical distribution of study participants involved in the discussion spanned across 46 different countries in every continent except Antarctica. Study participants' professions included public health workers, health care providers, and researchers, among others. Study participants' affiliation included nongovernment organizations (NGOs), commercial organizations, academic institutions, the United Nations (UN), the World Health Organization (WHO), and others.

**Conclusions:** The themes that emerged from this analysis highlight personal recounts, reflections, suggestions, and evidence around addressing COVID-19 related misinformation and might also help to understand the timeline of information evolution, focus, and needs surrounding the COVID-19 pandemic.

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**KEYWORDS**

infodemic; infodemiology; COVID-19; pandemic; misinformation; health information; theme; public health; qualitative study; global health



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## Introduction

Health systems fighting the COVID-19 pandemic worldwide are facing a secondary challenge of having to address the accompanying infodemic, defined by the World Health Organization (WHO) as an overabundance of information—some accurate and some not—that makes it hard for people to find trustworthy sources and reliable guidance when they need it [1].

Infodemics are a rapidly rising global health issue. The modern digitized world has amplified various information channels, such as social media and online forums, allowing them to spread information much faster and further due to the availability and accessibility of technology as well as a lack of traditional quality control [2,3]. The resulting increase in health-related overabundance of information and misinformation hinders policy makers and health care workers from finding trustworthy sources and reliable guidance when they need it [4]. Furthermore, infodemics have been linked to negative health consequences, as showcased by the measles outbreaks in countries such as the United Kingdom, the United States, Germany, and Italy as a result of vaccine hesitancy fueled by misinformation [5,6]. Likewise, infodemics have also led to violence and distrust, as seen by the targeted attacks on health care workers during the 2019 Ebola outbreak in the Democratic Republic of Congo [7]. Thus, the current infodemic surrounding COVID-19 is not a novel phenomenon but part of a global public health trend that has been significantly growing over the past few years.

Many recent studies have attempted to characterize the infodemic and its predisposing factors. In rapidly evolving situations, such as the COVID-19 pandemic, an explosive amount of new information is generated and researchers, policy makers, journalists, and ordinary citizens are unable to keep up with the evolving facts [8]. In addition, incoherent public health messaging and reversals in recommendations cause distrust in governments and health authorities [9]. Furthermore, people prefer and tend to accept information that confirms and is consistent with their preexisting attitudes and beliefs even if that information is not based in evidence [10]. Poor health literacy shapes interpretation of information. Poor health journalism by traditional forms of media is also found to be a factor [11]. Lastly, the lack of accurate and reliable scientific knowledge closer to the broader population allows for unverified information to fill the gaps left behind [12].

To effectively address the COVID-19 pandemic and future public health emergencies, infodemics must be understood and managed. WHO established the Information Network for Epidemics (EPI-WIN) [13] to counter the COVID-19 infodemic and mitigate its side effects. The United Nations (UN) launched a portal for the public to access reliable and up-to-date COVID-19 information through its Verified initiative [14]. Similarly, the US Centers for Disease Control and Prevention (CDC) created a series called “COVID-19 Science Update” to aid public health professionals’ response to COVID-19 [15]. Health authorities worldwide are working closely with online platforms, including Facebook, Google, Twitter, and YouTube, to provide and highlight evidence-based information [2]. Ultimately, the right message at the right time from the right messenger through the right medium can save lives [13].

Healthcare Information for All (HIFA) is a multidisciplinary global campaign consisting of more than 20,000 members worldwide committed to improve the availability and use of health care information in low- and middle-income countries (LMICs) [16]. Sponsored by the University of Edinburgh, HIFA is primarily based around virtual communities of practice that allow for the discussion of different health care topics with a focus on information needs. The forums use reader-focused moderation to create an organic atmosphere that allows for topics to emerge that are of interest to the forum members [17].

COVID-19 and the infodemic surrounding it have become a major discussion theme on the HIFA forums. The first post about COVID-19 on HIFA was published on January 24, 2020. Since then, over 1000 posts have been created on the topic—surpassing the number of posts made about any other topic previously on the forums. It was hypothesized that this discussion could provide an understanding of the information needs that surround the COVID-19 pandemic, particularly in LMICs, and what may be contributing to the infodemic.

This analysis aims to contribute to the global effort to track, understand, and respond to the infodemic surrounding the COVID-19 pandemic by identifying themes and perspectives shared by members on the HIFA forums.

## Methods

### Data Analysis

A thematic content analysis of the COVID-19 discussion on English HIFA forums was conducted (Figure 1). The full text of all 1059 COVID-19-related discussion posts between January 24 and October 31, 2020, on the forums was collected, and each post was coded by 4 team members (authors RG, SC, RM, and PK) using an inductive coding approach. We kept track of the codes on a common document to reduce redundancy and ensure intercoder reliability. Codes included geographic locations (ie, countries, continents), populations (ie, refugees, children, migrant workers), and topics of the post (ie, mental health, use of chloroquine, herd immunity). Of the original 1059 posts, 194 (18.32%) were removed because they were found to be general announcements, spam messages, and advertisements that did not contribute meaningfully to the COVID-19 discussion. The qualitative analysis software NVivo 12 (QSR International) [18] was then used to identify the most frequently appearing codes in the remaining 865 (81.68%) posts and develop themes and subthemes [19] using a grounded theory approach until no new themes were discerned.



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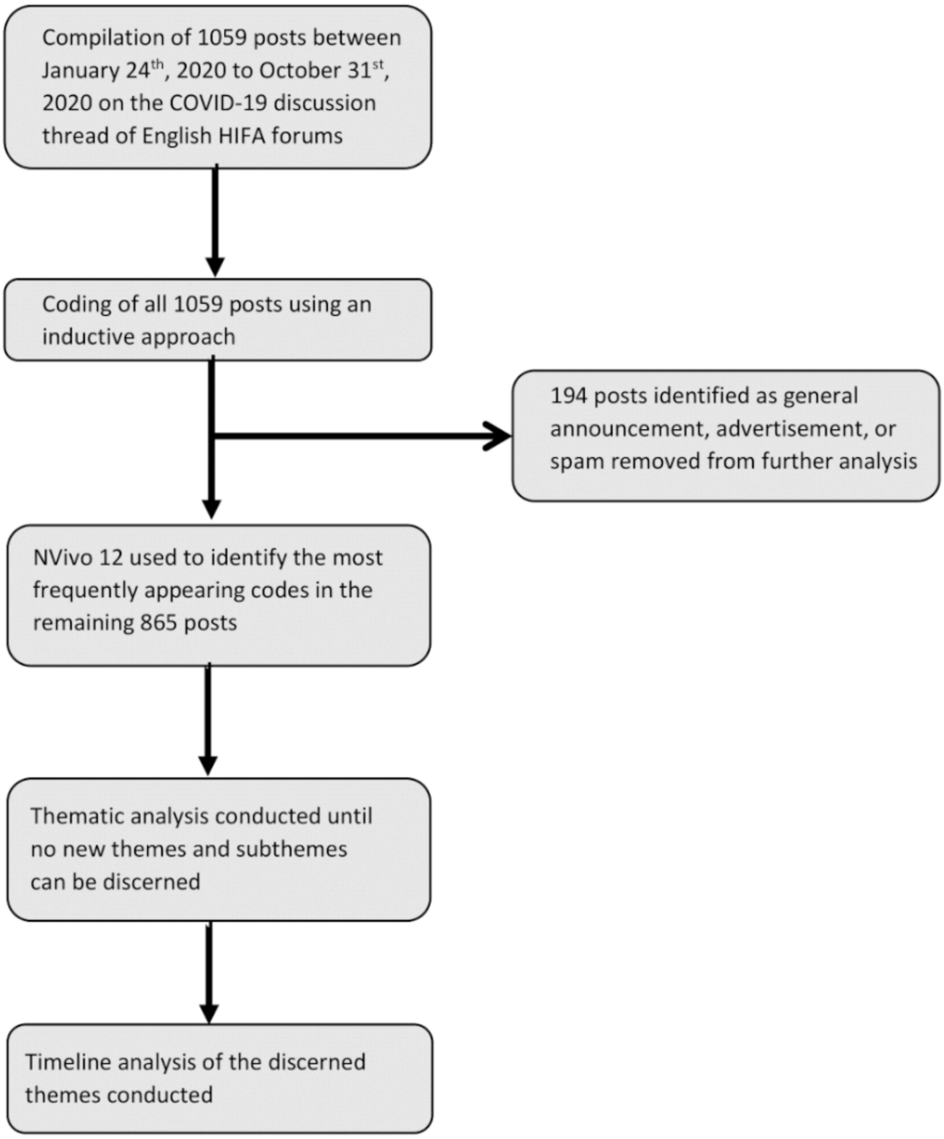
**Figure 1.** Schematic of the qualitative study analysis method.




A timeline analysis of the posts divided by month was also conducted. The 865 posts were divided according to the months in which they were posted. Within each month, the 20 most frequently mentioned words, excluding articles and conjunctions (ie, the, of, because) and similar nonmeaningful words, were acquired using NVivo 12. These words were then used to determine the most common topics for each month of the COVID-19 discussion on the HIFA forums.

A secondary analysis was conducted on the profile data of all HIFA members who contributed to the COVID-19 discussion in order to understand their backgrounds as study participants. This analysis included the members' location of residence, their profession, and their affiliation. The professions were broadly categorized into researchers, health care professionals, public health workers, information providers, and others. Similarly, the affiliations were broadly categorized into government, WHO, UN, commercial organizations, nonprofit nongovernment organizations (NGOs), academia, and others.

### Ethical Considerations

Prior to the study being undertaken, a formal message was sent to members of the HIFA forums, introducing its purpose and obtaining implied consent. Formal consent was not obtained from each individual member as all content on the HIFA forums, including the discussion posts and member data, is publicly shared information. The study was assessed by the researchers to be low risk. Identifying data, such as names and addresses, that can be reasonably used to identify individuals were removed from the posts during the initial coding process to ensure individual member confidentiality.

## Results

### Study Participants

In total, 246 members across 46 different countries participated in the discussion. The geographical data (Figure 2) revealed that the top 3 countries in descending order are the United Kingdom (n=62, 25.2%), the United States (n=54, 22%), and India (n=16, 6.5%). Every continent except Antarctica was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represented, with the main regions being Europe, North America, and Africa.

A significant number of HIFA members' professions (Figure 3) could be categorized as public health workers (eg, public health registrars and consultants at global health organizations), who numbered 92 (37.4%). Health care providers, such as physicians, nurses, and community health workers (CHWs), and researchers holding academic positions made up the second and third categories, with 57 (23.2%) and 53 (21.5%) members, respectively.

The affiliations of HIFA members contributing to the discussion (Figure 4) could be split into several different categories. Nonprofit NGOs were the largest affiliation category and included 77 (31.3%) members of the total. Academia also made up a sizable portion at 57 members (23.2%). The other category contained a number of independent or retired professionals and volunteers.

**Figure 2.** Geographical distribution of the study participants. In total, 246 members across 46 countries from every continent except Antarctica participated in the COVID-19 discussion. The United Kingdom had the greatest number of study participants at 62 (25.2%), with the United States being second with 54 (22%) participants and India being third with 16 (6.5%) participants.

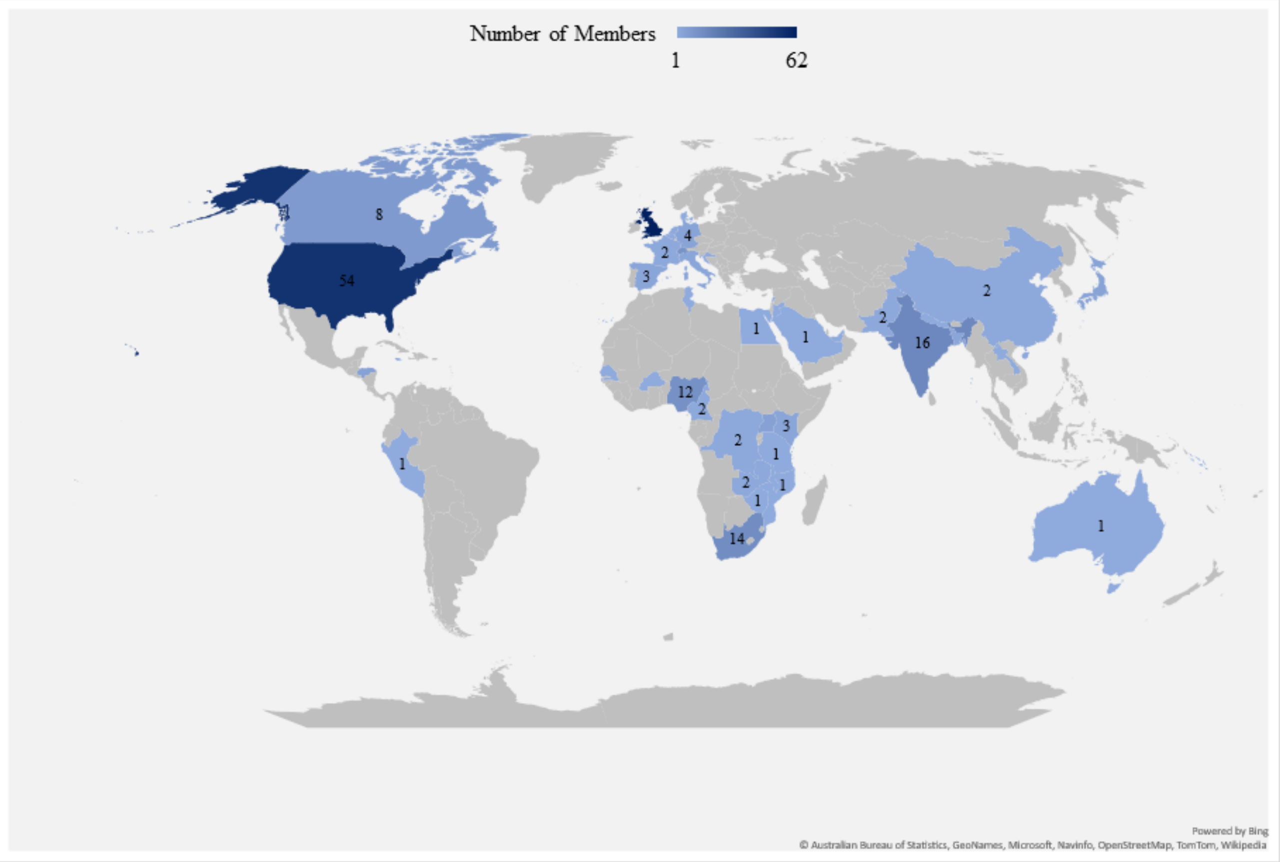



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**Figure 3.** Categories of professions represented by the study participants. Most of the study participants fell into the category of public health, which included public health officials, policy makers, and consultants. Health care providers included physicians, nurses, and CHWs. The category of information provider included librarians, editors and associate editors of journals, and communications specialists. The other category included students, volunteers, and retired members. CHW: community health worker.

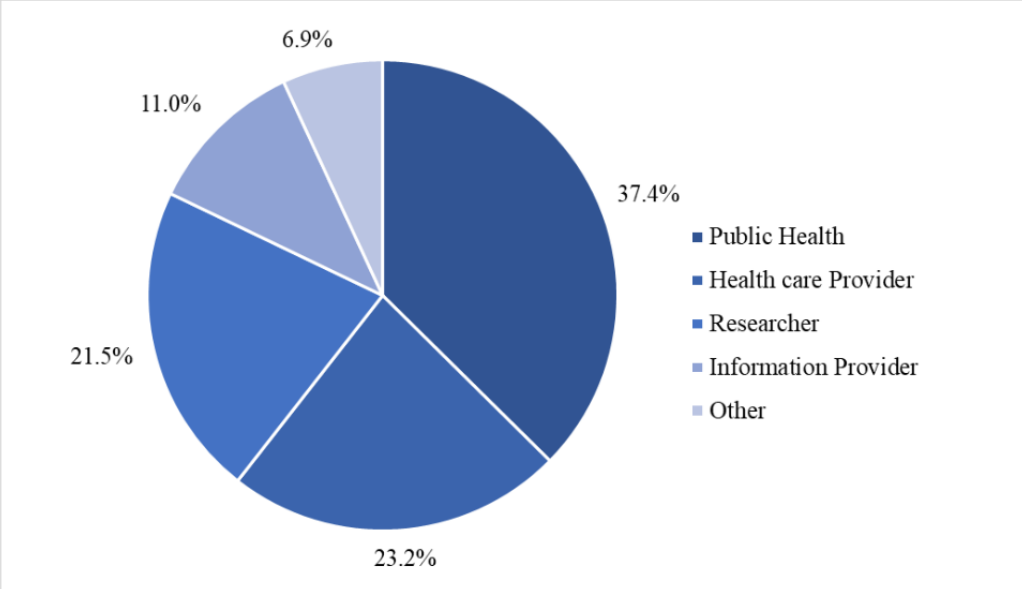
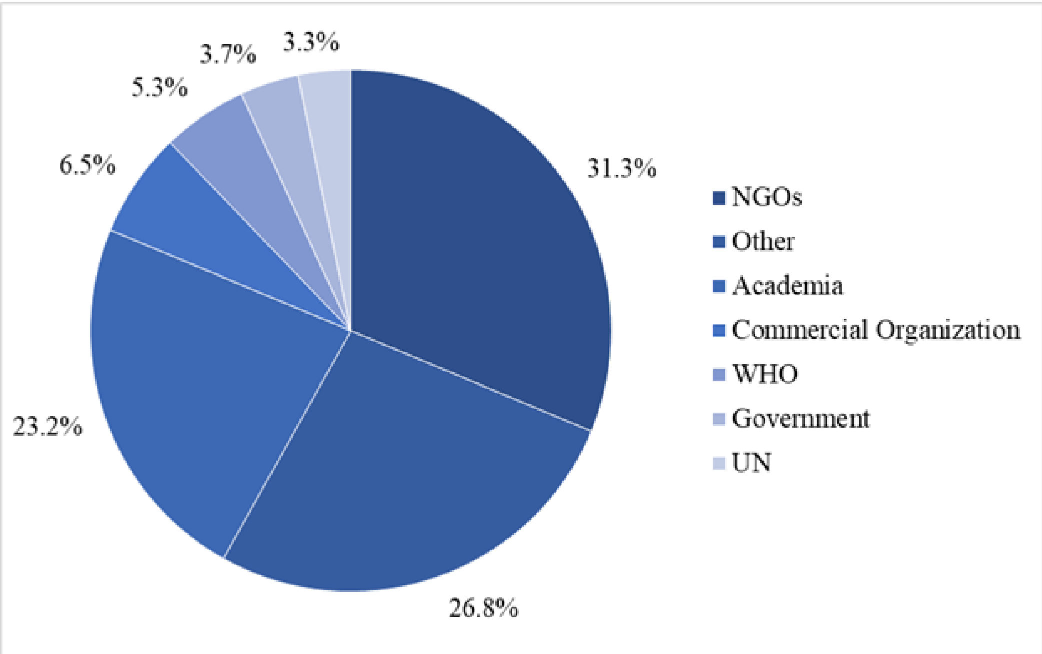



**Figure 4.** Affiliations of the study participants. The largest affiliation was nonprofit local NGOs with 77 (31.3%) members. The other category of affiliations included independent professionals, volunteers, and retired members. NGO: nongovernment organization; UN: United Nations; WHO: World Health Organization.




## Thematic Analysis

In total, 6 major themes, and their subthemes, were identified (Table 1).


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**Table 1.** Themes and subthemes identified through the analysis of the COVID-19 discussion on English HIFA[a] forums.

| Theme | Subthemes |
|---|---|
| Infodemic | • Distrust in authority and experts<br>• Inconsistent public health messaging<br>• Information overload<br>• Role of social media<br>• Translation needs<br>• False health claims |
| Health system | • Handwashing and PPEb<br>• Role of CHWsc<br>• Ability to test, trace, and conduct surveillance<br>• Impact on health care workers<br>• Impact on other health services |
| Digital health literacy | N/A[d] |
| Economic consequences | N/A |
| Marginalized peoples | N/A |
| Mental health | N/A |

[a]HIFA: Healthcare Information for All.

[b]PPE: personal protective equipment.

[c]CHW: community health worker.

[d]N/A: not applicable.

## *Theme 1: Infodemic*

By far, a significant amount of discussion in the HIFA forums about COVID-19 was regarding the infodemic surrounding it. Specifically, there was considerable input about the spread of misinformation through different mediums, its downstream effects, information gaps, and needs. The importance of making verified health care information accessible to all to prevent infodemics was a common consensus of the HIFA COVID-19 discussion, which is in line with HIFA's mission. Further, members noted that information that is filtered, simplified, and succinct must be provided through multiple mediums as access to technology can be a barrier. The right information must be presented through the right medium to the right people at the right time.

This theme includes the following subthemes: distrust in authority and experts, inconsistent public health messaging, information overload, the role of social media, translation needs, and false health claims.

### Distrust in Authority and Experts

A common factor that seemed to drive the infodemic and its impact on the management of the COVID-19 pandemic seemed to be distrust in authority and experts. According to members, many examples of misinformation they have seen circulate online and among their circles questioned the origins of COVID-19. These examples include claims that COVID-19 is a biological weapon, that it was made to sell medicines, or that it was part of a larger global vaccination conspiracy. A few members were concerned that such claims led to distrust in health workers, which has fueled attacks targeting them. In some countries, COVID-19 was seen as a disease of the wealthy and of immigrants due to its association with foreign travel, which has led to instances of racism and xenophobia.

Members also discussed the politicization of the COVID-19 pandemic. Some felt that their respective governments were not being transparent regarding the public health guidance they were providing or about the protocols they had put in place. The accuracy of the number of infections being projected and reported was also questioned. For example, many members questioned the validity of the UK public health officials claiming that 80% of their population could be infected.

Finally, frustration was expressed with how the United States was handling the pandemic. There was discussion that at a time when all governments should be working together, the US government's threats to pull funding from WHO was not helpful. Here are a few selected posts:

> *Quite rightly, the [g]overnment is being called to account. All health policy, and especially health policy in public health emergencies such as coronavirus, must be evidence-informed.*
>
> *Five months into the COVID-19 [p]andemic with daily briefings by [n]ational [g]overnments of African countries, like Nigeria, there is still widespread ignorance amongst the population about COVID-19 and whether it exists at all. Many felt that it (Covid19) is a "scam" by their government "to make money through new drugs and vaccination" (Anecdotal information)!*

### Inconsistent Public Health Messaging

Among the members' posts, there was general frustration regarding the inconsistency of the public health guidelines being provided. Many were unhappy that some countries were following the guidelines set by WHO, while others were not. Within individual countries, there seemed to be inconsistency in the messaging provided at various levels of government, such



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as between central and regional, as well as other institutions, such as workplaces and schools. Mass media apparently had also given out contradictory and inconsistent advice. A few members also pointed out that the evolution of public health messaging over time made it difficult to distinguish what the most recent guidelines and protocols were.

To combat this, members suggested consistent, evidence-based guidelines should be given out by all sources, including governments, NGOs, mass media, health care organizations, and individual officials. For this to happen, some supported introducing legislation to hold all these entities accountable in the interest of public health. Here is a selected post:

> *It is notable that the UK and US (and China) are giving different advice to the general public about what they should do if they develop symptoms and have [a] recent history of travel to affected countries. It's unclear why this is so. The [g]lobal advice on the WHO website indicates…With globalisation of social media among citizens worldwide, it seems important that governments provide the same advice unless there are special contextual reasons why this should not be the case (in which case such reasons should be explicit).*

### Information Overload

The prevalence of too much information about COVID-19 was an issue raised by many members. Information overload was a major factor contributing to the infodemic, as an excess of information makes it difficult to distinguish between what is accurate and what is not. Some members described that this was an issue for everyone, including those who were health literate, since, in some cases, false information was shared and amplified because health professionals themselves were unable to assess its source and accuracy. Many expressed concerns about how information overload overwhelmed the general public, leading to fatigue and a failure to discern the latest guidance.

The rapidly changing status of the pandemic as well as the onslaught of new evidence and research were brought up as some of the causes of the information overload. Moreover, there was duplication of information from multiple organizations attempting to provide knowledge and language translations.

The implementation of a universal and dynamic access point with the latest research, evidence, and guidance to coordinate the influx of information from all sources was put forward by members. Some believed that all sources need to be filtered for misinformation even at the risk of losing knowledge. Here are a few selected posts:

> *An international website should be created with the majority of languages, containing all the information on the virus, preventive measures, news of its spread and means, international efforts to fight against.*
>
> *The real problem…is the increase of misinformation, fake news, etc. Every attention and effort should be directed at culling and eliminating misinformation wherever and however it emerges. And as quickly as possible, even at the risk of too much information.*

### Role of Social Media

The role of social media during the COVID-19 pandemic received significant discussion. Social media, including WhatsApp, Facebook, Twitter, and YouTube, were believed by many members to have amplified the spread of misinformation and the infodemic. Concerns were expressed that social media companies were failing to carry out due diligence in filtering misinformation, because they were profiting from the increased engagement with their platforms. A call for companies to be held accountable was raised in a number of posts. An example was shared in which members noticed a significant drop in WhatsApp messages after the South African government threatened legal consequences for anyone engaging in and spreading misinformation on social media.

There was also a discussion that the onus to prevent misinformation should not solely lie with social media companies. Members felt that social media simply was a platform to amplify misinformation that already existed due to the lack of a proper and verified information channel for all to easily access. Thus, arguments were made that social media could be used as a tool to make accurate and verified information accessible.

Finally, the lack of health privacy on social media was a concern because identifying information about individuals who have tested positive for SARS-Cov-2 or were symptomatic was shared in their communities, thereby alienating them. Here is a selected post:

> *Misinformation has played a major role in worsening the situation across the world in its rapid response to the Covid-19 creating a state of widespread panic especially with readily available access to social media as compared to a decade ago. Although this could be beneficial in many ways, it is being misused time and again to spread conspiracy theories and other forms of misinformation about the Covid-19.*

### Translation Needs

Throughout the English HIFA thread on COVID-19, there were multiple requests for the rapid translation of current guidelines and resources to other languages and dialects. Members reported that automatic language translation tools, such as Google Translate, were not accurate and did not contain regional dialects. Additionally, misinformation was also prevalent in lesser known languages and dialects and it was not being addressed. General public health advice given out by international organizations, such as WHO, may not be applicable to local settings or consistent with local regulations, and so there was a need for contextualization.

Finally, some pointed out that governments and public health organizations were indirectly excluding foreigners, such as tourists and expats, by not providing local advice and guidance in languages other than the country's official ones. Here is a selected post:

> *it is important that evidence-based messages (from the World Health Organization & other reliable sources) are tailor-made in their local languages to reach and empower them.*



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### False Health Claims

The prevalence of false health claims regarding how COVID-19 spreads, its treatment, and its prevention was discussed. Although most of these claims did not pose a danger, some directly contradicted official public health and medical advice, such as gathering in places of worship and taking unproven medications. Religious prophets and self-appointed "experts" in LMICs were identified as primary promoters of such false information, although false claims have been made in many high-income countries.

The misuse of chloroquine as a medication to treat COVID-19 was a major topic of discussion. Members were frustrated that influential political leaders, news media, and medical professionals were endorsing chloroquine to be an effective medication for COVID-19 without verified evidence. Some members noticed that physicians and pharmacists in their regions have started to prescribe chloroquine to patients, causing shortages and, in some cases, deadly side effects. Here are a few selected posts:

> *With this outbreak I worry about Nigeria for the reason that already there are "prophets" with claims they can cure coronavirus and others are selling ANOINTED SOAP to prevent contracting the virus.*
>
> *This is probably the most shocking and most unethical practice I have heard of related to corona. How can a politician and a businessman dictate such medical practices? How can health personnel (doctors and pharmacists) allow this to happen for themselves and their families.*

## *Theme 2: Health System*

The ability of health systems to handle COVID-19 was another theme that emerged from the forums. This theme includes discussion about handwashing and personal protective equipment (PPE), the role of CHWs, the ability to conduct surveillance for COVID-19, and the impact on health care workers and other health services.

### Handwashing and Personal Protective Equipment

Members expressed concern about the reduced supply of PPE in both LMICs as well as in areas of the health care system outside of hospitals, such as long-term care homes. Suggested alternatives included cloth masks, reusable visors, and even steam inhalations as being better than nothing regardless of a lack of evidence of their efficacy. Government budgetary decisions were questioned as some members felt that public money should be spent toward acquiring critical health equipment over other areas. The lack of hand sanitizers and clean water in some regions had apparently made it difficult to follow WHO's advice on frequent handwashing. For this, an alternative solution of washing hands with ash was brought up. Here is a selected post:

> *We experienced a very severe and unjustifiable lack of protection devices for nurses and doctors: a severe lack of masks (all of them), a severe lack of vital supporting devices and many other criticalities.*

### Role of Community Health Workers

CHWs were seen as essential for addressing the COVID-19 pandemic. Their role included making home visits to persons under suspicion of having COVID-19, thereby reducing unnecessary exposure to others and triaging them to more advanced care, if needed. Furthermore, CHWs can educate the local communities they are part of, address any misinformation, and help conduct surveillance of cases. Here is a selected post:

> *CHWs promoted pandemic preparedness prior to the epidemics by increasing the access to health services and products within communities, communicating health concepts in a culturally appropriate fashion, and reducing the burdens felt by formal [health care] systems. During the epidemics, CHWs promoted pandemic preparedness by acting as community-level educators and mobilizers, contributing to surveillance systems, and filling health service gaps.*

### Ability to Test, Trace, and Conduct Surveillance

There was discussion and concern around some countries' ability to test, trace, and conduct surveillance. The limited number of testing kits and surveillance systems in African countries led to a number of unaccounted-for infections. Emphasis was placed on the importance of being proactive and taking a strict approach to travel restrictions and isolation even before COVID-19 became a considerable threat in such countries. Some suggested that certain African countries, such as Nigeria, may be better prepared due to their prior/continuing experience with Ebola, HIV/AIDS, tuberculosis, and other recent epidemics. Here is a selected post:

> *That surge in cases is causing deep unease in countries like Kenya, which have strong commercial ties to China, but, like many other developing nations, have only limited health and surveillance systems...At the moment, Kenyan hospitals would be unable to confirm whether someone has been infected as they do not have the "reagent kits" necessary to identify the coronavirus, officially designated 2019-nCoV.*

### Impact on Health Care Workers

The negative treatment of health care workers during COVID-19 and how it should be addressed arose in this theme. Experiences from Italy during the height of the epidemic were shared, showing instances of health care workers' physical and mental exhaustion. Similarly, it was shared that many health care workers were unprepared to make difficult triage decisions regarding who should be allocated valuable and limited health care resources, such as beds in intensive care units (ICUs). Increased instances of violence, abuse, and discrimination toward health care workers were reported.

Members mentioned that some occupations that make frequent contact with persons with COVID-19 were not being supported the same way as doctors and nurses were despite having an above-average risk of contracting the disease—specifically, allied health occupations, such as pharmacists and physiotherapists, as well as admin staff and hospital caretakers. Finally, the importance of addressing the SEISMIC (Skills, Equipment, Information, Systems support, Medicines,



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Incentives, Communication) needs of health care workers was brought up. Here is a selected post:

> *I am looking at the *self care* of front line workers working for COVID-19 prevention. We need practicable measures for the front line workers within their current working conditions and my guidelines must be seen in that context.*

### Impact on Other Health Services

The impact of COVID-19 on other health services generated discussion as well. Specifically, access to palliative care, cancer care, and reproductive and women's health, including the use of birth control, provision of abortions, HIV testing, and addressing of gender-based violence, were brought up. Here is a selected post:

> *I am increasingly concerned that the national response to the pandemic will (in some countries, at some stages in the evolution of the pandemic) have an even greater negative impact on health than the virus itself…Birth control, GBV-support, and HIV testing are out of reach to more women as COVID-19 shutters clinics around the globe…The closures are making it difficult for millions of women to access contraception, abortions, HIV testing, or support for gender-based violence.*

### *Theme 3: Digital Health Literacy*

Discussion on digital health literacy included access to technology/internet services and dissemination of information through alternative and innovative media. The lack of access to adequate internet services, especially in conflict-prone places with internet shutdowns and slow connectivity, presented barriers to the COVID-19 response. A few members also pointed out that censorship was imposed on news websites by several governments. Additionally, there was concern that in places such as India and Nigeria, reduced smartphone availability and internet penetration excluded many from access to online health care information.

Members iterated that unequal access to adequate health care information and COVID-19 guidelines online posed a gap that could potentially be fulfilled by the utilization of radio, posters, and television broadcasts. An innovative solution was introduced through highlighting the work of the Bangladesh NGO Network for Radio and Communication (BNNRC), which disseminates information to internet deserts through an innovative network of radio broadcasters. Here are a few selected posts:

> *In Nigeria and most of Africa, smartphone and internet penetration varies between 20 [and] 40% in different areas…due to this a large number of the population is excluded from access to online health care information.*

> *In the response to COVID-19, we see how vital it is to get accurate and trusted messages to people so that they know what they need to do and where they can get help when they need it. Now 18 Community Radios stations in Bangladesh have been broadcasting 165 hours of [c]oronavirus prevention education with the active participation of community people. There are 1000 community youth and youth women community radio broadcasters broadcast programs for 6.5 million listeners and viewers.*

### *Theme 4: Economic Consequences*

Discussion regarding the economic consequences of the pandemic and resulting lockdown was another emergent theme. Various members shared their experiences and opinions highlighting challenges being faced and solutions or actions in implementation. Specifically, members deliberated about the economic sustainability of a lockdown in LMICs, the inability to meet basic needs leading to increased poverty-related deaths, and the importance of government relief and stimulus. Here is a selected post:

> *For regions like [s]ub-Saharan Africa, COVID-19 can be a perfect storm in the form of a health problem, and above all, an economic catastrophe for which they lack a safety net…I could think that although these people do not want to be exposed to the virus, it is a population that must continue working to survive, unless the government does something about it.*

### *Theme 5: Marginalized Peoples*

The impact of COVID-19 on marginalized communities focused particularly on the impact on slums in India and Nigeria, the favelas in Brazil, people experiencing homelessness, immigrants, refugees, and those at risk for severe manifestations of the disease. Furthermore, members raised concerns that the public health advice being provided was not helpful for these communities, as it may be impossible for them to follow (eg, social distancing in overcrowded shelters and slums). Here is a selected post:

> *Yes, what is the minimum distance? The overcrowding is unavoidable in my environment…I know some homes and settlements in my environment are more crowded than the schools. They live in slums.*

### *Theme 6: Mental Health*

The impact of COVID-19 on mental health included topics centered around the mental health of vulnerable populations and addressing fear, anxiety, and psychological stress stemming directly or indirectly from COVID-19. A few members shared their personal struggles with mental health. Here is a selected post:

> *India is currently under [lockdown] to reduce the risk of coronavirus infection. The plight of senior citizens has become pitiable. I would, if there are any organizations in India or other countries, who can speak to them to alleviate their depression.*

## Timeline Analysis

The timeline analysis (Figure 5) identified topics of discussion surrounding COVID-19 on the English HIFA forums from March 2020 to October 2020. From the timeline analysis, discussion during the earlier months was centered around access to verified health information, translation of public health



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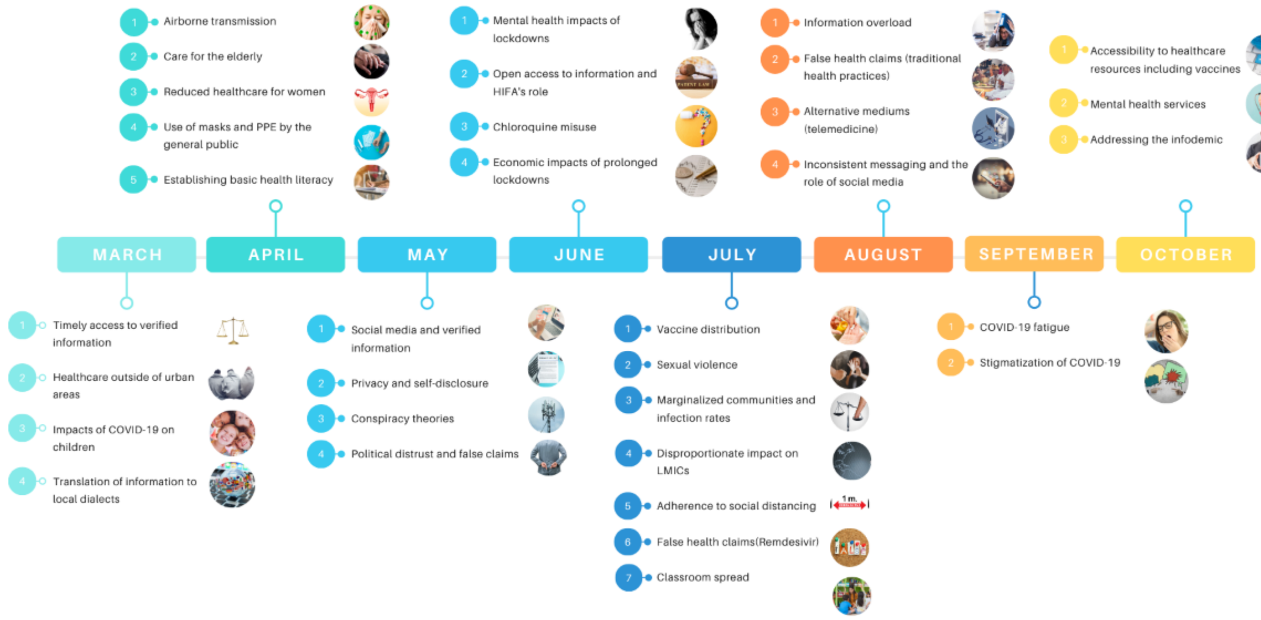
guidelines, understanding what can be done to prevent the spread of COVID-19, and the preparedness of different health systems. Discussion around the prevalence of the infodemic and misinformation took place mostly during May and June 2020. The end of June going into July 2020 saw the discussion focused on the impacts of a lockdown, including its economic consequences, its effects on marginalized communities, and its toll on mental health. Discussion during August and September 2020 revolved around COVID-19 fatigue and changing public health guidelines amid a second wave. Finally, vaccine production, distribution and administration as well as addressing the infodemic were discussed in October 2020.

**Figure 5.** Timeline analysis of the HIFA COVID-19 discussion highlighting major topics from March to October 2020. HIFA: Healthcare Information for All; LMIC: low- and middle-income country; PPE: personal protective equipment.




# Discussion

## Principal Findings

We present 8 months of spontaneous discussion relating to COVID-19 on English HIFA forums. Themes included the infodemic, health system, digital health literacy, economic consequences, marginalized peoples, and mental health. The infodemic and related issues of access to reliable health care information and misinformation were the predominant topic.

## Infodemic and Related Issues

An infodemic, as defined by WHO, is an overload of information, some reliable and some unreliable [20]. Never have we all been so aware of the importance of reliable health care information and yet so vulnerable to misinformation. The central problem is that the general population is unable to differentiate between reliable and unreliable information. This is not new: it has always been the case that unreliable information has misled people, with disastrous consequences. For example, the widespread belief that one should stop giving fluids to a child with diarrhea is 1 of hundreds of examples. More recently, the Ebola outbreak was associated with an infodemic [21]. However, the current infodemic relating to COVID-19 is far worse. What has changed is that increasingly more people are vulnerable to misinformation on social media [22], which propagates false information much more readily than true information. Increased connectivity has paradoxically worsened access to reliable health care information.

Contributing factors include public distrust of the authorities that are responsible for public health messaging, leading to conspiracy theories and denial of the existence of COVID-19. We have seen how public health messaging is partly to blame. Communication with the public may be ineffective due to inappropriate content and format, changing messages as the pandemic unfolds, and inconsistency of messaging. In some countries, politicization drives misinformation; in the United States, for example, vaccine refusal is strongly associated with Republican voters.

## Implications for Policy and Practice

A fresh and important perspective was brought by the participants in this discussion, namely the central importance of facilitating access to reliable health care information as a vital aspect of protecting people from misinformation. Increasing people's access to the internet alone will not help and may make things worse. The key is to help people differentiate between reliable and unreliable health care information. One approach is to increase health literacy, but we have noted in our discussions that even WHO staff are vulnerable to misinformation. Although health literacy is important, new approaches are needed to help people differentiate reliable from unreliable information. The Health on the Net Foundation has led the way in certifying websites that have robust methods of ensuring reliability, but few people are aware of it. Recently, a case was made for WHO to steward a new top-level health domain for reliable health care information [23], but this failed in favor of commercial forces. Better solutions are needed to ensure that every person has access to the reliable health care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information they need to protect their own health and the health of others.

### Future Research

Future research should explore the role of various approaches to helping people differentiate between reliable and unreliable information, drawing on mixed methods, such as systematic review and consultations. Furthermore, emerging research surrounding the COVID-19 infodemic has demonstrated a correlation between susceptibility to misinformation and both vaccine hesitancy and a reduced likelihood to comply with health guidance measures [24]. As such, interventions that aim to improve critical thinking and trust in science may be a promising avenue for future research with regard to addressing infodemics and their downstream consequences.

### Strengths and Limitations

One major strength of this analysis is that it brings forth several perspectives of the global COVID-19 response from study participants spanning many geographical regions, professions, and affiliations. The themes that have emerged from this analysis highlight personal recounts, reflections, suggestions, and evidence around dealing with COVID-19-related misinformation. The timeline also provides additional pointers on how discussions surrounding COVID-19 evolved and help to understand the shift in focus across themes and topics that took place. However, this information must be interpreted with caution and cannot be generalized as a global exchange of discussions on COVID-19.

One limitation is that this analysis does not present any novel information or findings. Furthermore, as many of the study participants are from a public health, health policy, or related background, certain views and opinions are overexpressed.

### Conclusion

This qualitative analysis study highlights the major themes that emerged from the discussions surrounding COVID-19 on the multidisciplinary HIFA forums and can help to understand the type of information needs that arose during the pandemic. The timeline analysis from this study highlights how discussions surrounding the COVID-19 pandemic evolved and when the various themes took place. The perspectives identified provide a multilateral insight into what can contribute to infodemics and enable the development of solutions to manage both the current and future infodemics.

This study used an observational method to understand the themes and perspectives surrounding the evolving COVID-19 pandemic shared in an online multidisciplinary global health forum with a focus on misinformation, information needs, and regional impacts. The results show that the discussion was rich and had representation from multiple disciplines and geographical locations. Many members shared common concerns and frustrations regarding the ensuing infodemic, with the consensus being that all public health organizations and institutions must effectively anticipate and address infodemics in the future to achieve maximal public adherence to guidelines and mitigate danger. Multiple approaches must be used, including holding influential figures and mass media accountable, deploying rapid knowledge and language translation efforts, using multiple channels of communication to disseminate information, and, most importantly, making verified health care information accessible. As such, HIFA stands in solidarity with WHO in its call to action to distribute the right message at the right time from the right messenger through the right medium.

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We would like to acknowledge the contributions of all members of the Healthcare Information for All (HIFA) forums for actively engaging in taking the discussion forward as well as for sharing their perspectives, ongoing work, solutions, and resources related to the global efforts in dealing with the COVID-19 pandemic. Others to thank include Dr Liz Grant from the Global Health Academy at the University of Edinburgh, Edinburgh, Scotland, for guidance and partnership and Enku Kebede-Francis for help in formatting and organizing the HIFA discussion posts. We would also like to thank Nikhil Nema from the University of Warwick, Coventry, United Kingdom, for assistance in creating the figures for the study participants' demographics.

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## Conflicts of Interest

None declared.

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## Abbreviations

**CHW:** community health worker
**HIFA:** Healthcare Information for All
**LMIC:** low- and middle-income country
**NGO:** nongovernment organization
**PPE:** personal protective equipment
**UN:** United Nations
**WHO:** World Health Organization


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Original Paper

# The Association Between Dissemination and Characteristics of Pro-/Anti-COVID-19 Vaccine Messages on Twitter: Application of the Elaboration Likelihood Model

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## *Abstract*

**Background:** Messages on one's stance toward vaccination on microblogging sites may affect the reader's decision on whether to receive a vaccine. Understanding the dissemination of provaccine and antivaccine messages relating to COVID-19 on social media is crucial; however, studies on this topic have remained limited.

**Objective:** This study applies the elaboration likelihood model (ELM) to explore the characteristics of vaccine stance messages that may appeal to Twitter users. First, we examined the associations between the characteristics of vaccine stance tweets and the likelihood and number of retweets. Second, we identified the relative importance of the central and peripheral routes in decision-making on sharing a message.

**Methods:** English-language tweets from the United States that contained provaccine and antivaccine hashtags (N=150,338) were analyzed between April 26 and August 26, 2021. Logistic and generalized negative binomial regressions were conducted to predict retweet outcomes. The content-related central-route predictors were measured using the numbers of hashtags and mentions, emotional valence, emotional intensity, and concreteness. The content-unrelated peripheral-route predictors were measured using the numbers of likes and followers and whether the source was a verified user.

**Results:** Content-related characteristics played a prominent role in shaping decisions regarding whether to retweet antivaccine messages. Particularly, positive valence (incidence rate ratio [IRR]=1.32, *P*=.03) and concreteness (odds ratio [OR]=1.17, *P*=.01) were associated with higher numbers and likelihood of retweets of antivaccine messages, respectively; emotional intensity (subjectivity) was associated with fewer retweets of antivaccine messages (OR=0.78, *P*=.03; IRR=0.80, *P*=.04). However, these factors had either no or only small effects on the sharing of provaccine tweets. Retweets of provaccine messages were primarily determined by content-unrelated characteristics, such as the numbers of likes (OR=2.55, IRR=2.24, *P*<.001) and followers (OR=1.31, IRR=1.28, *P*<.001).

**Conclusions:** The dissemination of antivaccine messages is associated with both content-related and content-unrelated characteristics. By contrast, the dissemination of provaccine messages is primarily driven by content-unrelated characteristics. These findings signify the importance of leveraging the peripheral route to promote the dissemination of provaccine messages.



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Because antivaccine tweets with positive emotions, objective content, and concrete words are more likely to be disseminated, policymakers should pay attention to antivaccine messages with such characteristics.

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**KEYWORDS**

COVID-19; Twitter; provaccine; antivaccine; elaboration likelihood model; infodemiology; dissemination; content analysis; emotional valence; social media

## Introduction

### Background

Vaccination against COVID-19 has been promoted by governments as a key strategy to prevent infections and fatalities. The wide spread of the highly contagious omicron variant has made vaccination coverage more imperative than ever. However, an overabundance of information has prevented people from protecting themselves against COVID-19 [1]. Scholars have discovered that people are easily influenced by vaccine-related opinion pieces published on microblogging sites. For example, vaccine hesitancy is closely related to antivaccination campaigns on social media [2,3]. Therefore, understanding the dissemination of provaccine and antivaccine messages on social media websites is crucial. The World Health Organization has called for a greater focus on infodemiology, the area of science research dedicated to understanding the distribution of information through electronic mediums [4-6]. This study examined what characteristics of vaccine stance messages are likely to result in dissemination and whether those characteristics differ between provaccine and antivaccine messages. Answers to these questions will help governments proactively engage in disseminating provaccine messages and identify potentially influential antivaccine messages.

We selected Twitter as the data source because it is the most popular microblogging site, with 397 million active global users as of January 2022 [7]. Microblogging sites have proven their effectiveness in public information adoption and decision-making when used to promote a government vaccination policy [8]. Twitter allows users to retweet another user's text to disseminate information among their followers, thus enabling widespread information diffusion.

Prior to the COVID-19 pandemic, researchers have used Twitter data to examine public opinion on vaccinations through text analysis, image analysis, topic modeling, and community detection [9,10]. More recently, studies have analyzed the sentiments, opinions, topics, and persuasion techniques related to COVID-19 vaccination on Twitter [11-14]. Furthermore, much effort has been devoted to identifying the determinants of attitudes toward COVID-19 vaccines [15-18], the origin of vaccine misinformation, and its negative effect on vaccine acceptance [19]. One paper by Germani and Biller-Andorno [20] reported that compared with provaxxers, antivaxxers tweet less but are more engaged in discussions (through replies or retweets) on Twitter.

Another line of the literature focused on persuasive message appeals, including logos (fact/logic of the argument), pathos (emotion of the argument), and ethos (credibility of the author) [21]. Those rhetoric appeals have been applied to political campaigns, health issues, fund raising, promotion of technological products, and vaccination intake [22-26]. In the *Gazette* of Australia, logos appeal has been widely utilized for vaccination strategy [26]. Utilization of pathos on antivaccine websites has been found to provide the functionality of social interactivity [27]. During the COVID-19 pandemic, New York City Department of Health and Mental Hygiene and the official Twitter account of the US government have extensively utilized rhetoric appeals for vaccine communication and to promote COVID-19 vaccination [28,29].

The existing literature suggests that research on the dissemination of provaccine and antivaccine messages during the COVID-19 pandemic has remained limited. This study applied a theoretical framework called the elaboration likelihood model (ELM) to explore message characteristics that may appeal to Twitter users. Specifically, the aims are (1) to examine the associations between message characteristics and the likelihood and number of retweets and (2) to identify the relative importance of the central and peripheral routes in decision-making on sharing a message. Because vaccine discourse on social media is polarized between groups of provaccine and antivaccine communities [30], and since provaxxers and antivaxxers hardly interact with each other on Twitter [31], we conjectured that provaccine messages were predominately shared by provaxxers and antivaccine messages predominately shared by antivaxxers. As a result, we used a common set of message characteristics and tested them separately on provaccine and antivaccine messages. We then explored the role of each route in 2 different groups and compared whether the decision-making on retweets is the same for provaxxers and antivaxxers. To the best of our knowledge, this study is the first to examine the association between the dissemination and characteristics of COVID-19 vaccine stance tweets. The results will facilitate the design of effective messages by scientists, clinicians, and policymakers to promote vaccination.

### Theoretical Framework: The Elaboration Likelihood Model

The ELM was developed by Petty and Cacioppo in 1986 [32] and is 1 of the most popular persuasion models in consumer research and social psychology. The ELM proposes that attitude changes and consequent behavior changes among individuals may be caused by 2 processing approaches: the central route and the peripheral route. The central route requires an individual to think deeply about relevant arguments in a message and reflect on the relative merits and relevance of those arguments before developing an informed decision about the target behavior. In the context of decisions to retweet on Twitter, such



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arguments refer to the message content, such as information richness, argument sentiment, and concreteness, of the tweet. The peripheral route, however, involves less cognitive effort. A message is accepted or rejected without any critical thinking or conscious thought. Recipients simply rely on general criteria or content-unrelated characteristics, such as the information source, to make quick decisions [33]. In the context of making a decision to retweet, such cues include the number of likes received by the tweet and whether the tweet was posted by a verified user. The ELM predicts that decisions made through central-route processing will be more difficult to alter than those formed through peripheral-route processing.

The ELM has been adopted to study the effects of persuasive communication on attitude and behavioral changes with respect to online reviews [34], health information [35], and false reviews [36]. Drawing on the ELM, Guo et al [33] investigated patients' continual usage intentions of mobile health services and Ju and Zhang [37] investigated the factors influencing patients' continual use of web-based diagnosis and treatment. The ELM has also been applied to explain users' decisions to share online reviews of consumer products [38] and information on social networking sites [39]. In the field of health communication, the ELM model has helped understand the effectiveness of tobacco package warning labels [40] and designing of peripheral messages to prevent drunkorexia [41]. Despite the various empirical studies, applications of the ELM for dissemination of COVID-19 vaccine stance messages are still limited.

Other researchers have explored the effects of message content on users' retweeting decisions without applying the ELM. Their findings have revealed the impact of argument sentiment [42,43] and hashtags [44]. Studies that did not apply the ELM and focused on content-unrelated factors have also reported positive results. Source trustworthiness, source attractiveness, and favorite counts [45] affect retweeting decisions.

In practice, to explore the central route, this study used a natural language processing (NLP) technique to construct content-related variables. Content analysis was useful for this study because it exploited timely and real-world messages collected from Twitter and allowed us to identify the actual response (retweet decisions) to specific content. Furthermore, the use of algorithmic content analysis in this study helped the analysis of big data from online discourse faster compared to traditional content analysis methods (where researchers need to formulate a coding scheme and train coders to analyze the text manually) and at scale [46]. Alternatively, experiment and survey methods can be used to discover message characteristics that appeal to users. However, concerns have been raised that convenient sampling widely used by those methods could result in sample selection bias and that the survey methodology captures self-reported behavior rather than the actual behavior/response [47].

This study is original in a number of ways. We extended the scope of the ELM to vaccine communication and clarified the relative importance of 2 psychological routes in sharing pro- and antivaccine messages. We discovered that both the central and the peripheral route play key roles in the decision-making on whether to share an antivaccine message, whereas dissemination of a provaccine message was mostly determined by the peripheral route. These findings are useful for devising effective messages to promote COVID-19 vaccination and to reach out to different communities on social media. Furthermore, we included a new variable in the central route, called concreteness, that has not been explicitly considered by ELM studies before. We borrowed the concreteness construct from construal level theory (CLT) [48], which states that concrete words help individuals understand psychological proximity to the respective object or event. Originally, CLT was developed to explain how people think about an event at a concrete or abstract level [49,50]. CLT studies have demonstrated the ability of natural language to prime concrete or abstract mindsets [51,52]—association between lexical concreteness and psychological proximity [53]. By incorporating concreteness, we have not only enriched the ELM but also extended applications of CLT to vaccine stance message dissemination.

## Methods

### The Elaboration Likelihood Model

Our empirical analysis focused on the 2 routes of the ELM, as presented in Figure 1. We expected that when users processed information through the central route, message content would be a key predictor of dissemination, whereas when users processed information through a peripheral route, content-unrelated characteristics would be more important predictors. The central route is composed of variables for information richness, argument sentiment (emotional valence and emotional intensity), and concreteness. The peripheral route is composed of variables for informational social influence, source trustworthiness, and source attractiveness.


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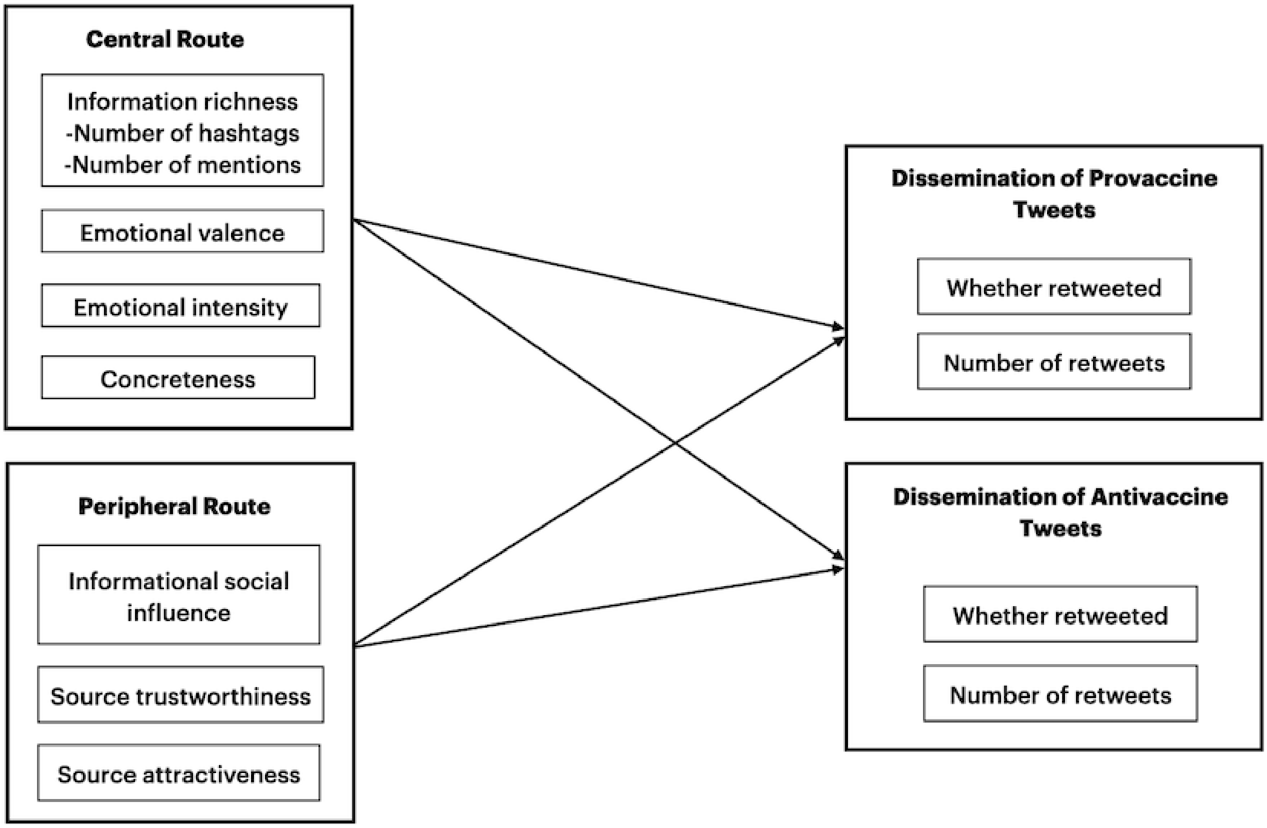
**Figure 1.** The ELM: central and peripheral routes for disseminating pro- and antivaccine tweets. ELM: elaboration likelihood model.




## Study Design, Outcome Variables, and Data Collection

To investigate retweeting behavior, a cross-sectional study design was applied to United States data. The outcome variables were (1) whether a provaccine or antivaccine tweet (collectively termed "vaccine stance tweets") was retweeted and (2) the number of times a vaccine stance tweet was retweeted.

We used the R library (R Core Team and the R Foundation for Statistical Computing) package *rtweet* [54] to access the Twitter application programming interface (API) service to collect provaccine- and antivaccine-related tweets between April 26 and August 26, 2021. We excluded non-English tweets and tweets with a geolocation outside the United States. The provaccine search term hashtags were as follows: #GetVaccinated, #GetVaxxex, #Immunization, #Jab, #Vaccinate, #Vaccinated, #VaccinateNY, #Vaccinesafety, #vaccineswork, and #vaxxed. The following terms were used to target antivaccine tweets: #antivaxx, #antivaxxer, #naturalimmunity, #novaccinepassports, #vaccinefailure, #vaccineinjury, #vaccinemurder, #vaccinesarepoison, #vaccinedontwork, and #vaccinekill. Additionally, we looked into user IDs associated with individual tweets and excluded users who tweeted both pro- and antivaccine messages. This reduced approximately 8.8% of vaccine stance tweets identified in the original data set. The inclusion of only users whose vaccine stances remained consistent during the study period ensured that the tweets analyzed conveyed a clear stance. The final sample was composed of 141,782 provaccine and 8556 antivaccine tweets posted by 57,067 and 4308 distinct users (authors), respectively. The flowchart of Twitter data collection is presented in Figure 2.



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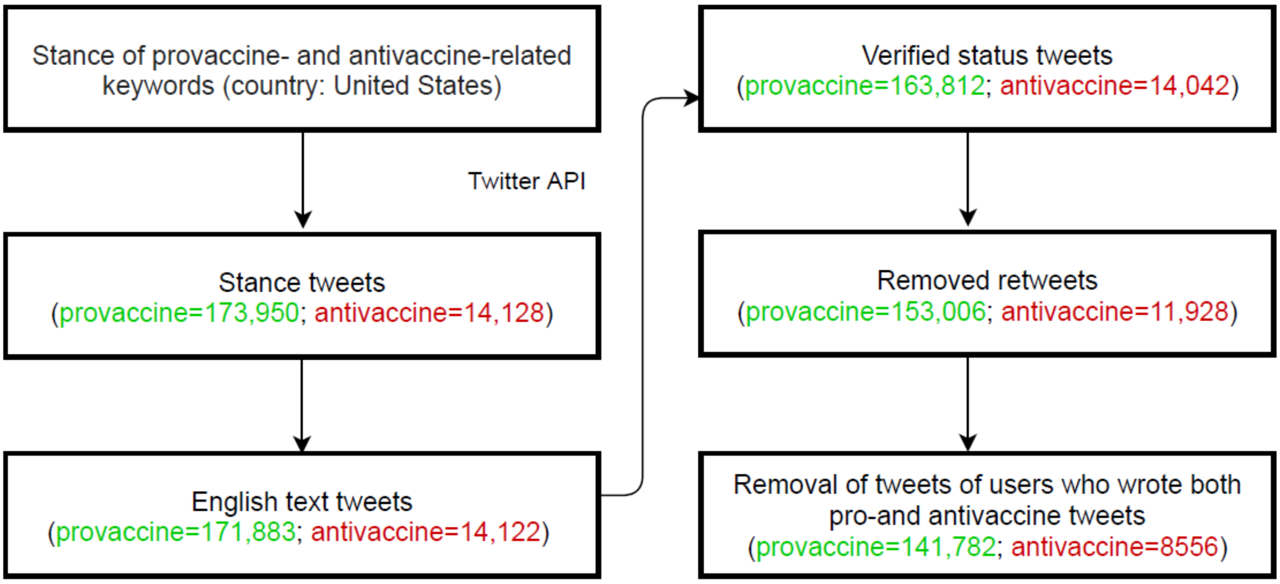
**Figure 2.** Data collection for provaccine and antivaccine tweets. This flowchart illustrates the data collection and cleaning of the final data set of vaccine stance tweets from the United States. We filtered out retweets and retained tweets from original users who had a consistent vaccine stance throughout the study periods. The green color refers to the number of provaccine tweets, and the red color refers to antivaccine tweets that remained in each step. API: application programming interface.




## Predictors: Central Route

### *Information Richness*

We operationalized the information richness of a tweet by using 2 measures: the number of hashtags and mentions. A hashtag is a word beginning with the # symbol, which is added to posts to aggregate messages of the same topic. A mention references another user in a microblog with the @ symbol and represents an active user interaction [55]. In the literature, the number of mentions is operationalized as a subdimension of information richness [56], and we adopted a similar method in this work.

### *Emotional Valence and Emotional Intensity*

In psychology, emotional valence indicates the emotional value expressed on a continuum from unpleasant to pleasant or from negative to positive [57]. Emotional intensity is the expression of emotion in content, indicating the level of subjectivity from no emotion (objective) to highly emotional [58]. We operationalized these 2 dimensions of argument strength [43] by using TextBlob [59,60], which generated scores for these dimensions. The values of emotional valence range from −1 to 1, where −1 is extremely negative, 1 is extremely positive, and 0 is neutral. The emotional intensity values range from 0 to 1, where 0 is highly objective and 1 is highly subjective. Multimedia Appendix 1 provides examples of emotional valence and emotional intensity. For example, tweets with positive emotions/valance often contained positive words, such as “natural,” “granted,” “better,” “fine,” “good,” and “healthy.” In contrast, tweets with negative valence used negative words, including “bad,” “evil,” “terrible,” “criminal,” “sick,” “illegal,” and “painful.” TextBlob assigns individual scores to all the words in a set of predefined dictionaries and takes an average of all the sentiments in a sentence to generate the final valence score. Studies have suggested that positive emotions are significantly related to retweets [61].

TextBlob is a Python library for processing textual data. It provides a simple API for examining common NLP tasks, such as part-of-speech tagging, noun phrase extraction, sentiment analysis, classification, and translation. To extract emotional valence (polarity) and emotional intensity (subjectivity) data, we processed the data set pooled from the final analysis corpus of each vaccine stance. Initially, we used the Python function *NeatText*, a simple NLP package for cleaning textual data and text preprocessing; we removed user handlers, Universal Resource Locators (URLs), punctuation, non–American Standard Code for Information Interchange characters, numbers, hypertext markup language (html) tags, stopwords, special characters, emojis, and multiple spaces. We then used TextBlob to calculate the value of emotional valence and emotional intensity. Generally, the data are supplied as a bag-of-words, and after assigning individual scores to each word, the final sentiment is represented through a sum pooling of all the sentiments. TextBlob has semantic labels that facilitate fine-grained sentiment analysis. The workflow for calculating emotional valence and emotional intensity is presented in Multimedia Appendix 2.

### *Concreteness*

Concreteness is an aspect of communication in which the information provided in a message is highly descriptive, specific, and vivid; users generally rely more on concrete wording to make their decisions [58]. Studies have suggested that individuals recall concrete words more effectively than abstract words [62] and that concrete words are more persuasive in affecting user behavior [61]; thus, we expected language concreteness to play a role in users’ decision to disseminate vaccine stance tweets. Examples of concreteness are presented in Multimedia Appendix 1.

To measure the content concreteness of cleaned tweets, we relied on the R package *doc2concrete* [63], which uses a dictionary of 40,000 common English words and expressions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[64]. The concrete score has a range of 0-5, where 0 is abstract and 5 is concrete. The validity and reliability of this dictionary have been confirmed in the medical setting [65] and in online reviews [66]. Furthermore, this dictionary includes words from the medical domain. For example, "virus" has a concreteness rating of 3.48, whereas "vaccination" has a concreteness rating of 4.24. We calculated concreteness through the workflow presented in Multimedia Appendix 2.

### Predictors: Peripheral Route

#### *Informational Social Influence*

We measured informational social influence by using the "favorite" count (ie, number of likes) of a tweet. Researchers have studied informational social influence under the bandwagon effect and related concepts, such as herd behavior and social proof [45]. In practice, we took the square root of the favorite count to resolve convergence problems caused by its large scale (from 0 to nearly 30,000) in regression analysis. This approach has been used by researchers to normalize a skewed distribution. The resultant scale for the favorite count was from 0 to 173.1 for provaccine and from 0 to 100.5 for antivaccine tweets. We also used other normalization techniques, including the *z* score and min-max normalization; however, for the current model, these methods performed less well in the iterative procedure of maximum likelihood estimation.

#### *Source Trustworthiness*

The trustworthiness of a tweet is determined by whether the tweet is from a user whose status has been verified [56]. Twitter uses an authentication mechanism to ensure the authenticity of user identity, and a verified user is signified by a blue tick next to the screen name. Therefore, this variable is binary, with 1 indicating a trustworthy user and 0 reflecting a nontrustworthy user. Researchers have noted that tweets from verified users disseminate more rapidly than those from nonverified users [67].

#### *Source Attractiveness*

A Twitter user can follow any other user, and the number of followers reflects the likeability of the user's real-world status. We measured source attractiveness as the number of followers. Studies that have utilized source attractiveness have identified a substantial effect of a user's number of followers on the retweetability of a tweet [39,56]. We log-transformed the variable to render its scale comparable to other predictors.

### Regression Analysis and Sensitivity Analysis

We performed logistic regression and generalized negative binomial (NB) regression on the binary retweet outcome and the number of retweets, respectively. The generalized NB extends the NB mean dispersion model by providing flexibility in parameterizing the dispersion parameter α. We specified that the log of α is a linear function of the same covariates used in the main model. The chi-squared test rejected the null hypothesis that none of the covariates in the dispersion function have predictive power ($P$<.001). Akaike and Bayesian information criteria also indicated that the generalized NB is preferable to the NB model (Multimedia Appendix 3). The user-clustered sandwich variance estimator, which accommodates intragroup correlation of observations, was used to improve statistical inferences about regression coefficients. Because vaccine stance tweets were posted across multiple points in time, accounting for various exposures in generalized NB regressions was necessary. We included the log-transformed exposure variable, defined as the number of days from the tweet date to the last day of the study period, August 26, 2021. The correlation coefficient matrix (Multimedia Appendix 4) indicated that the correlation between predictors were generally low, except for the 3 peripheral-route variables, which were moderately correlated (0.3-0.4). All regressions were performed using Stata 16 software (Stata Corp Inc.).

We conducted sensitivity analyses to verify whether the results were robust for various model specifications. First, to capture common trends that may affect decisions of retweets, we included monthly binary variables for June, July, and August in logistic regression models. Data for April and May were combined to serve as the reference group; the results are summarized in Multimedia Appendix 5. Second, to avoid results being driven by outliers, we excluded tweets that had an exceptionally high number of retweets, using the top 0.5% as a cut-off point. As a result, provaccine tweets that had more than 83 retweets and antivaccine tweets with more than 325 retweets were excluded; see the results in Multimedia Appendix 6. All analyses revealed that our regression results remained consistent across various model specifications.

### Ethical Considerations

Informed consent cannot be obtained to analyze Twitter postings as Twitter posts are publicly available information.

## Results

### Summary Statistics

The summary statistics of the model variables are presented in Table 1. For provaccine and antivaccine tweets, 28% and 32% were retweeted and the average number of retweets was 3.16 and 8.86, respectively. These findings are consistent with the existing evidence that antivaxxers are more active in message sharing on Twitter [20]. The average number of hashtags was higher for antivaccine (3.18, SD 2.83) than for provaccine (2.82, SD 2.50) tweets. The mean emotional valence score was 0.07 (SD 0.30) for provaccine and 0.03 (SD 0.28) for antivaccine tweets, indicating that provaccine tweets had more positive emotions than antivaccine tweets. The mean emotional intensity score was similar (0.37, SD 0.34, and 0.35, SD 0.33) for the 2 groups. The mean concreteness score was 2.12 (SD 0.68) for provaccine and 1.92 (SD 0.66) for antivaccine tweets. The mean square root of the number of "likes" was 1.55 (SD 3.41) for provaccine and 1.76 (SD 4.56) for antivaccine tweets. Approximately 6% and 1% of provaccine and antivaccine messages, respectively, were tweeted by a verified user, which was considerably low. This finding accords with research that antivaccine messages are led by nonverified Twitter users [68]. The mean log number of followers was 6.82 (SD 2.06) for provaccine and 5.94 (SD 1.98) for antivaccine tweets.



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**Table 1.** Summary of provaccine and antivaccine model variables.

| Model variables | Provaccine tweets (N=141,782) | | | Antivaccine tweets (N=8556) | | |
|---|---|---|---|---|---|---|
| | Mean (SD) | Minimum | Maximum | Mean (SD) | Minimum | Maximum |
| **Outcome variable** | | | | | | |
| Whether retweeted (0/1) | 0.28 (0.45) | 0 | 1 | 0.32 (0.47) | 0 | 1 |
| Retweet count | 3.16 (60.87) | 0 | 12,500 | 8.86 (99.72) | 0 | 5141 |
| **Central route** | | | | | | |
| Number of hashtags | 2.82 (2.50) | 1 | 32 | 3.18 (2.83) | 1 | 35 |
| Number of mentions | 0.72 (1.47) | 0 | 24 | 0.70 (1.23) | 0 | 14 |
| Emotional valence score (–1 to 1) | 0.07 (0.30) | –1 | 1 | 0.03 (0.28) | –1 | 1 |
| Emotional intensity score (0–1) | 0.37 (0.34) | 0 | 1 | 0.35 (0.33) | 0 | 1 |
| Concreteness score (0–5) | 2.12 (0.68) | 0 | 4.59 | 1.92 (0.66) | 0 | 3.74 |
| **Peripheral route** | | | | | | |
| Informational social influence: number of likes (square root) | 1.55 (3.41) | 0 | 173.12 | 1.76 (4.56) | 0 | 100.5 |
| Source trustworthiness: a verified user (0/1) | 0.06 (0.24) | 0 | 1 | 0.01 (0.12) | 0 | 1 |
| Source attractiveness: number of followers (log) | 6.82 (2.06) | 0 | 16.55 | 5.94 (1.98) | 0 | 12.83 |
| Exposure[a] (log days) | 3.20 (1.01) | 0 | 4.81 | 3.39 (1.16) | 0 | 4.81 |

[a]Exposure is defined as the number of days from the tweet date to the last day of the study period, August 26, 2021.

## Central-Route Predictors

The results from the logistic and generalized NB regressions are presented in Figures 3 and 4, respectively. All regressions were run separately for provaccine (green color) and antivaccine (red color) tweets to examine the characteristics of messages that may determine the likelihood and number of retweets.

An additional hashtag increased the odds of sharing by 13.3% (95% CI 1.12-1.15, *P*<.001) and 9.1% (95% CI 1.06-1.12, *P*<.001) for provaccine and antivaccine tweets, respectively. An additional mention (of another user) increased the odds of sharing provaccine tweets by 3.1% (95% CI 1.01-1.06, *P*=.02) but reduced the odds of retweeting antivaccine tweets by 10.2% (95% CI 0.84-0.96, *P*=.002). A 1-point increase in the emotional intensity (subjectivity) score reduced the odds of sharing an antivaccine tweet substantially by 21.6% (95% CI 0.63-0.97, *P*=.03). Finally, a 1-point increase in concreteness scores increased the odds of sharing an antivaccine tweet substantially by 16.9% (95% CI 1.05-1.30, *P*=.01).

When the outcome variable was the number of retweets, we obtained similar results to those of the likelihood of retweets. The number of hashtags increased the retweet rate for both provaccine (incidence rate ratio [IRR]=1.07, 95% CI 1.06-1.09, *P*<.001) and antivaccine (IRR=1.08, 95% CI 1.05-1.11, *P*<.001) tweets. For antivaccine tweets, the number of mentions decreased the retweet rate by 12% (IRR=0.88, 95% CI 0.83-0.93, *P*<.001); positive valence increased the retweet rate substantially by 31.8% (IRR=1.32, 95% CI 1.03-1.69, *P*=.03), and emotional intensity decreased the retweet rate substantially by 20.5% (IRR=0.80, 95% CI 0.64-0.99, *P*=.04). With respect to provaccine tweets, a 1-point increase in the concreteness score increased the incidence rate of retweets marginally (IRR=1.06, 95% CI 1.00-1.12, *P*=.046).


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**Figure 3.** Results from logistic regressions of whether a vaccine stance message was retweeted. This figure illustrates the estimated OR associated with different characteristics of vaccine stance messages. The green color refers to provaccine tweets (N=141,782), and the red color refers to antivaccine tweets (N=8556). The horizontal line represents the 95% CI; the dot in the middle represents the estimate of the coefficient. The user-clustered sandwich variance estimator was used. OR: odds ratios.

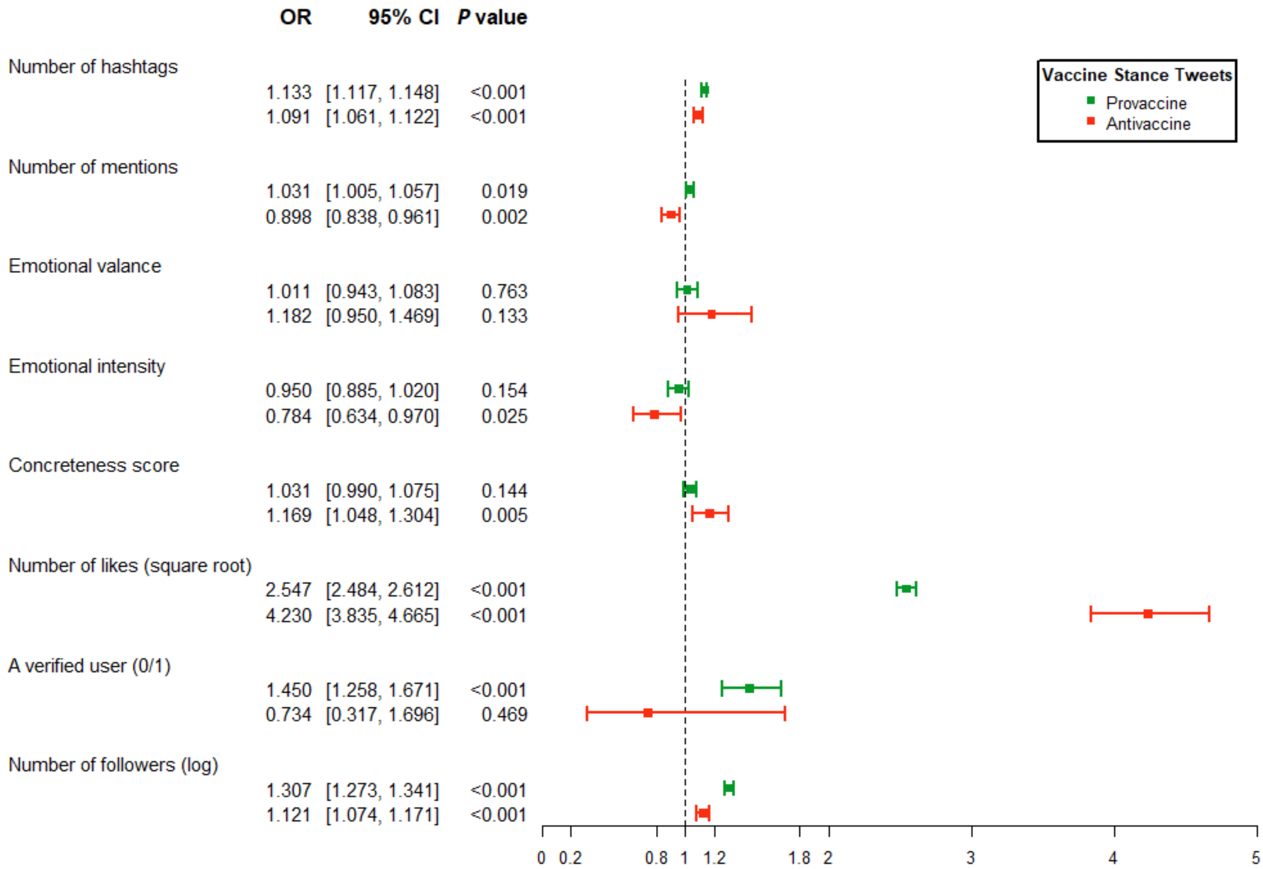



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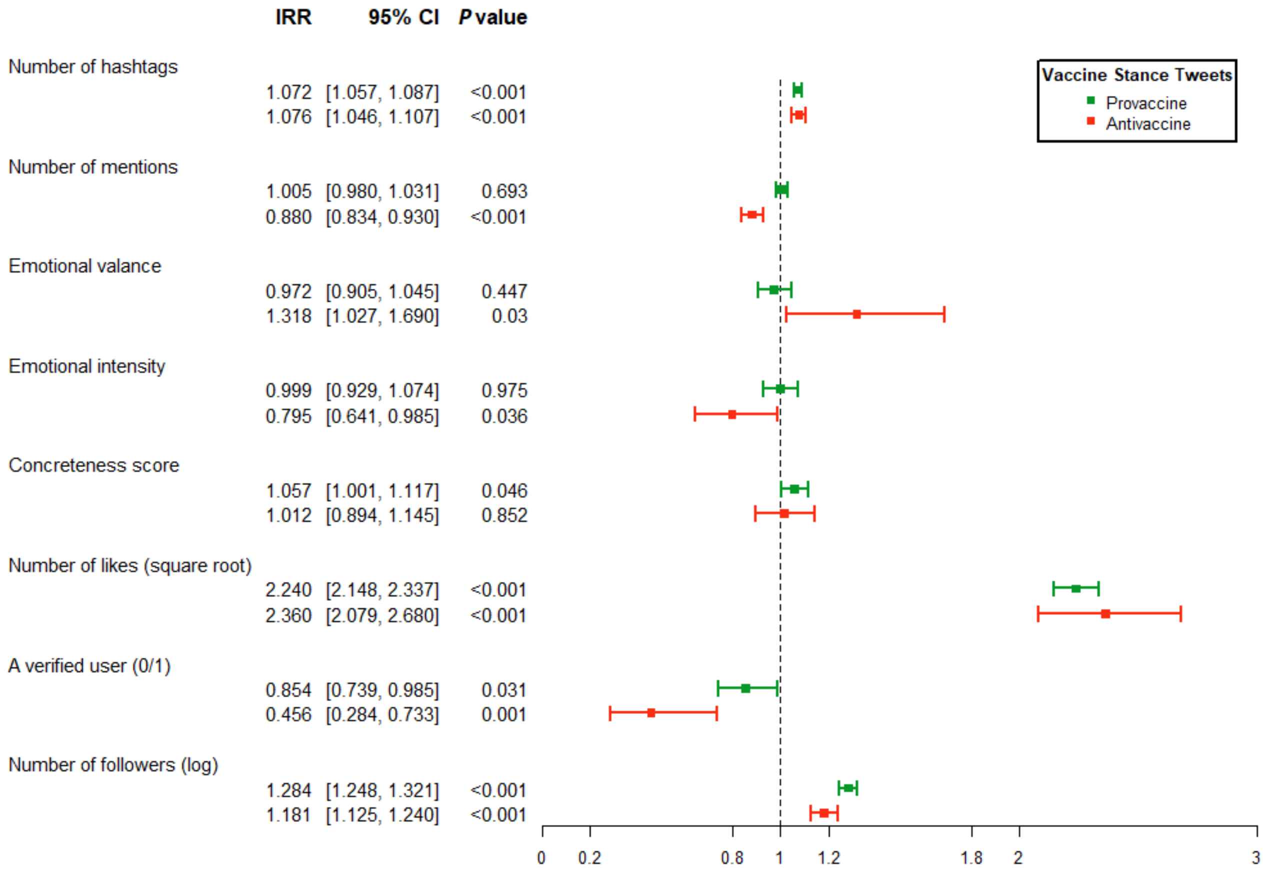
**Figure 4.** Results from generalized negative binomial regressions of the retweet count. This figure illustrates the estimated IRRs associated with different characteristics of vaccine stance messages. The green color refers to provaccine tweets (N=141,782), and the red color refers to antivaccine tweets (N=8556). The horizontal line represents the 95% CI; the dot in the middle represents the estimate of the coefficient. The user-clustered sandwich variance estimator was used. Exposure was included in the model with the coefficient constrained to 1. IRR: incidence rate ratio.




### Peripheral-Route Predictors

The results associated with peripheral routes are presented in Figures 3 and 4 for the likelihood and number of retweets, respectively. An additional square-root number of likes increased the odds of retweets for provaccine and antivaccine messages by a factor of 2.55 (95% CI 2.48-2.61, *P*<.001) and 4.23 (95% CI 3.84-4.67, *P*<.001), respectively. Verification of user status increased the odds of retweets for provaccine messages substantially by 45% (95% CI 1.26-1.67, *P*<.001). A 1% increase in the number of followers increased the odds of retweeting provaccine and antivaccine messages by 30.7% (95% CI 1.27-1.34, *P*<.001) and 12.1% (95% CI 1.07-1.17, *P*<.001), respectively.

The generalized NB model indicated that provaccine and antivaccine tweets that had 1 more square-root number of likes had 2.24 (95% CI 2.15-2.34, *P*<.001) and 2.36 (95% CI 2.08-2.68, *P*<.001) times more retweets, respectively. When the author was a verified user, the rate of retweeting decreased for both groups (IRR=0.85 [pro], IRR=0.46 [anti], *P*=.03 [pro], *P*=.001 [anti]). In contrast, the number of followers increased the incidence rate of retweeting for both groups (IRR=1.28 [pro], IRR=1.18 [anti], *P*<.001).

## Discussion

### Principal Findings

This study applied the ELM to investigate characteristics of COVID-19 vaccine stance–related tweets that were associated with the likelihood and number of retweets on Twitter. The key finding is that content-related (central-route) predictors are strongly associated with retweets of antivaccine messages. Specifically, for antivaccine messages, the number of hashtags was positively associated with (the likelihood and number of) retweets; positive valence was associated with a higher number of retweets, concreteness was positively associated with the likelihood of retweets, whereas the number of mentions and emotional intensity were negatively associated with (the likelihood and number of) retweets. Regarding provaccine messages, only the number of hashtags was strongly and positively associated with (the likelihood and number of) retweets; the number of mentions and concreteness were positively but weakly associated with the likelihood of retweets. Among the content-unrelated (peripheral-route) predictors, the number of likes and followers were strongly and positively associated with (the likelihood and number of) retweets of provaccine and antivaccine messages.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### Central-Route Predictors Predominantly Associated with Dissemination of Antivaccine Tweets

The ELM predicts that if recipients have a high desire or ability to process a message, they will use the central route and spend more time deliberating on their decision. In this context, if antivaccine messages were mostly shared by antivaxxers, our finding of strong associations between central-route predictors and dissemination of antivaccine messages may imply that antivaxxers have relied more on cognitive cues than provaxxers to make retweeting decisions. Particularly, having positive emotions, low emotional intensity (objective content), and concrete words considerably increased the dissemination of antivaccine tweets. These results warrant attention because they conflict with the general perception that antivaxxers are irrational and attracted by negative emotions and abstract slogans [69-71].

The positive associations between concreteness and dissemination of antivaccine messages may be explained by the strategy used by antivaccine message creators to specify the harm caused by COVID-19 vaccines. Specifically, if antivaccine messages include concrete words, then it is likely to motivate the reader to share a descriptive, specific, and factual vaccine stance message. However, the same cannot be said when it comes to utilizing concrete words in provaccine messages, where there is little impact on readers' sharing of vaccine stance messages in this study.

The information systems literature contains inconsistent findings on valence (positive and negative) in electronic word-of-mouth studies [39,42,56]. A study demonstrated that negative valence has more influence on sharing online reviews of consumer products than positive valence [38]. Our work provides additional evidence that emotional valence predominantly has positive effects on retweeting antivaccine messages. Furthermore, the negative association between emotional intensity (subjectivity) and dissemination of antivaccine messages supports the existing research [39] that also indicates a negative effect of emotional intensity on the sharing of information behavior.

With respect to information richness, we discovered that hashtags increase the dissemination of both provaccine and antivaccine tweets, which is consistent with the findings of prior research [39]. Mentioning another user had a small negative effect on the dissemination of antivaccine messages, which is consistent with results that indicate mentions have a negative effect on information sharing [39]. One possible explanation for this is that in antivaccine messages, mentions are used to cite provaccine users, which is not welcomed by the antivaxxer community.

### Peripheral-Route Predictors Associated with Dissemination of Both Provaccine and Antivaccine Tweets

The number of likes (favorite count) measures social influence. It consistently demonstrated a positive association with dissemination of vaccine stance tweets in all models. The finding can be explained by the bandwagon effect, where people follow a trend regardless of the underlying evidence. This trend was stronger for antivaccine users than for provaccine users probably because of their desire to fit into the antivaxxers' groups [72]. Existing research has revealed that a strong sense of community is a key factor contributing to the success of the antivaccination movement [20].

In the provaccine models, the association between the verified user status and retweets was inconsistent; in the antivaccine models, the verified user status was negatively associated with the number of retweets. This contradicts our hypothesis that tweets from verified users are more likely to be retweeted. One possible explanation for this trend is that the percentage of verified users was low in both groups (6% and 1% in the provaccine and antivaccine groups, respectively). The predictor varied little, which made fitting the regression line difficult. Moreover, the data revealed that the verified users received more likes and had more followers compared to the nonverified users; the 3 variables were correlated (correlation coefficients=0.3-0.4). When we excluded either the favorite count or the number of followers, the verified user status was positively associated with retweets in all models for provaccine tweets and in 1 model for antivaccine tweets (Multimedia Appendix 7).

Source attractiveness (number of followers) had positive associations with disseminating both provaccine and antivaccine messages. The literature indicates that having many followers leads to a higher probability of information dissemination [39].

### Recommendations for COVID-19 Vaccination Campaigns Using Social Media

This study provides several insights into how COVID-19 vaccination campaigns can be strengthened. First, to promote the dissemination of provaccine messages, policymakers may consider focusing on peripheral-route predictors (content-unrelated characteristics), such as increasing the likeability of their tweets, engaging with provaxxers who have many followers, and gaining more followers on Twitter. Moreover, to leverage central-route predictors, policymakers may use more hashtags in their messages. Using concrete words in a provaccine message may also increase the number of retweets the message receives, although the effect of doing so was small in this study.

Second, because antivaccine tweets with positive emotions, objective content, and concrete words are more likely to be disseminated, policymakers should pay attention to antivaccine messages with such characteristics. Additionally, paying attention to antivaccine tweets with many likes and followers could be crucial because those tweets are likely to be widely circulated. Research has demonstrated that dissemination of antivaccine messages is driven by strong influencers [20].

### Limitations

This study has several limitations. First, despite the popularity of Twitter, its users are a selected population and may not be representative of the general United States population. The identification of tweets may be incomplete because of a limited use of hashtags. Second, because Twitter has a strict policy of removing vaccine misinformation tweets from its platform, our data set may have been limited. Third, we examined a user's



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retweeting decision when confronting a particular tweet. We were not able to identify people who retweeted those vaccine stance messages, and thus we could not be sure of their vaccine stances. Although most people retweet messages that are consistent with their own principles, some may retweet information that contradicts their beliefs. This limitation has been discussed in another Twitter studies [9] and should be considered when interpreting the results. Fourth, this study adopted content analysis and did not incorporate the effects of images or emoticons. In a literature review, we found that researchers removed emojis during preprocessing and cleaning of vaccine message text data to study multiple topics in Twitter, such as online vaccination debates [73], childhood vaccination opinions [74], COVID-19 vaccine sentiment in the United States [75], and key themes and topics on COVID-19 vaccines [76]. On similar lines of the literature, we removed emojis from the Twitter text corpus to analyze our dissemination model. However, emojis can enrich our findings by providing useful information alongside text tweets. Future research may consider including emojis in empirical analysis. Finally, 1 study utilized the data from Twitter posts and compared the sentiment outcomes of TextBlob, VADER, and Word2Vec–bidirectional long short-term memory (Word2Vec-BiLSTM) models. The results showed that TextBlob provides fewer positive sentiments compared to Word2Vec-BiLSTM but provides more positive sentiments compared to VADER [60]. Despite the wide applications of TextBlob on Twitter data for sentiment analysis [77,78], using different tools to validate emotional valence will help confirm the main findings of this study.

### Conclusion

This study identified the characteristics of COVID-19 vaccine stance tweets that are associated with the likelihood and number of retweets. This was performed by applying the ELM and examining 2 psychological routes involved in retweet decisions. A major finding of this study is that the dissemination of antivaccine messages is strongly associated with characteristics related to message content (central-route processing), including emotional valence and intensity. However, message content exhibited a much weaker association with dissemination of provaccine messages. We discovered that dissemination of provaccine messages is predominately determined by content-unrelated characteristics, such as the numbers of likes and followers.

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## Conflicts of Interest

None declared.

Multimedia Appendix 1
Examples of emotional valence, emotional intensity, and concreteness in pro- and antivaccine tweets.
[DOCX File , 22 KB - infodemiology_v2i1e37077_app1.docx ]

Multimedia Appendix 2
Workflow for calculating emotional valence, emotional intensity, and concreteness.
[DOCX File , 35 KB - infodemiology_v2i1e37077_app2.docx ]

Multimedia Appendix 3
Akaike information criterion (AIC) and Bayesian information criterion (BIC) for model selection.
[DOCX File , 16 KB - infodemiology_v2i1e37077_app3.docx ]

Multimedia Appendix 4
Correlation coefficient matrices for variables in the pro- and the antivaccine model.
[DOCX File , 22 KB - infodemiology_v2i1e37077_app4.docx ]

Multimedia Appendix 5
Logistic regressions of whether a message was retweeted, with month indicators included.
[DOCX File , 16 KB - infodemiology_v2i1e37077_app5.docx ]


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Multimedia Appendix 6
Excluding vaccine stance–related tweets that had an exceptionally high number of retweets, using the top 0.5% as a cut-off point.
[DOCX File , 17 KB - infodemiology_v2i1e37077_app6.docx ]

Multimedia Appendix 7
Regression results from the pro- and antivaccine models, excluding either the number of likes or the number of followers.
[DOCX File , 18 KB - infodemiology_v2i1e37077_app7.docx ]

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## Abbreviations

**API:** application programming interface
**BiLSTM:** bidirectional long short-term memory
**CLT:** construal level theory
**ELM:** elaboration likelihood model
**IRR:** incidence rate ratio
**NB:** negative binomial
**NLP:** natural language processing
**OR:** odds ratio


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Original Paper

# The Role of Influential Actors in Fostering the Polarized COVID-19 Vaccine Discourse on Twitter: Mixed Methods of Machine Learning and Inductive Coding

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## Abstract

**Background:** Since COVID-19 vaccines became broadly available to the adult population, sharp divergences in uptake have emerged along partisan lines. Researchers have indicated a polarized social media presence contributing to the spread of mis- or disinformation as being responsible for these growing partisan gaps in uptake.

**Objective:** The major aim of this study was to investigate the role of influential actors in the context of the community structures and discourse related to COVID-19 vaccine conversations on Twitter that emerged prior to the vaccine rollout to the general population and discuss implications for vaccine promotion and policy.

**Methods:** We collected tweets on COVID-19 between July 1, 2020, and July 31, 2020, a time when attitudes toward the vaccines were forming but before the vaccines were widely available to the public. Using network analysis, we identified different naturally emerging Twitter communities based on their internal information sharing. A PageRank algorithm was used to quantitively measure the level of "influentialness" of Twitter accounts and identifying the "influencers," followed by coding them into different actor categories. Inductive coding was conducted to describe discourses shared in each of the 7 communities.

**Results:** Twitter vaccine conversations were highly polarized, with different actors occupying separate "clusters." The antivaccine cluster was the most densely connected group. Among the 100 most influential actors, medical experts were outnumbered both by partisan actors and by activist vaccine skeptics or conspiracy theorists. Scientists and medical actors were largely absent from the conservative network, and antivaccine sentiment was especially salient among actors on the political right. Conversations related to COVID-19 vaccines were highly polarized along partisan lines, with "trust" in vaccines being manipulated to the political advantage of partisan actors.

**Conclusions:** These findings are informative for designing improved vaccine information communication strategies to be delivered on social media especially by incorporating influential actors. Although polarization and echo chamber effect are not new in political conversations in social media, it was concerning to observe these in health conversations on COVID-19 vaccines during the vaccine development process.

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**KEYWORDS**

COVID-19, vaccine hesitancy, social media, influential actors; influencer; Twitter

## Introduction

The rollout of COVID-19 vaccines in the United States has been characterized by high degrees of hesitancy and mistrust. Vaccine hesitancy is defined as "the decision to delay vaccination or the refusal to vaccinate despite available vaccination services" [1]. By mid-2020, only 50% of Americans were estimated to be willing to receive a COVID-19 vaccination right away [2]. Although estimates improved by December 2020, with 70% of Americans indicating they "definitely" or "probably" would vaccinate against COVID-19 [3], hesitancy began to take a sharp partisan turn subsequent to the 2020 election, and uptake has been characterized by acute partisan divides overtaking other forms of hesitancy [3-6]. Nearly 6 months after all Americans aged at least 12 years old became eligible for the vaccine, counties with a larger share of Trump voters had consistently lower vaccination rates contributing to ongoing surges in hospitalizations fueled by the more transmissible Delta variant [6-8]. That vaccine hesitancy should be higher among political conservatives and Trump supporters was not inevitable. Rather, research shows that it may be related to a deliberate strategy undertaken by the antivaccine movement in 2015 to pivot to the far right under the label of "medical freedom" and the formation of political action committees linked to the American Tea Party and its protests against government interference [9]. Moreover, hesitancy was first amplified by the political nature of the vaccine development process, occurring under intense political pressure to reopen the economy and heightened by public concern about the safety and efficacy of emergent COVID-19 vaccines.

Infodemiology is the science of tracing the "distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy" [10]. Due to increasing use of social media for health information-seeking [11], it is becoming increasingly important for public health professionals to better engage with social media [12]. Studies have made progress in measuring *information prevalence* by adopting computational methods to track the trends of public discourse and emotions on social media [13-16]. Although social media holds the potential to raise awareness and positive endorsement of vaccines, these conversations are vulnerable to political manipulation and tend to silo users into echo chambers (where beliefs are reinforced by exposure to repeated information associated with individual attitudes inside a closed system) [17].

Even prior to the COVID-19 pandemic, there was evidence that social media vaccine conversations have been targeted by Russian trolls and bots to purposefully manipulate and stoke antivaccine sentiment for political ends [18]. Antivaccine groups are reported to be more active on social media than provaccine accounts [19]. A study of 1344 tweets with the "vaccine" hashtag (#vaccine) between 2010 and 2016 found that antivaccine tweets were 4.13 times more likely to be retweeted than neutral tweets in comparison to 1.58 for provaccine tweets [19]. Evidence from over 100 million Facebook users found that antivaccine communities had the highest growth during the measles outbreak of 2019, dominating the main vaccine conversation with narratives that were targeted at swaying the undecided group toward greater skepticism. Meanwhile, provaccine groups were isolated within their community believing they were "winning" [20].

These findings highlight the outsized role that the most active influencers on social media play in spreading health information. In fact, a recent study found that just 12 influential people on social media were responsible for 73% of the total antivaccine posts on Facebook [21]. Likewise, the most active 25% of US Twitter accounts create 97% of tweets [22].

To devise more practical eHealth communication strategies, it is crucial to investigate the role of influential "actors" and their contribution to the amplification of vaccine information in targeted networks. This study, therefore, sought to identify the most influential actors related to COVID-19 vaccine conversations on Twitter and describe their communication patterns and content during July 2020, a time when attitudes toward the vaccines were forming but before the vaccines were widely available to the public [23].

## Methods

### Research Questions

Our research examined the following research questions pertaining to influential actors and discourse in the polarization of the COVID-19 conversations on Twitter:

Research question (RQ) 1 was "What distinctive communities naturally emerged within the COVID-19 vaccine conversation on Twitter at a time when COVID-19 vaccine hesitancy was at its peak? What does that community structure look like? "

RQ2 was "Who are the most influential actors in this Twitter conversation? What is the role of science and medical experts in the vaccine conversation?"

RQ3 was "What is the level of engagement of retweeting activities in each community?"

RQ4 was "What are the primary topics discussed among the most influential actors within each community?"

### Data Collection

Data were collected in 2 phases. In the first phase, we collected COVID-19–relevant tweets, and in the second phase, we selected vaccine-relevant tweets from the first data set. We initially collected all COVID-19 relevant data on Twitter using the Twitter application programming interface (API) between July 1, 2020, and July 31, 2020, using a query list composed by the University of Southern California [24]. From the collected Twitter data, we further filtered tweets about vaccines that included any of the following keywords: "vaccine," "antivaxxers," "antivaccine," "coronavirusvaccine," "vaccines," "CoronavirusVaccine" (Multimedia Appendix 1).



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The keyword sets yielded 1,300,828 tweets, which included a total of 751,691 unique Twitter accounts.

## Data Preparation

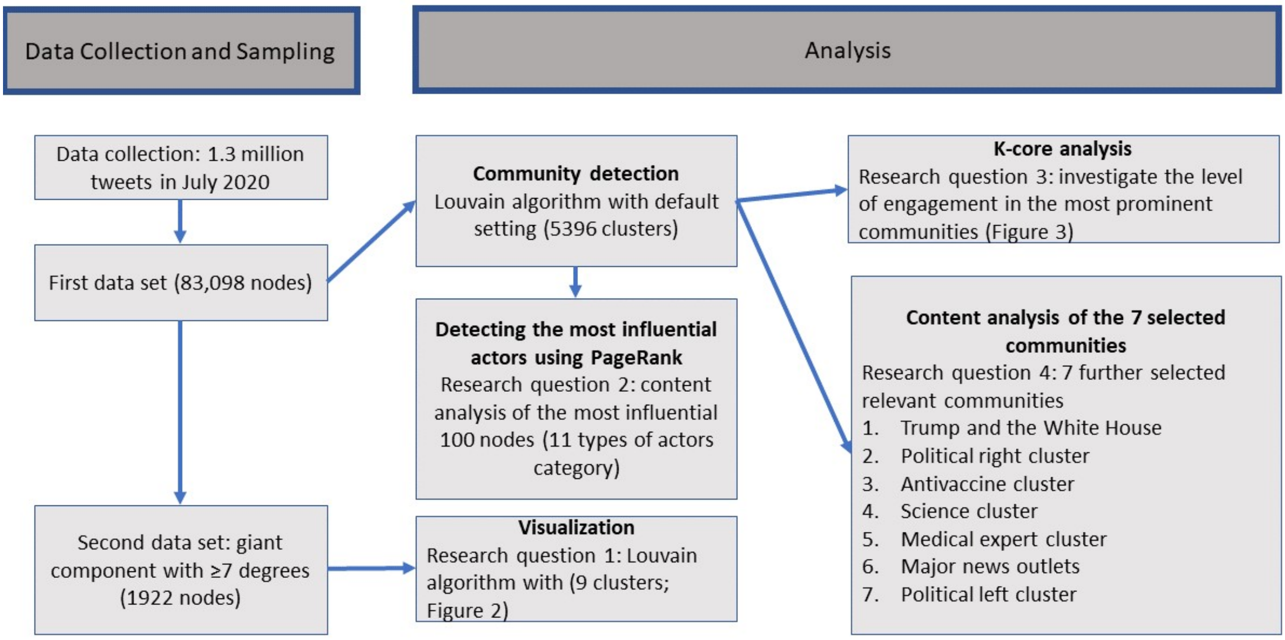
A node is a Twitter account, which we interchangeably call an actor when we refer to its behavior. We defined an edge as a retweet focusing on information sharing among Twitter accounts [25,26]. When Twitter account A retweets a tweet created by account B, there is a directed edge from A to B. The weight of an edge is the frequency of retweets from A to B. Our data set yielded a total of 617,497 nodes and 910,483 edges, which we sorted by decreasing order based on the weights of edges in order to sample the most active nodes in the discussion network. Gephi version 0.9.2 [27] was used for data analysis and network visualization, which has upper limits on the size of the data it can handle. Initially a total of 100,000 edges (83,098 of the most active nodes) with the highest weights was sampled, which is the approximate maximum volume of data Gephi can handle with the local machine (Ryzen 5800x 8 core 16 thread CPU, 16 GB of DDR4 memory, and dedicated GPU Nvidia 3060ti). This process is sampling the top 11% of the most highly influential Twitter accounts based on the number of retweets. We called this the "first data set," which was used to answer RQ2, RQ3, and RQ4.

However, since this initial volume of data was still too large for meaningful visualization, highly active nodes were further filtered by selecting nodes with edge weights of 7 or higher within the giant components. This data set with a total of 7382 edges and 1992 nodes was used for the visualization to answer RQ1. We called this the "second data set."

## Analysis

For rich understanding of a phenomenon from social media data, a mixed methods approach was used by incorporating computational analysis with manual analyses. Figure 1 demonstrates the data collection and analysis process, and the following sections explain the methods used to answer each of the 4 research questions.

**Figure 1.** Data collection and analysis.




### *Community Detection and Visualization*

To detect and visualize the social landscape of the communities, Gephi [27], an open source software, was used for network analysis and visualization. To detect naturally emerging communities, the Louvain [28] algorithm, an unsupervised clustering algorithm, was used on account of its high-quality results [29]. The Louvain algorithm automatically creates clusters (or communities) from a given data set by partitioning a network into "communities of densely connected nodes" by separating these nodes from other nodes in different communities [28].

The first data set yielded a total of 5397 clusters using only the default settings of the Louvain algorithm. The top 20 clusters explained about 71% of the nodes, which means that, when using the default settings of Louvain algorithm, many clusters include only a small number of nodes (some contain only 1 or 2 nodes).

We used these initial clustering results, with minimal manipulation, for the sampling data for the annotation tasks in RQ2 and RQ4 and for the K-core analysis to answer RQ3. To make sure that the clustering results were not created from random chance, we ran the algorithm with the same default setting over 10 times and assured that the produced outcomes were consistent—we validated that the network structure was identical and the 100 most influential nodes were almost identical each time.

Since the initial visualization results from the first data set were too complex due to the overwhelming number of clusters, the Louvain algorithm was run one more time using the second data set, which included a smaller number of nodes: those with the most active retweeting behavior (a total of 1992 nodes, ≥7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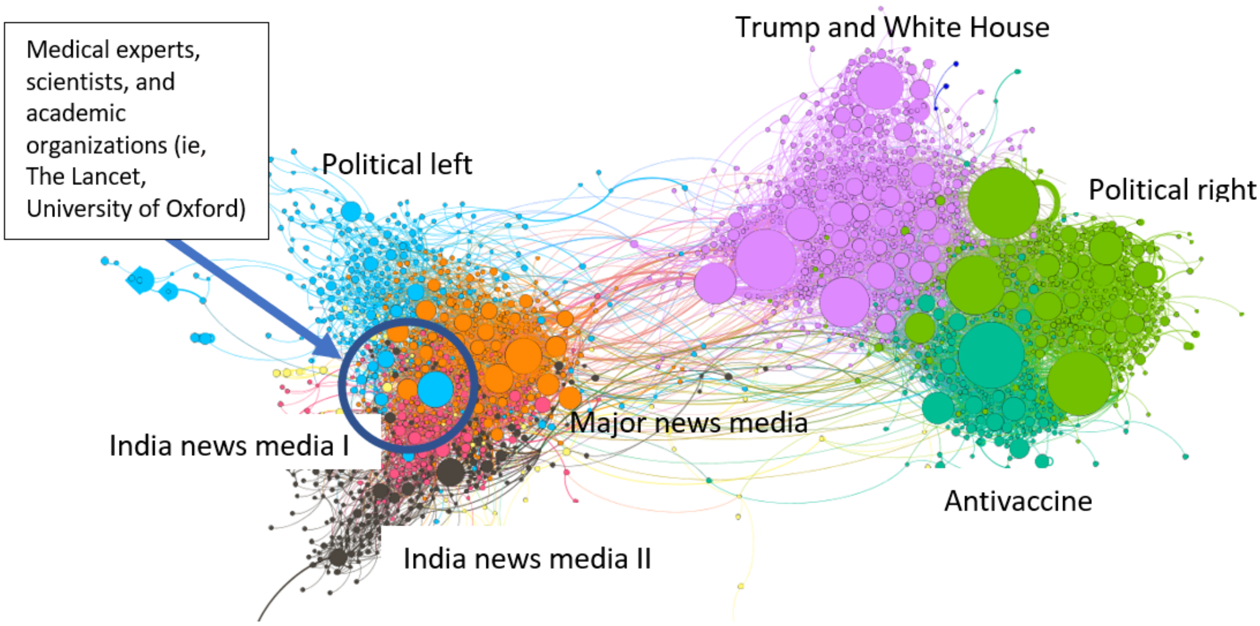
degree weight). The default parameters of the Louvain algorithm produced 9 clusters with the second data set. Figure 2 is from this second data set. Multimedia Appendix 2 shows the top 7 clusters from the first data set (of the 5397 clusters) and second data set (of the 9 clusters), respectively. All 7 clusters were the same in both results, which validates that the Louvain algorithm produced consistent results with minor proportional changes.

For a spatial representation of the network, we used ForceAtlas2 [30], in which nodes, sharing similar local environments, appear closer to each other. The visualized map shows locations the nodes occupy in networks to indicate the strategic importance of them in specific topic communication.

**Figure 2.** Network graph of Twitter conversations about COVID 19 vaccines using the 1992 accounts with the highest PageRank; 2 clusters (explaining 3% and 0% of all the nodes) were excluded. Node color indicates a unique cluster, and node size indicates the level of influence (according to PageRank), with bigger nodes more influential among the networks.




### *Influential Actors and the Role of Science and Medical Experts in Vaccine Conversations*

Diverse measures were available to quantitatively capture the level of influentialness of a node. Betweenness centrality measures may capture the high brokerage potential of a node. Eigenvector centrality can measure the level of popularity of a node based on the connection to other important nodes. PageRank [31] is a variant of eigenvector centrality that counts if a node is endorsed by important nodes. PageRank, formulated by Page and Brin [31], was developed to measure the level of influentialness of a website by giving weights to a website with a higher number of incoming links by *other importantwebsites*. We used PageRank to measure the influentialness of a node because a high PageRank value indicates trust and reliability of a node [32], instead of the eigenvector centrality that simply measures the popularity of a node. In our data, a node with a high PageRank means that the node is highly endorsed and trusted by others because its content is frequently retweeted by *other important nodes*.

The goal of this work was to investigate the types of influential actors in the vaccine discussion and to understand the role of scientific and medical experts. In the preparation of the analysis, we sampled the top 100 most influential nodes based on the PageRank value. First, the 30 most influential accounts, according to their PageRank value, were used to develop a category scheme of actor types. To develop the categories of these actors, researchers manually reviewed (1) publicly available Twitter profiles, (2) tweets created or shared by these influential actors, and (3) subsequent web searches (ie, Wikipedia pages) when necessary. A total of 11 actor categories were developed (see Table 1), and 30 accounts were enough to reach a saturation. Second, in order to have a robust categorization of the influential actor types, 70 additional nodes with the highest PageRank value were further sampled. A graduate student followed the category scheme to code the additional nodes. The first researcher revisited the later codes to validate the coding and double checked the consistency. The researcher further consulted with vaccine and medical experts to validate the coding results.



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**Table 1.** Category scheme developed for the annotation of actor types.

| Number | Category scheme | Definition |
|---|---|---|
| 1 | News media | Mainstream news media |
| 2 | Activist | Individual actors, not organizations, who campaign to bring about social and political changes |
| 3 | Partisan | An individual or official account in which the main goal is to support a political figure or a political party |
| 4 | Medical expert | An individual with an official medical expertise (ie, medical doctor, researcher, and registered nurse) |
| 5 | Academic institution | An official account representing academic institution (ie, universities, medical journals) |
| 6 | Culture | The main content of the Twitter account is about culture (ie, a BTS fan account) |
| 7 | Government | A government organization |
| 8 | Business | A company's official account or an account that clearly pursues financial gain |
| 9 | Politician | Elected officials |
| 10 | Random individual | A personal account that does not correspond to any of the above categories |
| 11 | Suspended | An account that existed during the data collection but was suspended before the category development phase |

### Ethics Review

The institutional review board (IRB) of the leading author's institution responded that our work was considered to be not-human subject research; therefore, IRB review and approval was not required. Although it is not legally required, our research team decided to follow the best practices for ethical Twitter research [33]. The Belmont principle of "respect for persons" requires receiving informed consent from the study subjects. Receiving informed consent from a large data set is not feasible. Instead, Fiesler and Proferes [33] suggested that scholars should identify users only when "the benefits of doing so clearly outweigh the potential harms." Our goal was to identify the role of the accounts, not the specific identity of the accounts. Revealing the identity of personal accounts may violate the *respect for persons* principle considering the majority of Twitter users are not aware of use of tweets by researchers, and thus feel that researchers should not be able to use tweets without consent [33]. One exception might be "verified accounts" for which Twitter provides a blue badge for accounts "that are of high public interest." Since this verification process requires the account owners to apply for it *by themselves* and only specific types of accounts are eligible (ie, government, news organizations, activists) [34], we can safely assume that the owners of verified accounts are "public figures" who "waive a substantial part of their right to privacy" for academic research purposes [35,36]. We anonymized personal and unverified Twitter accounts to protect the privacy of these users and only revealed the account names of "verified" accounts.

### K-Core Analysis

K-core analysis was used to investigate the level of tight connections. A k-core is "a maximal group of nodes, all of which are connected to at least K other nodes in the group" [37]. For example, K=3 means that every member of the clique (a small and highly interconnected group) is connected to at least 3 other clique members. K-core, a relaxed measure of a clique, is a measure to capture the level of interconnectivity. *Clique* is a term that refers to a small and highly connected group in which all nodes in the clique are connected to all other nodes. Identifying cliques is important because information can be shared quickly within a clique and members of a clique behave in a cohesive manner [37].

### Inductive Coding

Lastly, inductive coding was conducted by manually reading tweets assigned to each cluster. In preparation for the inductive coding, 7 clusters were purposefully selected from the first data set: 5 of the biggest clusters (political right; major news media; antivaccine; Trump and the White House; political left) were selected (see the size of the clusters in Multimedia Appendix 2), and 2 clusters (science, medical experts) from the top 20 clusters were purposefully included in the sample because we were interested in the role of scientists and medical experts.

This was followed by sampling a maximum of 200 tweets created by the top 5 Twitter accounts with the highest PageRank value from each of the 7 selected clusters. Inductive coding techniques, modeled on grounded theory, were used for the analysis. The first coding phase used open coding followed by a second phase, axial coding, to document trends in each cluster for (1) thematic topic of concern; (2) manifest content such as explicitly stated vaccine risks or benefits and actors (beneficiaries or agents); and (3) latent content such as the function of discourse. The third phase used selective coding to yield brief summaries of patterns in the coded clusters. To establish intercoder agreement in each cluster's blind coding, 10% of each cluster's coded data were randomized and verified to exceed 90% agreement. Following practices of social reliability in qualitative research [38], disagreement was discussed and collaboratively recoded as "code unspecified." If a cluster had more than 10% of codes that disagreed in the sample, the entire cluster was coded by the second coder, and differences were again discussed. This created higher metrics of researcher social reliability [39], which improves the overall accuracy and validity.

## Results

### Naturally Emerging Communities

Using the second data set (a total of 7382 edges and 1992 nodes), the Louvain algorithm automatically detected 9 clusters


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and assigned numeric values (from 0 to 8) to each of the cluster. Since assigned numbers are not meaningful, we assigned meaningful labels to the biggest 6 clusters (2 clusters were too small to discuss, and 2 clusters were adjacent to each other and thematically the same, so we combined the 2 as Indian news media). The labels were decided based on the user profile description of the top 10 most influential nodes (based on the PageRank value) in each of the clusters.

Figure 2 shows the labels of the 6 major clusters (Trump White House, political right, political left, major news media, Indian news media, and antivaccine). The biggest community was Trump White House (27%), followed by political right (15%) and political left (14%). Figure 2 illustrates that the political right and antivaccine clusters included the most influential actors (the bigger sized nodes are more influential actors in the entire discussion network in Figure 2).

Analyzing the relationship among the clusters, academic organizations and medical experts (discussed in the Primary Topics Discussed Within Communities section) were located close to the major news media and political left clusters (in Figure 2). This means that the major news media and political left tend to depend on information sources from scientific sources and medical experts in contrast with the political right and antivaccine activists who tend to depend on their own information sources.

### Most Influential Accounts and the Role of Science and Medical Experts in Vaccine Conversation

Using an iterative coding approach, a total of 11 categories were developed (academic organization, activist, business, culture, government, medical expert, news media, partisan, personal, politician, and suspended) for the manual coding of the 100 most influential accounts. Table 2 presents the manual coding results, reporting that the news media (27%) and partisan actors (20%) were the biggest actor categories. The polarized network graphs and active involvement by supporters of President Trump showed direct involvement of politics in COVID-19 vaccine discussions. In an inquiry to find the role of science and medical experts, results showed that only 10% and 2% of the 100 most influential accounts were medical experts and academic organizations, respectively. The activists, explaining 11% of the 100 most influential actors, were either antivaccine activists or “conspiracy theorists” who believe that COVID-19 is a human-engineered disaster. Multimedia Appendix 3 shows the account names and the typology of the top 11 partisan actors (in red font). The partisan actors are more frequently from the Trump White House and political right clusters. A total of 5 accounts was suspended, all of which (blue font in Multimedia Appendix 3) appear on the right side of the polarized network. Suspension follows Twitter’s internal policy, whereby accounts are suspended mainly for spamming, security at risk, abusive tweets, or abusive behavior [40].

**Table 2.** Categories of the top 100 influential actors.

| Category | Description and verified Twitter handles[a] | Frequency, n |
|---|---|---|
| News media | Major news media such as Bloomberg, Reuters, and the Associated Press | 27 |
| Partisan | 16 accounts out of 20 were Trump supporters. All the verified accounts were @TeamTrump, @ASlavitt, @ksorbs, @charliekirk11, @TrumpWarRoom, @AndrewHClark, @Jillie_Alexis, @AntonioSabatoJr, @tribelaw | 20 |
| Activist | 7 accounts had antivaccine attitudes; 4 accounts were so called “conspiracy theorists.” Verified accounts were @Jimcorrsays, @RobertKennedyJr | 11 |
| Medical expert | @Drdavidsamadi (urologist and Fox News pundit); @FaheemYounus (MD and Chief of Infectious Diseases at a university hospital); @DrEricDing (epidemiologist, National Foundation of Infectious Diseases); @ProfKarolSikora (oncologist) | 10 |
| Academic Organizations | @UniofOxford, and @TheLancet | 2 |
| Others | Government (n=2), business (n=2), culture (n=6), personal (n=10), suspended (n=5), politician (n=5) | 30 |

[a]The coding took place in December 2020. It is possible some account statuses could have changed since our initial coding.

### Level of Engagement in Each Community

K-core was investigated by eliminating minimal edge connections with other nodes. The 7-core graph in Figure 3 shows that the antivaccination group is a “tier one” group, which includes actors who are densely connected to each other by heavily retweeting content generated among themselves. Many actors in the antivaccine group were connected to at least 7 other clique members, most of whom were in the same community. Therefore, information can be shared quickly within the antivaccine group, and members of this clique behave in a cohesive manner. In contrast, the political left, science, and medical expert communities lost most of the cliques by 5-core. This means that actors in these communities are less cohesive and depend on heterogeneous information sources compared to those in the antivaccine group.


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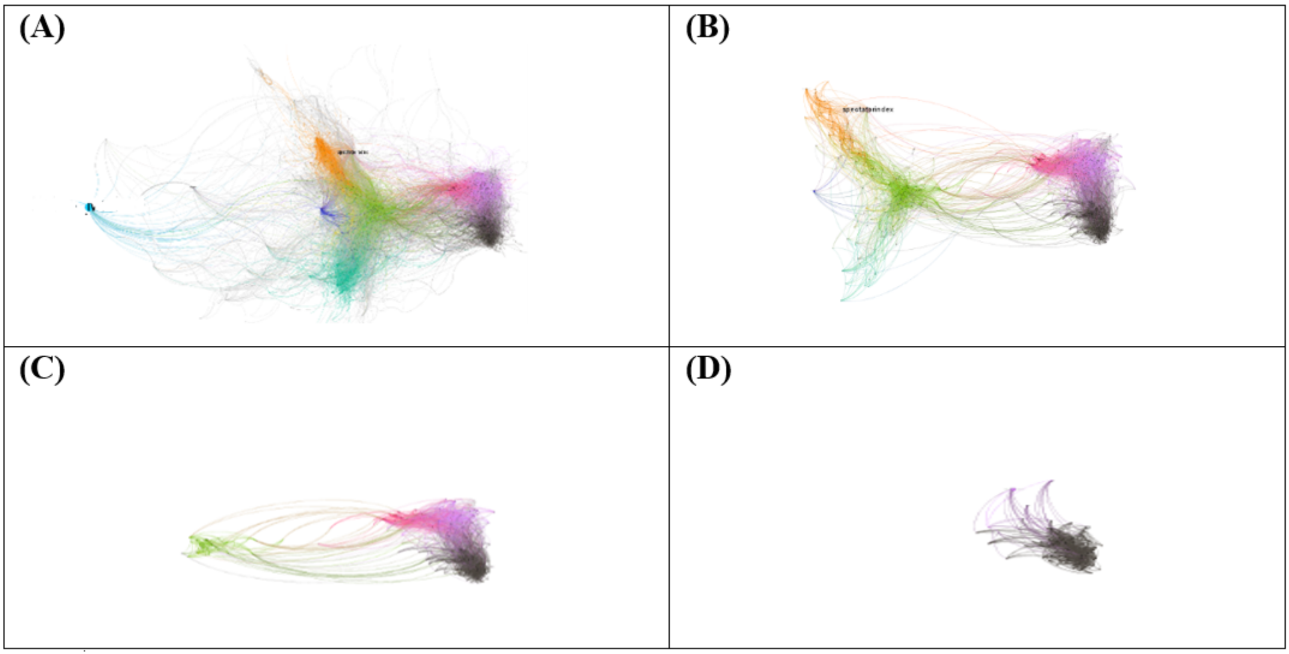
**Figure 3.** K-core graphs demonstrating the density of groups: (A) 2-core, (B) 5-core, (C) 6-core, and (D) 7-core.




## Primary Topics Discussed Within Communities

In order to understand the content discussed in the major communities, we conducted content analysis of tweets created and shared by influential actors. The result showed the concerns of the political right and antivaccine community included vaccine safety and infringing on rights and liberty. The Trump and White House and political left clusters used vaccines as a partisan tool to gain political advantage. The following paragraphs provide summaries of the inductive coding results for the 7 selected clusters.

The content of the Trump and the White House cluster showed the COVID-19 vaccine was a major presidential deliverable as evidence of political legitimacy in the present and future. This cluster's tweets were highly partisan, showing President Trump was successfully managing the rollout of the vaccine—hence worthy of political trust (eg, White House Press Secretary @KayleighMcEnany: "These critical investments in a coronavirus vaccine are due to the fact that we have a businessman in the White House." [41]).

Two major arguments that were repeatedly called out in the Tweets were (1) use of the COVID-19 vaccine to demonstrate Trump's sound management and growth of the national economy, legitimizing his presidency, and (2) use of "speed of planning" for vaccine development, manufacturing, and distribution to demonstrate Trump's capable management of complex national processes, again legitimizing his presidency. These markers—money and time—were likewise used in some oppositional Tweets proposing political mismanagement by Biden.

The content of the political right cluster was closely linked to themes of antivaccine and Trump and the White House clusters, with about one-third citing conspiracies, often naming the untrustworthy beneficiaries with motives of depopulation, corruption, and DNA disruption: "Bill Gates vaccine agenda #DEPOPULATION Fauci awarded a $3.7M research grant to the Wuhan lab, working on BioW Coronavirus. Wuhan labs wants to Patent Gilead's Remdesivir. Fauci is on the board of Gates Foundation. Gates gave CDC $13.5M & is second largest funder to the W.H.O." [42].

This cluster also expressed distrust of Big Pharma, the Centers for Disease Control and Prevention (CDC) and scientific and medical decision makers. Surprisingly, the cluster indicated a degree of distrust in Big Government and the Trump administration; when present, the distrust was largely related to suspicion of direct financial benefits (patents, stock ownership).

Other conspiracy themes included unauthorized collection of personal information (eg, DNA, tracking). An emergent conspiracy theme in the conservative activist cluster included beliefs that the vaccine was deliberately designed to depopulate through killing recipients or causing sterility. This cluster also made accusations tying them as conscious agendas of the social movement and having a reluctance to mandatory vaccination challenging their American values of freedom and liberty. Conspiracies, paralleled in less radical tweets, reported government and pharmaceutical sectors negotiated release from liability for known side effects from the vaccine. Extreme conspiracies cited cover-ups for massive death and complication rates in ongoing human trials that were complemented by vaccines being unnecessary due to supposedly promising alternative treatments and therapies—most notably hydroxychloroquine.

The antivaccine cluster was highly connected within and with the political right cluster. The top 5 influential nodes in the antivaccine cluster were either not verified (n=4) or suspended (n=1). Topical trends related to conservative ideology including freedom and rights, and the forcible control over citizen's actions and bodies included narratives like the arguments in the political right cluster. Topical trends included that the vaccine was unnecessary or ineffective, referencing claims of health, fitness, and cognitive ability to beat an infection. The topic of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lack of trust of Big Pharma and the justice system was expressed as suspicion of releasing manufacturer liability by minimizing vaccination risks and manufacturer culpability. Mistrust was high in specific conspiracies in this cluster that often linked Big Tech, Big Pharma, and Big Government. Topics also included DNA disruption and fears of adding unknown substances to the vaccine like tracking devices, genetic material theft, and general "unknown" materials. There were few scientific claims; more widespread were claims of censorship.

The content of the science cluster indicated broad approval and encouragement of the vaccine and its makers with some distrust against the Trump administration. The latter explains the distance between the Trump and the White House cluster and scientists in Figure 2. Expressed concerns centered around the rapidity of vaccine development with compromise of safety. This content was saliently tied to Trump in 3 core ways: (1) Tweets criticized Trump's rapid vaccine rollout citing it as the "October election vaccine;" (2) tweets focused on corruption and equity, demanding Trump provide a universal, free vaccine; and (3) tweets highlighted Trump's retweets of a doctor who claimed the vaccine was from alien DNA, reinforcing his schism with the scientific community and principles. This cluster did demonstrate some trust of the Trump administration through the surrogate of Fauci as expressed in tweets on Fauci's role and advice being "spot on" or discussed his disinterest in the vaccine "race" as against Russia, all highlighting partisan messaging during the development process. Aside from these fears, this cluster exhibited apprehensions about the growing role of antivaccine advocacy groups with general concerns that "antisocial" messages will coincide with the public inoculation timeline.

The content of the medical expert cluster demonstrated similar themes to the science cluster by containing specific evidence—for example, not just documenting progress milestones but including supporting descriptive statistics. Like the media cluster, references and links were used to promote longer content with articles and interviews serving as evidence. This cluster used historical and comparative rhetoric with other diseases and responses, but unlike other clusters, used the historical or comparative references to overcome current barriers or cause for optimism. Similar to other clusters, structural limitations in manufacturing and distribution were raised. A functional clue to expected audience is demonstrated in the dissemination of medical analyses and science claims, noted by dense jargon without a primer for the public. Although a small number of tweets actively engaged the malignment of the vaccine by addressing antivaccine propaganda or misinformation, it was not distributed among many accounts. Likewise, conspiracy tweets from (2) accounts demonstrated how people without medical expertise cross talked the medical cluster.

The content of the major news media cluster involved broad support for the vaccine and its makers and differed from other clusters in its analysis of the vaccine narrative through 3 main topics. First, nearly one-quarter of the content either documented the status of vaccine manufacturing progress or suspected date of availability. Second, a timing theme speculated about plans for vaccine manufacture and distribution. Although other clusters were concerned about timing, the media's concern largely focused on milestones and speculated about deliverables, rather than expounding on vaccine safety risks or economic outcomes. Third, elements of skepticism and distrust were present in the form of the attention given to "dose deals" (where countries contracted future access to vaccines) and ethical violations (intellectual property violations, deliberate risks to human trial volunteers). This was complemented by content with overt and secondary implications of vaccine nationalism or of international cooperation. Although political implications were present in many tweets, they were less partisan in nature than other clusters.

The political left cluster contained mixed messages about trust regarding the vaccine. A small number believed the vaccine is one method to combat the virus, most were divisive, and approximately 20% circulated conspiracy theories. Contributors expressed distrust through vaccine hesitancy patterns; others expressed trust that the vaccine is the "lynchpin" by which society can return to normal. Within this cluster, there were claims that (1) vaccine science is sound, but Trump's political manipulation of the timeline to optimize the election has compromised the trusted process; (2) vaccine manufacturing is being used as a conspiratorial economic investment to Trump's allies, again compromising the manufacture and distribution; and (3) the Trump administration was subverting American ethics like hard work, integrity, and innovation by ignoring or supporting international violations of intellectual property. This cluster also included a pattern of partisan rhetoric in tweets that explicitly used Trump as a metaphor or symbol for the virus (eg, the Trump Virus or Trump is the Virus/Biden is the Cure).

## Discussion

### Principal Findings

Using network analysis and unsupervised machine learning with samples from Twitter data and conducting inductive coding to characterize tweet discourse, we found that, during this period, COVID-19 vaccine Twitter conversations were already highly polarized. The most influential Twitter actors were not scientists and medical experts but rather partisan actors and antivaxxers. Actors on both the political left and political right expressed skepticism and misgivings toward the COVID-19 vaccine development process but were motivated by different concerns and used different language to describe their concerns. Conspiracy theories were raised on both sides.

Our analyses of Twitter posts during the height of stay-at-home measures in the United States and amid the race to develop COVID-19 vaccines demonstrated a high degree of Twitter social media activity related to vaccine development. Twitter vaccine conversations were highly polarized, with different actors occupying separate "clusters," reinforcing concerns about "information bubbles." The level of polarization was similar to a deeply political event such as the Muller investigation of Russian interference in the 2016 US elections [43].

Media and science or medical actors were especially absent from the conservative clusters, and antivaccine sentiment was especially salient in the political right cluster. Results also



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showed "antivaccine" groups to be highly engaged actors in the COVID-19 vaccine conversation, circulating information particularly within a tight conservative cluster.

### Health Information Sources and the Politicization of Science

These findings have important implications for health professionals' communication and education about vaccines. Although it may not be public health professionals' traditional roles to address the politicized nature of vaccine acceptance, it is increasingly important for them to understand how patients gather health information from online platforms and "adjudicate the merits of such information" [11].

Previous research has shown how a small but influential handful of actors with medical credentials or authority can disproportionately sway Twitter conversations and promote the spread of misinformation. This misinformation can then be further amplified by partisan actors who misrepresent and exaggerate these statements for political gain. For instance, Haupt et al [44] found that a single group claiming medical and scientific credibility and authority (ie, Dr Immanuel and America's Frontline Doctors) successfully promoted the use of hydroxychloroquine, even though the efficacy of hydroxychloroquine had not yet been fully demonstrated. Political (eg, Trump) and media sources then amplified and disseminated this information in support of the use of hydroxychloroquine [44]. Our empirical evidence shows that the vaccine conversation had already become politicized along partisan lines before the vaccine was available, with vaccine acceptance driven by ideological beliefs and attitudes, particularly among Twitter influencers. As previous research shows, when disease threats become partisan, or "politicized," people look to their preferred political party to decide how much they ought to worry [45,46]. Once politicized, issues can be hard to depoliticize, and rather than looking to science or medical experts, people look to less credible sources of information or adopt practices, such as vaccine refusal, that may be hard to alter.

The politicization of the COVID-19 vaccine conversation is an important empirical outcome because, although politicization of science has existed in environmental politics and policy [47], this is a relatively newer development for public health policy. Although certain public health issues have long been politicized (eg, sexual and reproductive health, HIV policy) [48], other infectious disease threats have not been politicized in the same way as COVID-19. For instance, the findings from this study contrast with the findings from a Twitter analysis during the Zika pandemic. Research showed that the Twitter conversation about Zika was not polarized; instead, there was higher trust in medical and scientific authorities, even though the Zika health crisis data were collected during the summer of the Presidential 2016 election campaign, just as our data set was also collected (July 2020) [49]. By contrast, the issue environment surrounding our data collection was highly politicized during—and even before—the pandemic [45,50,51], thereby enabling partisan actors and political elites, not medical experts or scientists, to play an important role in leading the discourse.

### Political Attitudes, Health Beliefs, and Behaviors

Our findings contribute to knowledge development examining the relationship between political ideology and attitudes toward science [52-54]. Although the conservative network was marked by an overrepresentation of partisan and vaccine skeptic actors and an underrepresentation of science or medical experts, this may be the result of deliberate targeting of political conservatives rather than a reflection of an inherent skepticism of the scientific community rooted in ideological differences [53]. Rather, this research demonstrates that actors on both the political left and political right expressed skepticism and misgivings toward the COVID-19 vaccine but were motivated by different concerns and language, suggesting both conservative and liberal actors are susceptible to political manipulation and framing of issues. Notably, conspiracy theories were present in both liberal and conservative clusters, further supporting the contextual hypothesis that both liberals and conservatives are likely to doubt science if scientific information contradicts their preconceived worldviews [52,54].

Although the analysis of tweets in each cluster revealed highly divided vaccine discourses among specific political communities, "distrust" arose as a common (and primary) construct advanced by partisan actors throughout the content analysis. On the liberal side, general distrust of the COVID-19 vaccine development process was expressed through fears that its speed would compromise safety (science cluster), dosing deals and ethical violations (major news media cluster), and the intentional abuse of the progress timeline for political gain (political left cluster).

Within the political right and antivaccine clusters, themes that emerged included distrust and antivaccine rationales rooted in conservative ideology including language of freedom or rights, forcible control over citizen actions and bodies, and large-scale economic profit.

Evidence that "antivaccine actors" were more heavily present in conservative networks was prominent in this study, and conspiracy theories and conservative ideologies of freedom and rights were prevalent themes that were not previously evident in the vaccine hesitancy literature. This is consistent with concerns that have been raised about how the antivax movement is specifically targeting political conservatives and the far right through a campaign of "medical freedom" to advance their cause [9,55]. Further investigation of this finding may help explain why White Republicans have been identified as the most vaccine hesitant group in recent polls [56,57].

### Implications for Public Health Communication Using Social Media

Given the growing proportion of the population that attains health news through social media [58,59], it is important for public health professionals to harness the power of social media to support situational awareness (ie, public's behavior, emotion, information demand) [12]. Additionally, the findings from our study and related studies can be used to help identify and counter the narrow group of influencers that are most responsible for amplifying antivaccine sentiment such as through better enforcement of platforms' existing standards [21].


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### Methodological Implications and Limitations

Methodologically, this study demonstrated how to identify the most influential actors during an acute public health crisis and how information clusters have formed on social media at a critical moment when people's attitudes toward the vaccines were being formed. This knowledge is beneficial for developing health communication strategies on which social media "influencers" to target for information distribution or for counter-messaging.

Nevertheless, there are limitations to this study. First, interpretation of the results of our study are necessarily bounded by the Twitter platform, which does not always reflect the general public (ie, Twitters are younger, likely to be liberal with higher incomes than US adults, and strongly influenced by a small number of prolific users) [60]. Consequently, Twitter reactions do not always reflect overall public opinion [61]. Therefore, the results of this analysis should not be regarded as emblematic of broader attitudes and beliefs on COVID-19 vaccines. Also, we do not know if the platform specifically affected the differences between Twitter and survey studies on vaccine hesitancy discourse. Therefore, future studies may investigate the same phenomenon using different methods. Traditional survey methods rely on self-report and may create incentives for participants to give politically correct responses; however. these do not allow elaboration due to standardized question wordings [62]. By contrast, Twitter data include expression of users in their natural environment and enable synchronous data collection as one's expressions occur. Therefore, Twitter (or other social media) data include more current sentiments on vaccine hesitancy.

Second, we decided not to delete bots because (1) determining bot accounts requires further investigation on setting a proper threshold, (2) accounts with higher bot scores do not seem to seriously interfere with discussions, and (3) deleting bots means artificially manipulating a raw data set because bots are part of the Twitter ecosystem. Using our data set, we detected bots to investigate to what extent bots are interfering with vaccine conversations by running one of the most popular bot detection algorithms called Botometer [63]. Emulating the study by Hagen et al [43] that found political bots' effect on the network structure, we investigated the proportions of bots among the most influential actors. We were not able to find outstanding evidence of bots systematically interfering with the conversation in our data set to the extent to justify deletion of bot accounts. More importantly, when we initially set a relatively conservative threshold of a 0.7 complete automation probability (CAP) score following previous Botometer research [64], human accounts were frequently tagged as bots (ie, the Twitter account of former President Obama had a bot score of 0.8). This means that, without further detailed study to decide a proper threshold for the Botometer to accurately detect bots (we conducted a separate study for this), it is better not to delete bots from the data to preserve the natural ecosystem of Twitter.

### Conclusions

COVID-19 vaccine conversations in July 2020 were highly polarized along partisan political lines. Specifically, "actors" on the political right of the spectrum formed a tight information-sharing cluster that was highly siloed and infiltrated by the antivaccine community; this group tended to circulate conspiracy theories and were far less likely to distribute vaccine knowledge from scientific and medical expert clusters. Concerningly, "trust" in a COVID-19 vaccine was highly manipulated by partisan actors on both the left and the right for political advantage. These findings are informative for designing improved vaccine information communication strategies to be delivered on social media. Although polarization and the echo chamber effect are not new in political conversations on social media, it was a concern to observe these in health conversations on COVID-19 vaccines during the vaccine development process.

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## Conflicts of Interest

None declared.

Multimedia Appendix 1
Full keyword list for data collection.
[DOCX File , 14 KB - infodemiology_v2i1e34231_app1.docx ]

Multimedia Appendix 2
Supplemental table.
[DOCX File , 13 KB - infodemiology_v2i1e34231_app2.docx ]

Multimedia Appendix 3
Supplemental figure.
[DOCX File , 330 KB - infodemiology_v2i1e34231_app3.docx ]


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## Abbreviations

**API:** application programming interface
**CAP:** complete automation probability
**CDC:** Centers for Disease Control and Prevention
**IRB:** institutional review board
**RQ:** research question


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Original Paper

# Charting the Information and Misinformation Landscape to Characterize Misinfodemics on Social Media: COVID-19 Infodemiology Study at a Planetary Scale

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## Abstract

**Background:** The novel coronavirus, also known as SARS-CoV-2, has come to define much of our lives since the beginning of 2020. During this time, countries around the world imposed lockdowns and social distancing measures. The physical movements of people ground to a halt, while their online interactions increased as they turned to engaging with each other virtually. As the means of communication shifted online, information consumption also shifted online. Governing authorities and health agencies have intentionally shifted their focus to use social media and online platforms to spread factual and timely information. However, this has also opened the gate for misinformation, contributing to and accelerating the phenomenon of misinfodemics.

**Objective:** We carried out an analysis of Twitter discourse on over 1 billion tweets related to COVID-19 over a year to identify and investigate prevalent misinformation narratives and trends. We also aimed to describe the Twitter audience that is more susceptible to health-related misinformation and the network mechanisms driving misinfodemics.

**Methods:** We leveraged a data set that we collected and made public, which contained over 1 billion tweets related to COVID-19 between January 2020 and April 2021. We created a subset of this larger data set by isolating tweets that included URLs with domains that had been identified by Media Bias/Fact Check as being prone to questionable and misinformation content. By leveraging clustering and topic modeling techniques, we identified major narratives, including health misinformation and conspiracies, which were present within this subset of tweets.

**Results:** Our focus was on a subset of 12,689,165 tweets that we determined were representative of COVID-19 misinformation narratives in our full data set. When analyzing tweets that shared content from domains known to be questionable or that promoted misinformation, we found that a few key misinformation narratives emerged about hydroxychloroquine and alternative medicines, US officials and governing agencies, and COVID-19 prevention measures. We further analyzed the misinformation retweet network and found that users who shared both questionable and conspiracy-related content were clustered more closely in the network than others, supporting the hypothesis that echo chambers can contribute to the spread of health misinfodemics.

**Conclusions:** We presented a summary and analysis of the major misinformation discourse surrounding COVID-19 and those who promoted and engaged with it. While misinformation is not limited to social media platforms, we hope that our insights, particularly pertaining to health-related emergencies, will help pave the way for computational infodemiology to inform health surveillance and interventions.



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**KEYWORDS**

social media; social networks; Twitter; COVID-19; infodemics; misinfodemics; infodemiology; misinformation

## Introduction

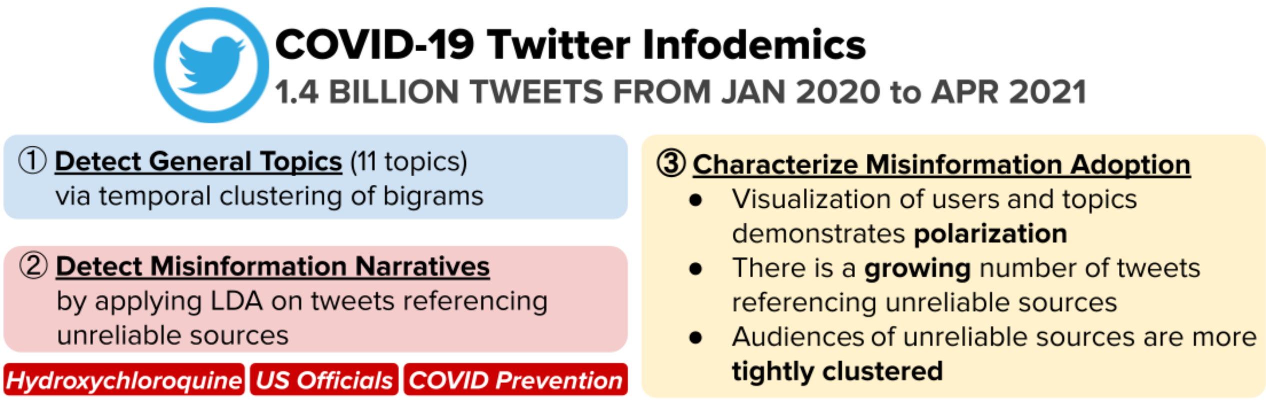
As COVID-19 forced more of the world to undergo lockdowns and to adopt physical distancing, the public sought refuge and community support online to replace the interactions that were no longer possible in person. Social media platforms soon became a means for messaging involving the COVID-19 pandemic, with policy makers and medical experts taking to social media to reach the public, and the public using these platforms as forums for debate and information exchange.

Twitter remains one of the main platforms used as a vehicle for communication in the COVID-19 era. This and other similar platforms, however, enabled false or misleading information with the potential to cause harm to public health to take root. The increasing reliance on platforms as a means for communication during COVID-19 underscored the importance of *infodemiology*, which is the study of the spread of "health information and misinformation" on online platforms [1,2], and brought the concept of *infodemics*, defined as the epidemic-like spread of information, to the public eye [3]. While the intensity of its effects varies based on country and culture, infodemics was and continues to be a salient issue in COVID-19 discourse [4,5]. Misinformation, particularly during a pandemic, can dissuade some individuals from readily adopting health practices that would contribute to curbing the spread of the disease [6].

Efforts are being made to combat misinformation, including identifying intervention points in social networks to mitigate misinformation [7], teaching the community how to identify misinformation [6], rating source reliability [8], and using both crowdsourced and official fact checkers to identify misinformation [9,10]. Social media platforms have also begun adding notifications to remind users to be cautious when reading certain information [11].

In this paper, we take a deeper look into both the general COVID-19 conversation and the misinformation narratives on Twitter between January 2020 and April 2021 (Figure 1). The contributions we make in this paper are as follows: (1) We identified 11 major topics of general discussion present throughout our overarching data set, which are temporally in line with the progression of current events; (2) We detected 3 prominent misinformation narratives (namely, hydroxychloroquine and alternative medicines, US officials and governing agencies, and COVID-19 prevention efforts); (3) We found that there are distinct political echo chambers and that a user's political alignment is linked to the misinformation narratives the user engages with; and (4) We took a closer look at the types of misinformation domains that are shared and found that the consumption of conspiratorial and questionable content is on the rise. Users who share unreliable health-related content also tend to be in more tightly connected communities compared with the average Twitter user.

**Figure 1.** Overall roadmap of this paper. LDA: latent Dirichlet allocation.




## Methods

### Data

We began collecting and curating a COVID-19 Twitter data set right at the beginning of the pandemic, in January 2020, to continuously track, in real time, public discourse about the coronavirus pandemic. We have made the data set publicly accessible to the wider research community [12]. This study uses publicly available data, and the data collection and analysis are approved by the University of Southern California Institutional Review Board (protocols UP-17-00610 and UP-21-00005).

Our complete data set, as of this writing (mid-July 2021), contains 1,497,893,426 tweets from January 21, 2020, through July 9, 2021 (release v2.55). While we provide a brief overview of our data set here, a full description of our data set can be found elsewhere [12]. We leveraged release v2.45 for this paper, which contains 1,443,871,621 tweets from January 21, 2020, through April 30, 2021. All our tweets were collected in real time using Twitter's streaming application programming interface (API), which gave us access to a 1% stream of tweets [13]. We leveraged a manually curated list of keywords to filter for tweets that contained content related to the COVID-19 pandemic and surrounding issues. We list a sample of the keywords we tracked in Table 1. The full list of up-to-date



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keywords can be found in our GitHub repository [14]. While we did our best to capture as much discourse as we could in our collection, a limitation of our data set is that our keywords were all in English and were manually selected for tracking. This may have influenced the collected tweets and our subsequent observations. A language breakdown for the tweets found in release v2.45 can be found in Table 2.

**Table 1.** A sample of keywords that were tracked during this release (v2.45; May 3, 2021).

| Keyword[a] | Tracked since |
|---|---|
| Coronavirus | January 28, 2020 |
| CDC | January 28, 2020 |
| Wuhanlockdown | January 28, 2020 |
| Kungflu | January 28, 2020 |
| corona virus | March 2, 2020 |
| covid | March 6, 2020 |
| covid19 | March 6, 2020 |
| sars-cov-2 | March 6, 2020 |
| COVID–19 | March 8, 2020 |
| coronapocalypse | March 13, 2020 |
| SocialDistancing | March 13, 2020 |
| shelteringinplace | March 18, 2020 |
| flatten the curve | March 18, 2020 |

[a]We do not need to track every permutation of a keyword. As of this writing, Twitter returns all tweets that contain the keyword as a substring, and it is case insensitive.

**Table 2.** The top 10 languages and their prevalence in all tweets collected in this release (v2.45; May 3, 2021).

| Language[a] | ISO[b] | Tweets (N=1,443,871,621), n (%) |
|---|---|---|
| English | en | 928,225,493 (64.29) |
| Spanish | es | 186,880,167 (12.94) |
| Portuguese | pt | 62,398,113 (4.32) |
| French | fr | 44,097,563 (3.05) |
| Undefined | und | 41,140,188 (2.85) |
| Indonesian | in | 35,683,876 (2.47) |
| German | de | 25,970,256 (1.80) |
| Japanese | ja | 16,865,989 (1.17) |
| Italian | it | 15,697,293 (1.09) |
| Turkish | tr | 14,931,506 (1.03) |

[a]The language tags are automatically detected by Twitter and returned in the tweet metadata.

[b]ISO: International Organization for Standardization.

### *Identifying Discussion Topics*

To understand the general COVID-19–related topics that were discussed on Twitter, we identified the bigrams (ie, consecutive word pairs) used in our data set and clustered bigrams that share similar temporal usage characteristics.

#### Bigrams

To retrieve bigrams, we first tokenized the tweets, lowercased all tokens, and removed stop words and select punctuations (including hash signs used for hashtags in Twitter). For example, the (fictitious) tweet "Thousands of new #covid cases reported in Los Angeles County!!" reduces to the sequence of tokens "thousands new covid cases reported los angeles county;" all bigrams would be extracted, such as "thousands new," "new covid," "covid cases," "cases reported," etc. To avoid sparsity of data and to reduce computational costs, we focused on only the 50,000 most frequent bigrams that appeared in this data set. We replicated this step with 10,000 and 100,000 bigrams and found the results to be consistent. We built a time-series vector for each bigram to characterize its popularity over time. This time series was built by counting the number of times each



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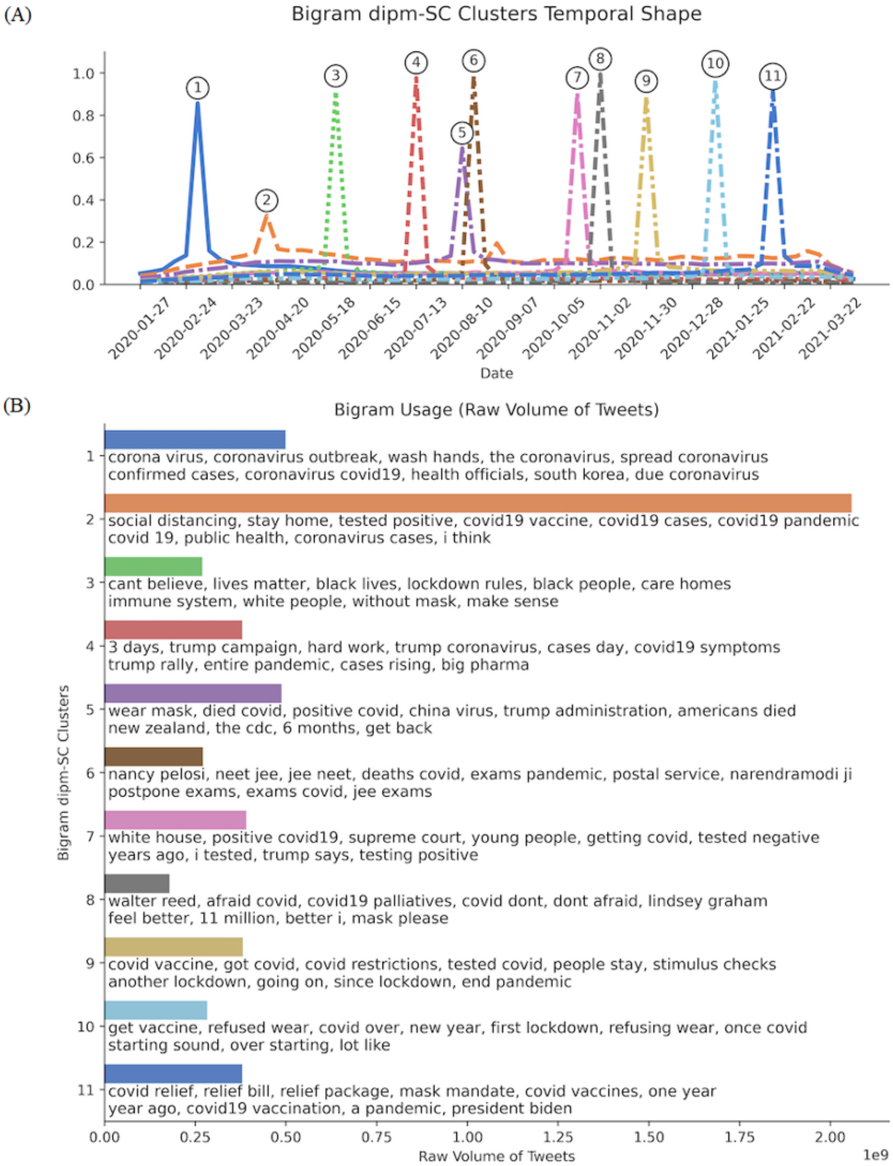
selected bigram was used on a weekly basis and normalizing that count by the total number of bigrams used that week.

### Temporal Clustering

With the normalized bigram usage counts, we used *dipm-SC* [15], a shape-based time-series clustering algorithm that we designed specifically for social media data. The algorithm finds *K* clusters of bigrams that exhibit similar temporal behaviors, within a certain prespecified time window *W*. We set the window to *W*=21 days to detect topics that had been trending for at the most 3 weeks, automatically filtering out general trending topics that had a tendency to continuously dominate the discussion over time (eg, bigrams like "covid 19" or "corona virus"). The results were consistent with similar assignments of *W*. We also explored various settings of *K*, the number of clusters, ranging from 5 to 15. While results were robust with similar assignments of *K*, we found that *K*=11 produced the optimal number of clusters in terms of the coherency of extracted topics and the amount of temporal overlap observed in the detected temporal shapes (eg, Figure 2A) via manual inspection.

**Figure 2.** (A) Detected shapes of identified clusters, ordered by when each cluster peaked in popularity. Each line indicates the respective cluster's popularity over time. (B) The top 10 most used bigrams associated with each cluster and bar chart showing their total usage in terms of raw volume of tweets. The 11 clusters were (1) general coronavirus concerns, (2) public health measures, (3) Black Lives Matter, (4) Trump rallies, (5) 6 months after the first COVID-19 case, (6) Indian national exams, (7) the second COVID-19 wave, (8) Trump tests positive, (9) vaccine development, (10) vaccine rollout, and (11) COVID relief bill.




### Topic Clustering

Latent Dirichlet allocation (LDA) [16] is a popular topic modeling approach, which finds *N* latent topics in a group of documents (in our case tweets). The number of clusters (or topics) that yields the largest *coherence value* is determined to be the optimal *N* value [16]. We again tokenized, lowercased, and removed all stop words and select punctuations from the tweets, and used LDA to cluster tweets by general topic. We found that *N*=4 yielded the largest coherence value.

### *Misinformation Subset*

From our broader COVID-19 data set, we wanted to understand the kinds of narratives and discourse that promoted questionable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content and misinformation. We created a subset of our data set for published tweets that contain a URL belonging to a domain that has been determined to be prone to publish questionable or conspiracy-pseudoscience–related content according to the third-party service Media Bias/Fact Check (MBFC) [17]. We used this as a proxy to identify users who have engaged with misinformation. This resulted in a COVID-19 misinformation data subset totaling 12,689,165 tweets.

### Identifying Conspiratorial, Questionable, and Random Sources

To identify conspiratorial and questionable tweets, we used the following 2 lists compiled by MBFC: *conspiracy-pseudoscience sources* and *questionable sources*. MBFC is "an independent website that rates the bias, factual accuracy, and credibility of media sources" [17]. MBFC classifies domains as *conspiracy-pseudoscience* if the domain "*may* publish unverifiable information that is *not always* supported by evidence. These sources may be untrustworthy for credible or verifiable information" [17]. For the sake of brevity, we also refer to these conspiracy-pseudoscience domains as simply *conspiracy* or *conspiratorial* domains. MBFC states that questionable sources are domains that "exhibit one or more of the following: extreme bias, consistent promotion of propaganda/conspiracies, poor or no sourcing to credible information, a complete lack of transparency and/or is fake news. Fake news is the deliberate attempt to publish hoaxes and/or disinformation for the purpose of profit or influence" [17].

We also obtained a set of randomly selected sources by taking a random sample from the set of media sources that appeared in the full data set. We called this set of sources "*random* sources." The set of *random* sources has the same number of elements (URLs) as *conspiratorial* and *questionable* sources. The *random* sources served as a baseline for comparison with *conspiratorial* and *questionable* sources.

### Identifying a Source's Political Bias

MBFC also classifies media domains by their political affiliations, with the following 5 political affiliation categories: left bias, left-center bias, least biased, right-center bias, and right bias. We used their lists of domains to identify tweets with a particular political affiliation. Left and right bias sources are "moderately to strongly biased," may be untrustworthy, and can "publish misleading reports and omit reporting of information that may damage [their] cause" [17]. Left-center and right-center bias sources have "slight to moderate" bias and are "generally trustworthy for information but may require further investigation" [17]. MBFC goes on to describe sources tagged as least biased as sources with "minimal bias," "factual and usually sourced," and "the most credible media sources" [17].

### Classifying a User's Misinformation and Political Engagement

For every user in our misinformation subset, we tabulated the number of times they shared domains and identified the political bias of these domains. This gave us a proxy of each user's political lean. The political lean was determined by the political lean of the majority of a user's shared domains. In the case of a tie between 2 political biases, we randomly assigned the user a political bias. Any user who shared one or more questionable or conspiracy-pseudoscience domains (as identified by MBFC) within our data set was considered to have engaged with misinformation. This does not mean that a user in our misinformation subset exclusively or mostly shared misinformation content. We restricted our analysis to only users who had shared more than five URLs.

### User Retweet Network Misinformation Analysis

Taking advantage of the retweeting dynamics of Twitter, we constructed a network to conduct social network analysis on the users in our misinformation subset. Nodes represent users and links (or ties) represent retweets between users. If user A (retweeting) retweets user B (retweeted), then the strength of their tie increases with the frequency of retweets. To visualize this network, we adopted a force-based algorithm, Force Atlas [18], which plots nodes that share strong links close together. For the sake of clarity, the ties are not explicitly shown. There were a total of 4,164,572 users and 22,894,165 unique ties between users in our misinformation subset. We labeled the most prominent users, sorted by their highest out-degree.

This retweet network is constructed from the tweets of users who had retweeted at least one tweet that contained a domain that MBFC had classified as a questionable or conspiracy-pseudoscience domain. This means that each link between a retweeted and retweeting user does not necessarily mean that the retweet contained a misinformation domain or that the retweeted user engaged with a misinformation domain. Thus, the entire retweet network (contained within our dataset) included users who had interacted with a misinformation domain at least once.

### Linear Regression Model Over Time

We analyzed the content coming from the following 3 groups of sources, each containing 250 URL domains: *conspiracy* sources, *questionable* sources, and *random* sources. *Conspiracy* and *questionable* sources were domains classified as such by MBFC, whereas *random* sources were chosen from a set of URLs selected at random to serve as a baseline for comparison.

To calculate the temporal trends in the amount of news coming from unreliable sources, we performed 2 multiple linear regression analyses using standard ordinary least-squares models. The first model estimated the association between the number of *conspiratorial* URLs and time, adjusting for an average number of URLs observed on a platform. The model can be represented as follows: $V_C \sim t\beta_1 + V_R\,\beta_2$, where $V_C$ is the number of *conspiratorial* URLs shared, $t$ is time measured in days, and $V_R$ is the number of *random* URLs shared on Twitter. The second model estimated the association between the number of *questionable* URLs and time, adjusting for an average number of URLs on a platform. Similarly, it can be represented as follows: $V_Q \sim t\beta_1 + V_R\,\beta_2$, where $V_Q$ is the number of *questionable* URLs shared.



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### Domain Sharing Network Analysis

To better understand the relative impact of unreliable sources, we looked at their respective audiences and the communities that formed around sharing these unreliable sources. It is important to quantify the community structure and relationships between the consumers of certain kinds of information, as the strength of these communities can be indicative of the potential of an idea within the community to grow and become dominant over time. According to organizational theory, interpersonal networks that exhibit densely configured ties have a greater likelihood of attaining their goals and retaining the network structure (committed to staying together). Networks of strong ties are also significantly more robust with respect to the connectivity and small world property of social networks [19,20].

To quantify the relative strength of a connection between information sources that spread unreliable information about COVID-19, we constructed 3 networks of the following group of domains as defined earlier: *conspiracy*, *questionable*, and *random* sources. The nodes in the network represent the domains, and a link was drawn between 2 domains if a user shared content from both domains. The weight of a link was set to the number of users who shared both domains. To quantify the density of connections in these networks, we calculated the average clustering coefficient [21] and the average link weight for each respective audience network.

## Results

### Clusters of Major Discussion Topics About COVID-19 on Twitter

We used a clustering strategy based on *dipm-SC* [15], described in the Methods section, to identify topics that exhibit similar temporal behaviors and group them into distinct clusters. The detected clusters are visualized in Figure 2. We found that all clusters exhibited distinct peaks, suggesting minimal overlap between distinct clusters and hence robust and reliable clustering results. We now briefly describe the key topics that were detected in the 11 clusters we identified.

#### General Coronavirus Concerns

This concerns general coronavirus-related tweets, including reminders to "wash hands," which was the first and most repeated advice to safeguard against the virus. It peaked in popularity early in the outbreak, in January and February 2020. It gradually declined in popularity until June 2020, from which point on it sustained its popularity consistently by accounting for around 10% of all tweets. This topic's popularity trajectory tracks well with the initial phase of the COVID-19 outbreak unfolding worldwide.

#### Public Health Measures

Messages promoting public health measures, such as "social distancing" and to "stay home," have been popular during COVID-19. This kind of messaging peaked in popularity during March and April 2020, after the lockdowns were imposed, and commanded attention throughout the rest of the study period. While this cluster had the shortest peak in terms of temporal shapes, we noticed that it was overwhelmingly the single most popular topic of all time points (Figure 2B). This contrast is due to the fact that this trending topic is relatively steady overtime rather than bursty during a short timeframe, like the other clusters. The high level of total activity indicates the high level of attention that the Twitter audience paid to public safety measures.

#### Black Lives Matter

The killings of George Floyd, Breonna Taylor, and others sparked national outrage [22]. This topic was brought up along with COVID-19 in late May through early June due to concerns that public protests would increase case counts. The protests were later found to have had no significant impact on the number of COVID-19 cases [23].

#### Trump Rallies

In June, former President Trump resumed his in-person rallies for his 2020 presidential re-election campaign. Rallies had been halted due to widespread coronavirus concerns over in-person gatherings [24].

#### Six Months After the First COVID-19 Case

Six months after the first COVID-19 case was reported, people were still battling the pandemic and isolating at home, unable to resume normal activities. The topic also includes the Trump administration's use of the anti-Asian term "China virus."

#### Indian National Exams

This temporal cluster of bigrams is primarily concerned with India's NEET and JEE national exams, which had been postponed twice due to COVID-19. This became controversial when the exams were scheduled for September 2020 during a time when cases in India were steadily rising [25]. This topic anticipates, by several months, the outbreaks associated with the Delta variant in India that began in December 2020 [26].

#### The Second COVID-19 Wave

The United States braced itself for another wave of COVID-19 cases in September 2020 [27], with major concerns for the younger population.

#### Trump Tests Positive

On October 2, 2020, the White House announced that former President Trump tested positive for the coronavirus; soon after, Trump was transported to Walter Reed Medical Center [28].

#### Vaccine Development

By November 2020, both Pfizer and Moderna published promising results regarding their vaccines [29]. Shortly thereafter, both vaccines were approved for emergency use by the United States Food and Drug Administration (FDA) [30].

#### Vaccine Rollout

In the final weeks of 2020, vaccine administration began rolling out in the United States and in many other parts of the world [29,30].


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### *COVID Relief Bill*

After more than a year since the first case of COVID-19 was reported, many parts of the world continued to operate under mask and social distancing mandates. The vaccine rollout promised to facilitate a long-anticipated return to normalcy. The 2021 COVID-19 stimulus package, or American Rescue Plan Act, was eventually passed and was signed into law in March, which amounts to US $1.9 trillion [31].

## COVID-19 Misinformation Narratives

We then turned to investigating misinformation and questionable narratives that spread in the context of COVID-19. We used our misinformation data subset, which contains tweets with URLs whose domains were deemed to be from a conspiracy-pseudoscience or questionable source according to MBFC, and leveraged both *dipm-SC* [15] and LDA [16] to cluster tweets by general topic. From the topics found in both clustering methods, we identified the following 3 major misinformation narratives that encapsulate the tweets that spread questionable media content on Twitter: (1) hydroxychloroquine and alternative medicines, (2) US officials and governing agencies, and (3) COVID-19 prevention interventions.

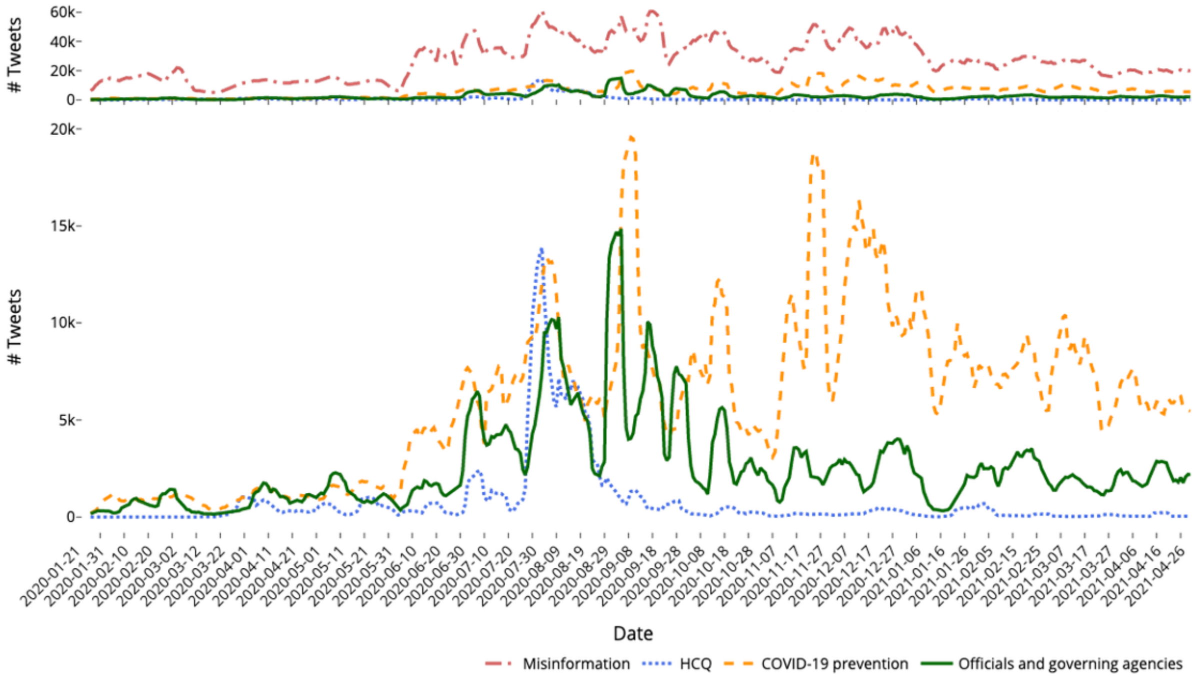
For each narrative of interest, we filtered our misinformation data set based on several defining keywords (Table 3). We identified the keywords in Table 3 by first isolating the most used keywords and bigrams in each narrative's cluster, and then manually selecting neutral keywords most reflective of the 3 narratives. This enabled us to isolate subsets of tweets that specifically mentioned keywords related to each misinformation narrative. We then plotted the volume of tweets from each narrative over time (Figure 3) to understand temporal trends in each narrative. We found that a constant flow of misinformation exists, despite Twitter's efforts to mitigate its spread. However, when we isolated tweets by narratives, we saw that each narrative experiences differing levels of engagement over time. Most of these spikes are driven by active retweeting of viral posts and/or articles that are sometimes related to real-time events. For each narrative, we also found the top hashtags that were used and grouped them into their relevant categories. We did a manual inspection of the tweets during these peaks and describe a few of the prominent topics that drove the volume surges in each narrative as seen in Figure 3.

**Table 3.** Tweets isolated from our misinformation data set that are related to each topic by filtering specific topic-related keywords (N=12,689,165).

| Topic[a] | Keywords | Total number of tweets |
| --- | --- | --- |
| Hydroxychloroquine and alternative medicines | hcq, hydroxychloroquine | 368,883 |
| US officials and governing agencies | fauci, brix, cdc | 1,205,824 |
| COVID-19 prevention | mask, vaccine, social distanc*, test | 2,804,985 |

[a]Note that a tweet can fall under multiple topics and count toward the narrative's total number of tweets.

**Figure 3.** Visualization of the 7-day moving average of the volume of tweets that have tweeted a URL from a domain that has been identified as having spread conspiracy-pseudoscience or questionable content according to Media Bias/Fact Check. We identify 3 major narratives and plot the volume of tweets over time that mention keywords related to each of the narratives (hydroxychloroquine [HCQ], US officials and governing agencies, and COVID-19 prevention) in the bottom figure. The top figure plots the same narratives but also includes the total volume of tweets that shared a conspiracy-pseudoscience or questionable domain (which we generalize as misinformation).



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### *Hydroxychloroquine*

Hydroxychloroquine was, at the beginning of the pandemic, considered to be a potential treatment for COVID-19. However, while the US FDA had issued an emergency use authorization for the drug and the World Health Organization (WHO) had considered hydroxychloroquine in clinical trials, the drug had not been proven to be effective against the novel coronavirus [32,33]. As it became clear that hydroxychloroquine was not an effective treatment, the US FDA withdrew the emergency use authorization in June 2020 [32,33] and the WHO removed it from its trials in July 2020 [34]. Despite the evidence of inefficacy brought by clinical testing, hydroxychloroquine remained a fixture to many as an alleged cure for the coronavirus, and henceforth, it is considered medical misinformation. The top hashtags used in this narrative can be found in Textbox 1.

**Textbox 1.** The top 20 hashtags from the misinformation data set related to hydroxychloroquine and alternative medicines (classified into 5 general topics).

**Hydroxychloroquine-related**

hydroxychloroquine, hcq, hcqworks, hydroxychloroquineworks, and earlytreatmentworks

**General coronavirus**

covid19, coronavirus, and covid

**Fauci**

arrestfauci, fauci, firefauci, politicalcoup, and liberalfascism

**Politics**

kag, tds, twgrp, and faucifraud

**Misinformation**

ccpvirus, chinavirus, and scamdemic

#### Period From July 30, 2020, to August 14, 2020

Upon a manual inspection of the most prevalent content, we found that many users on Twitter were still circulating early and preliminary studies that suggested that hydroxychloroquine might be a candidate for treating COVID-19. Many of these users also blamed Dr Anthony Fauci and other medical authorities for ignoring the alleged "evidence" that hydroxychloroquine was effective. These users also cited the Ohio Department of Health's prohibition on the use of hydroxychloroquine that was announced but rescinded before its July 30, 2021, effective date [35,36]. Finally, Twitter and other social media platforms began removing viral videos that featured Dr Stella Immanuel promoting unproven and unsubstantiated claims that hydroxychloroquine was an effective treatment for COVID-19 [37]. This resulted in users who engaged in hydroxychloroquine misinformation during this time claiming that Twitter was attempting to violate their freedom of speech.

### *US Officials and Governing Agencies*

Perhaps unsurprisingly, US officials and governing authorities were also a target for misinformation on online platforms such as Twitter. Given that our data set was curated with English keywords, there was a higher concentration of discourse surrounding events occurring in primarily English-speaking countries. In our prior work, we also found that a large percentage of Twitter users were located in the United States [38]. Thus, the major misinformation narratives surrounding authorities centered around US officials and authority figures. The top hashtags used in this narrative can be found in Textbox 2.

**Textbox 2.** The top 20 hashtags from the misinformation data set related to US officials and governing agencies (classified into 4 general topics).

**General coronavirus**

coronavirus, covid19, cdc, covid, vaccine, and vaccines

**Fauci**

fauci, firefauci, faucithefraud, arrestfauci, and anthonyfauci

**Misinformation**

qanon2018, qanon2020, thedefender, ccpvirus, and chinesecoronavirus

**Miscellaneous**

trump, china, un, and who

#### Period From July 4, 2020, to July 8, 2020

Users cited a report that the Centers for Disease Control and Prevention (CDC) was overcounting COVID-19 cases and used this to claim that the CDC was purposefully trying to force Americans to remain under lockdowns throughout the summer [39,40].


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### Period From August 4, 2020, to August 10, 2020

Reports from the far-right news outlet The Gateway Pundit surfaced claims from Robert F Kennedy Jr, an antivaxxer who was banned from Instagram in February 2021 for spreading misinformation [41]. He claimed that Dr Anthony Fauci would be heavily profiting off the success of vaccines, falsely stating that Fauci was a partial owner of a COVID-19 vaccine patent [42]. There was also another report from The Gateway Pundit that disparaged US government medical authorities for downplaying the benefits of hydroxychloroquine and ignoring lower mortality rates in countries that used hydroxychloroquine as a treatment [43].

### Period From August 30, 2020, to September 4, 2020

The Gateway Pundit published a report claiming that only 9210 Americans had died specifically from COVID-19, while all other deaths were related to other illnesses [44]. They then used this as grounds to push the narrative that the CDC was overreacting to and exaggerating the effects and impact of COVID-19.

### Period From September 15, 2020, to September 19, 2020

Former President Donald Trump issued an order for agencies to stop racial sensitivity training [45]. The Gateway Pundit published an article claiming that the CDC was disregarding Trump's orders [46].

### Period From September 26, 2020, to October 2, 2020

The CDC posted and then retracted a post on the airborne transmission of COVID-19 [47,48]. In reaction to the retraction, users accused the CDC of lying and intentionally misleading the public.

### Period From October 13, 2020, to October 19, 2020

The CDC released a report that surveyed a small group of individuals who had contracted COVID-19. One of the questions posed to the participants was regarding their mask usage, and over 70% of the COVID-19 patients reported using a mask [49]. Users on Twitter used this information to bolster their belief that masks are not effective. This claim has been fact checked and debunked, showing that these users disregarded the context and other findings that these numbers were presented with [50,51].

## *COVID-19 Prevention*

The last major narrative we identified in our misinformation data set focuses on COVID-19 prevention mechanisms. This includes testing, vaccines, masking, and social distancing. Many of the suggested and proven COVID-19 prevention strategies have been and continue to be at the center of much controversy, and as a result, are subject to much misinformation. The top hashtags used in this narrative can be found in Textbox 3.

**Textbox 3.** The top 20 hashtags from the misinformation data set related to COVID-19 prevention (classified into 4 general topics).

**General coronavirus**

covid19, covid, cdc, coronavirus, covid—19, covid 19, and fda

**Prevention mechanisms**

pfizer, moderna, vaccine, vaccines, masks, lockdown, and covidvaccine

**Misinformation**

ccpvirus, billgates, and thedefender

**Miscellaneous**

unmaskamerica, hankaaron, and science

### Period From August 2, 2020, to August 9, 2020

The Gateway Pundit interviewed Robert F Kennedy Jr, who claimed that Dr Fauci would "make millions" from vaccine developments. This is the same story that drove a peak of activity surrounding US officials and authorities (see the time frame August 4, 2020, to August 10, 2020, in the US Officials and Governing Agencies section). During this time, Ohio governor Michael DeWine tested positive with an antigen test (also referred to as a rapid test) when being screened for a White House event with former President Trump. DeWine later tested negative after taking the more accurate polymerase chain reaction test [52,53]. This discrepancy in test results, despite the known difference in accuracy, caused users on Twitter to question the necessity and effectiveness of testing.

### Period From September 4, 2020, to September 13, 2020

The Bill and Melinda Gates Foundation has invested heavily into developing vaccines for diseases such as Polio [54]. *Zerohedge*, a far-right news blog, published a post about the United Nations reporting a new vaccine-related polio outbreak in areas of Africa, specifically identifying the vaccine as a "Gates-Funded" vaccine [55,56]. This caused conspiracy theorists who were circulating this misinformation to blame Bill Gates for supposedly "funding" polio and for benefiting from it [57,58]. The same *Zerohedge* article then used this as evidence to try to bring the efficacy and safety of COVID-19 vaccines into doubt [55].

### Period From October 10, 2020, to October 20, 2020

Former President Trump tested positive for the novel coronavirus on October 2, 2020, and tested negative on October 12, 2020 [28,59]. The Gateway Pundit released an article attacking the efficacy and need for masks to prevent COVID-19, dismissing the CDC recommendation to wear masks [60]. The article questions the credibility of the CDC due to its initial recommendation to not wear masks and its subsequent recommendation for all to engage in mask wearing [60]. The initial policy was partially rooted in wanting to preserve the


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then-scarce personal protective equipment for hospital workers and those on the front line [61].

**Period From November 13, 2020, to November 29, 2020**

A post by a former Pfizer employee, Michael Yeadon, claimed that the pandemic was over in the United Kingdom and that a vaccine was not needed for COVID-19 to be overcome [62]. While this claim was debunked and marked false by news and social media platforms [63], users online capitalized on Yeadon's past association with Pfizer, one of the producers of the COVID-19 vaccine. They cited this as validation of their belief that the pandemic was a "scam" and that vaccines are not necessary. During this time, it was also revealed that Maryland governor Larry Hogan had spent over US $9 million on COVID-19 tests that were discovered to be flawed. This caused Hogan to purchase replacements for US $2.5 million using state funds, while not disclosing these flaws [64]. *Breitbart*, a far-right news platform, criticized Hogan on this, labeling Hogan as a Republican "anti-Trump hero" for the purchase of these tests [65], which had drawn former President Trump's ire [66].

**Period From December 8, 2020, to December 17, 2020**

Sources, such as *NationalFile* and *DailyMail*, both of which MBFC has rated as having low credibility, claimed that the Chinese Communist Party had "infiltrated" both Pfizer and AstraZeneca and that these pharmaceutical companies had provided employment to these individuals [67]. This information was then used to discredit and cast doubt upon the vaccines that both companies were producing. A claim also stated that the pharmaceutical company GlaxoSmithKline owned both the Wuhan Institute of Virology and pharmaceutical company Pfizer. These debunked claims [68,69] were an attempt to tie the Pfizer COVID-19 vaccine development to Wuhan, where the first cases of COVID-19 were reported. Finally, there was a false claim that 87,000 nurses from the Netherlands declined the COVID-19 vaccines [70,71]. This alleged "refusal" was used to promote the narrative that many medical professionals were against vaccination and as a reason for the public to also follow suit.

## Characterizing Misinformation Adoption

After identifying and describing the misinformation narratives permeating online discourse, we looked to understand the audience that is more susceptible to misinformation and the trends within the kind of misinformation that is being consumed. In the following text, we used network science as a lens to understand the structure and characteristics of misinformation echo chambers on Twitter, and suggest this as a possible mechanism to explain the spread of misinformation in specific communities.

### *Existence of Political Echo Chambers*

Figure 4 shows the retweet social network structure of Twitter users who engaged with at least one post containing a misinformation domain, as classified by MBFC, over the course of more than a year, which has been laid out using Force Atlas [18]. Some users, such as former President Donald Trump (*realDonaldTrump*) and President Joe Biden (*JoeBiden*), have rings of users around them, and these rings contain users that retweet almost exclusively from these prominent accounts. As a feature of the visualization, prominent users are also accompanied with "negative space" around them, which is a direct result of using the Force Atlas layout, where prominent users attract many small accounts who also repel each other.

**Figure 4.** (A) The political leanings of the users within our misinformation subset. Political leanings are determined by the political affiliation (as determined by Media Bias/Fact Check) of the domains a user tweets the most. (B) The 100-core decomposition of the graph into the top 1403 accounts.

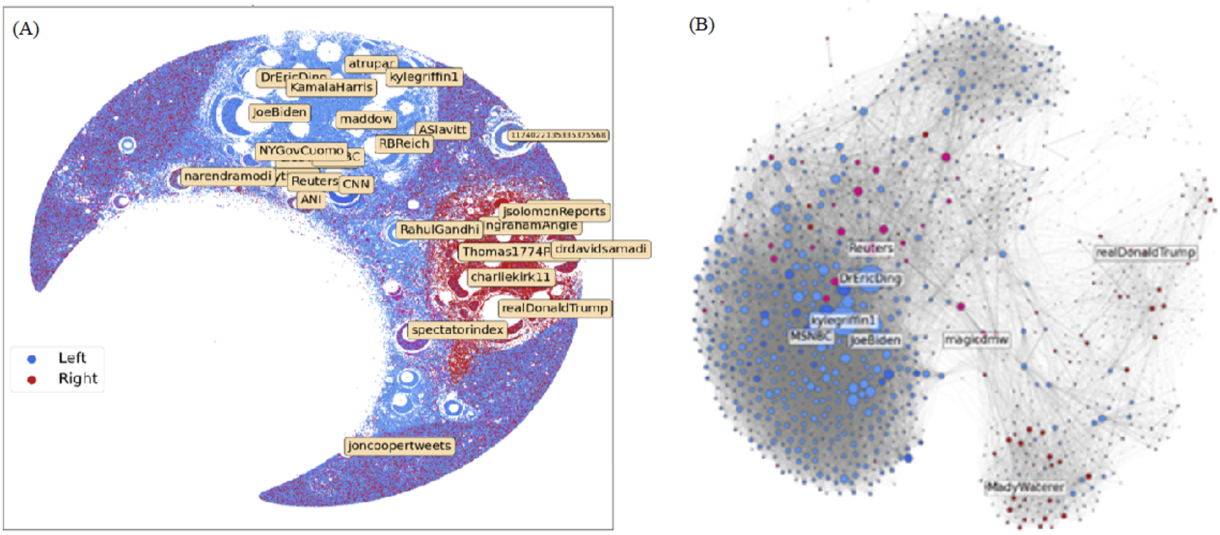


Figure 4 is helpful for revealing the overall structural properties of the Twittersphere and their interplay with the political orientation of users. By labeling the political diet of users based on the MBFC-classified political affiliation of the domains they share, we observed strong polarization across right- and left-leaning users. Right-leaning users (Figure 4, nodes in red) clustered around former President Donald Trump, David Samadi (physician and contributor to conservative news source Newsmax), Charlie Kirk (conservative activist), and other prominent right-leaning figures. Left-leaning users (Figure 4, nodes in blue) clustered around prominent liberal leaders, such as President Joe Biden and Vice President Kamala Harris, in


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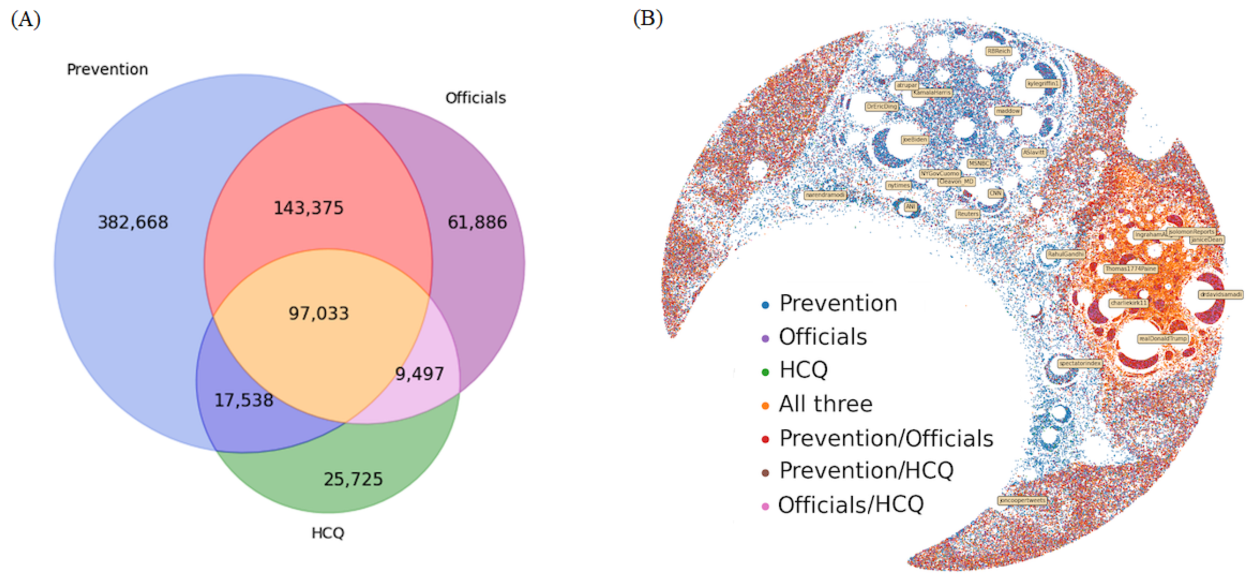
addition to certain journalists and physicians. Interestingly, international media outlets, such as BNO news, SkyNews, and Spectator Index, attracted a mix of both left- and right-leaning users, suggesting that they are more impartial than US-based media outlets.

Figure 4B further breaks down the visualization through a 100-core decomposition. Here, we additionally pruned out bots by removing those who tweet frequently but are never retweeted. This showed a similar partition of the network into communities, with left-leaning users on the left and right-leaning users on the right. Among elite users, as generated by the K-core decomposition, we can see how many more left-leaning users are engaging with COVID-19 messaging.

### *Discussions of the Misinformation Narratives are Politically Fractured*

Given the political orientation of users and the central users for which they coalesce around, we considered how the 3 narratives from Table 3 emerge. Figure 5A shows the overlap of these topics, aggregated over all users. We observed that users engaged primarily with COVID-19 prevention discourse, followed by discussion of US officials and governing authorities, and then hydroxychloroquine and alternative medicines. Additionally, 97,033 users discussed all 3 (Figure 5A), making up 13% of the 737,722 users tagged for engaging in these 3 topics.

**Figure 5.** Frequency of tagged users and their overlap. (A) Their numeric overlap. (B) Their overlap on the social network visualization from Figure 4A. HCQ: hydroxychloroquine.




What is more interesting is how these topics map on the Twitter social network, as illustrated in Figure 5B. We observed COVID-19 prevention discourse throughout the graph. However, within the left-leaning cluster from Figure 4, we observed an absence of discourse about US officials and hydroxychloroquine. Users near the conservative core in Figure 4 are active in nature, and their position in the network is indicative of their higher retweeting frequency. Two types of users emerged from the right-leaning cluster. One type included users who discuss both prevention and US officials (Figure 5, red portion). They appeared concentrated around specific prominent users, such as Donald Trump and Dr Samadi (these users are labeled in Figure 4). The other type included users who engaged in discourse about all 3 narratives (Figure 5, orange portion) in tandem. These users tended to retweet a diverse number of prominent users. This not only indicates that hydroxychloroquine-related discourse is largely concentrated around right-leaning users and absent among left-leaning users, but also suggests that there exists a fracture within the right-leaning base, with some users following political content exclusively and others engaging more generally with COVID-19 discourse. Additionally, we can conclude that hydroxychloroquine is contingent on the presence of 1 of the 2 other topics (US officials and COVID-19 prevention).

## Social Media Consumption of Unreliable Sources

### *The Rise of COVID-19 Information Coming From Unreliable Sources*

The prevalence of information shared from unreliable sources is known to be high on Twitter and can reach up to 40% depending on the classification criteria [72]. In our analysis, we did not focus solely on quantifying the amount of obviously false claims, but rather focused on the prevalence of information coming from domains known to share news with questionable factualness. To obtain a more complete picture of the spread of unreliable information related to COVID-19, we performed a longitudinal analysis by quantifying the temporal trends in the volume of information shared from *conspiracy*, *questionable*, and *random* sources (see the Methods section). Figure 6 illustrates the volume of content shared from *conspiracy*, *questionable*, and *random* sources over time, plotted using a 7-week moving average. By observing the absolute trends, we can conclude that the volume of content coming from unreliable sources is growing faster than the random baseline. We modeled the change in the amount of content over time and observed a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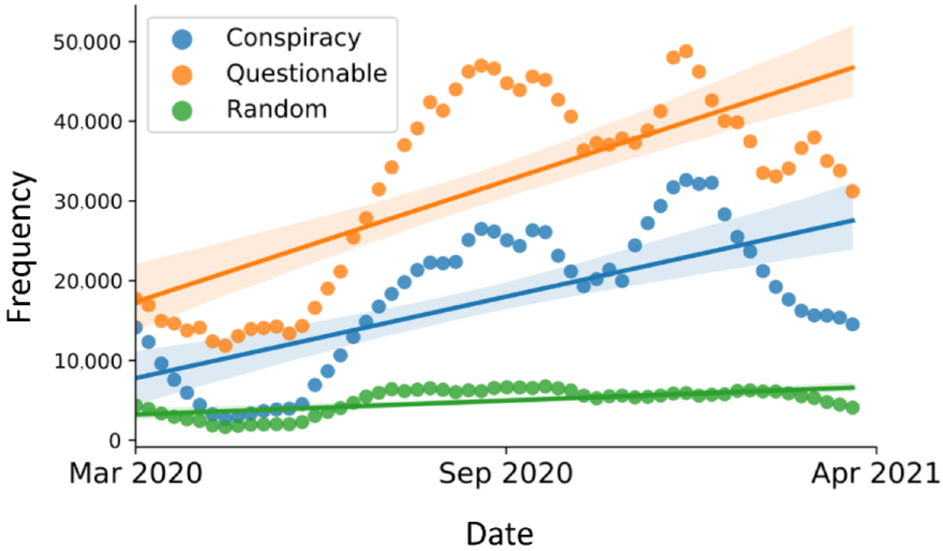
statistically significant increase in the volume of content from both groups of tracked sources, with $\beta_C$=4.4740 and $\beta_Q$=5.6964 representing the linear coefficients for *conspiracy* and *questionable* sources, respectively, and with *P*<.001 for both categories of sources.

**Figure 6.** Volume of unreliable information on Twitter over time. Total number of times the news from various groups of sources were shared. The points represent the values aggregated weekly, plotted as a 7-week moving average. The lines reflect the linear trends, and the shaded areas are the 95% CIs.




We observed a large and significant increase in the amount of content from *conspiracy* and *questionable* sources. Every day, on average, we observed an increase in the amount of *conspiratorial* URLs of 4.47 and *questionable* URLs of 5.69, when corrected for the average increase of *random* content on the platform. This trend should not be overlooked, as it shows that unreliable information is on the rise despite the known efforts by Twitter to curb the spread of misinformation.

### *Audiences and Communities Sharing Unreliable Information*

We considered the audiences and communities formed by users sharing from unreliable resources. We used the 3 domain sharing networks constructed for each group of domains: *conspiracy*, *questionable*, and *random* domain sources. The link between 2 domains was equal to the number of users who shared content from both domains. Each network comprised 250 nodes (domains). In Figure 7, only a sample of each network with 30 nodes is illustrated. From visual inspection, the networks of unreliable URLs clearly appeared to be more densely connected, suggesting greater levels of information sharing between the users and a tighter community structure.

The average clustering coefficients [21] of the *questionable* sources network and *conspiracy* sources network were 66.2 times and 27.4 times higher, respectively, than the average clustering coefficient of the *random* sources network (see Table 4 for network density measures). This is a strong indication that the connections between the URLs belonging to both groups of unreliable sources are more tightly grouped than the average set of URLs. Similarly, the average link weights of both unreliable sources' networks are orders of magnitude higher than the average link weight of the random source's network. The average link weights, which quantify the average number of users sharing the information from the same pair of domains, indicate that the audience sharing content from unreliable sources clusters more tightly together than the audience sharing random sources on Twitter.



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**Figure 7.** The network of audiences sharing information from various types of sources: (A) conspiracy sources, red; (B) questionable sources, green; and (C) random sources, blue. The nodes are domains that serve as the source of information. A link is drawn between the nodes if the corresponding domains have been shared by the same account. The weight of the link quantifies the number of users sharing the information from 2 domains. Each network consists of 30 nodes, randomly selected from the corresponding group of sources.


**Table 4.** Some measures quantifying the connectivity of the URL networks.

| Variable | Questionable sources | Conspiracy sources | Random sources |
|---|---|---|---|
| Average clustering coefficient | 0.0004 | 0.00016 | 0.000006 |
| Relative[a] average clustering coefficient | 66.21 | 27.43 | 1 |
| Average link weight | 4.69 | 1.36 | 0.01 |
| Relative[a] average link weight | 346.69 | 103.15 | 1 |

[a]Relative to the network of random sources.

## Discussion

### Understanding COVID-19 Narratives on Twitter

In this paper, we provide a comprehensive overview of public COVID-19 discourse on Twitter by analyzing 1.4 billion COVID-19–related tweets that spanned the course of over a year. We make several important contributions in this work.

First, using temporal clustering of bigrams, we report 11 major topics of discussion. Aside from 1 topic with general COVID-related phrases that had sustained interest throughout our study period, the rest of the 10 topics were bursty and closely aligned with the progression of current events. We observed 2 types of topics. The first type included political topics that arise due to congregation, such as the protests that occurred in the wake of George Floyd's death, Trump's rallies, and India's national exams. The second type encompassed news events that generated significant online traction, such as Trump testing positive, vaccine updates, and the relief bill. This demonstrates that observing Twitter usage is a valid way to monitor public sentiment and important events as they unfold in the real world.

We then identified misinformation narratives by analyzing latent topics detected from tweets that shared domains that have been identified as unreliable media sources. We found that the following 3 prominent misinformation narratives emerged: hydroxychloroquine and alternative medicines, US officials and governing agencies, and COVID-19 prevention practices. Each of these narratives experienced surges in mentions and engagement, the majority of which occurred in tandem with and in response to real-world events occurring at the same time.

We also characterized misinformation adoption by analyzing the retweet social network structures of users who had retweeted at least one tweet that contained a domain classified as unreliable by MBFC. We found that there exists an alignment between the misinformation topic a user tends to engage in and that user's political party. A large portion of the left-leaning userbase engaged specifically in COVID-19 prevention misinformation. The right-leaning userbase discussed COVID-19 prevention in the context of alternative medicines (such as hydroxychloroquine), and US officials and governing authorities. Interestingly, we observed a fracture in the right-leaning user base. Some users primarily discussed only 2 of the identified narratives (COVID-19 prevention and US officials), while others engaged with tweets surrounding all 3 narratives.

Lastly, and of great concern, we found that engagement with unreliable sources is increasing at a faster rate compared to engagement with our baseline of random sources. Our results show that, in the space of public health messaging on social media platforms, there is still significant work that needs to be done in order to combat misinformation. Although social media platforms are making efforts to stem the flow of misinformation and raise awareness of its presence, the dangers of misinformation, particularly surrounding public health, are increasingly apparent. In our network, there are dense and highly connected communities that form around unreliable sources (so-called misinformation bubbles [73]), which can serve to further promulgate health misinformation online.



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## Implications

Our study highlights how social media platforms can help us to shed light on the issue and consequences of misinfodemics, particularly during an unforeseen global health crisis. Social media platforms, such as Twitter, currently employ various tactics to counter misinformation, including the use of automated misinformation tags to raise awareness and partnerships with third-party fact checkers. Our research suggests that, while efforts are being made to mitigate misinformation, misinformation continues to be a mainstay on Twitter and is still growing in prevalence in the narratives we detected on online social platforms. We can also continue to understand the kinds of communities that form around sharing unreliable sources. In particular, we found that misinformation echo chambers exist within the COVID-19 misinfodemic landscape, and that the major echo chambers align with users' political affiliations (as determined by the political lean of the sources they engage with). This has significant implications for how we can use unreliable domain usage to not only identify more communities that are susceptible to misinformation, but also funnel resources and develop strategies to combat misinformation flow in these communities.

## Limitations

While our study leverages a large tweet data set, there are still several limitations that need to be considered when interpreting the results of our study. First, when collecting data through Twitter's free API, we were only able to collect 1% of all tweets in real time. Even with this limitation, we were able to collect several million tweets each day. We also only conducted our study on Twitter, which has been found to be used in the United States by a more liberal and left-leaning audience [74].

Due to the ever-evolving nature of misinformation, it is difficult to accurately judge and tag individual stories on Twitter as being misinformation or not. Thus, we used MBFC's list of unreliable domains and the domains a user decides to share as a proxy for misinformation and engagement with a known unreliable source. This, however, does not necessarily mean that every URL shared from these domains has misinformation.

We did not focus on delineating *social bots* from human users in our analysis [75]. The term *social bot* generally refers to an account that is automated through software, and detecting and characterizing bot behavior is an active research area on its own [76]. Bots are incredibly salient to the misinfodemics conversation and have been found playing roles in the perpetuation of misinformation on social networks [75,77-79]. However, this study focused on the content and veracity of narratives shared on Twitter, and we hope to explore automated manipulation in the context of infodemics in future expansions of this work.

## Conclusion

In this paper, we analyzed over 1 billion tweets posted during the COVID-19 pandemic and about the pandemic, spanning the course of over a year. We described the major topics of discussion that occurred over the broader COVID-19 Twitter discourse and identified the primary misinformation narratives that permeated the Twittersphere. We demonstrated that there are distinct misinformation echo chambers that form around specific topics and narratives, and that these echo chambers are also political echo chambers. This suggests that these echo chambers are driven by not only misinformation narratives, but also political alignment. Finally, we brought awareness to the increasing presence and consumption of unreliable content on Twitter, despite the current efforts being made to mitigate misinformation spread.

The COVID-19 pandemic and subsequent lockdowns around the world forced much of our forms of communication online, creating an environment where misinformation could more easily target a wider audience. We hope that our work will provide valuable insights into which communities are more susceptible to misinformation and contribute to laying the groundwork for other researchers in the field of misinfodemics.


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## Conflicts of Interest

None declared.


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## Abbreviations

**API:** application programming interface
**CDC:** Centers for Disease Control and Prevention
**FDA:** Food and Drug Administration
**LDA:** latent Dirichlet allocation
**MBFC:** Media Bias/Fact Check
**WHO:** World Health Organization

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Original Paper

# Misinformation About and Interest in Chlorine Dioxide During the COVID-19 Pandemic in Mexico Identified Using Google Trends Data: Infodemiology Study

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## Abstract

**Background:** The COVID-19 pandemic has prompted the increasing popularity of several emerging therapies or preventives that lack scientific evidence or go against medical directives. One such therapy involves the consumption of chlorine dioxide, which is commonly used in the cleaning industry and is available commercially as a mineral solution. This substance has been promoted as a preventive or treatment agent for several diseases, including SARS-CoV-2 infection. As interest in chlorine dioxide has grown since the start of the pandemic, health agencies, institutions, and organizations worldwide have tried to discourage and restrict the consumption of this substance.

**Objective:** The aim of this study is to analyze search engine trends in Mexico to evaluate changes in public interest in chlorine dioxide since the beginning of the COVID-19 pandemic.

**Methods:** We retrieved public query data for the Spanish equivalent of the term “chlorine dioxide” from the Google Trends platform. The location was set to Mexico, and the time frame was from March 3, 2019, to February 21, 2021. A descriptive analysis was performed. The Kruskal-Wallis and Dunn tests were used to identify significant changes in search volumes for this term between four consecutive time periods, each of 13 weeks, from March 1, 2020, to February 27, 2021.

**Results:** From the start of the pandemic in Mexico (February 2020), an upward trend was observed in the number of searches compared with that in 2019. Maximum volume trends were recorded during the week of July 19-25, 2020. The search volumes declined between September and November 2020, but another peak was registered in December 2020 through February 2021, which reached a maximum value on January 10. Percentage change from the first to the fourth time periods was +312.85, –71.35, and +228.18, respectively. Pairwise comparisons using the Kruskal-Wallis and Dunn tests showed significant differences between the four periods ($P$<.001).



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**Conclusions:** Misinformation is a public health risk because it can lower compliance with the recommended measures and encourage the use of therapies that have not been proven safe. The ingestion of chlorine dioxide presents a danger to the population, and several adverse reactions have been reported. Programs should be implemented to direct those interested in this substance to accurate medical information.

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**KEYWORDS**

coronavirus; COVID-19; Google Trends; chlorine dioxide; COVID-19 misinformation; public health surveillance; infodemiology; internet behavior; digital epidemiology; internet; mHealth; mobile health; pandemic; tele-epidemiology

## Introduction

### COVID-19 and Therapies

In December 2019, a new strain of coronavirus was detected for the first time in the city of Wuhan, China. The causative agent was identified as SARS-CoV-2. This virus spread across 218 countries and caused a global health crisis [1,2]. In March 2020, the disease was declared a pandemic by the World Health Organization [2]. In Mexico, the first case of COVID-19 was detected on February 27, 2020, in Mexico City. On March 30, 2020, with 328 confirmed cases and 12 deaths, a national health emergency was declared, given the exponential increase in confirmed cases and deaths from the disease [3]. According to the Pan American Health Organization on November 21, 2021, a total of 3,867,976 cases and 292,850 deaths from COVID-19 have been confirmed in Mexico, with a cumulative incidence rate of 2999.1 per 100,000 people [4].

Given the lack of specific preventive measures or treatment for COVID-19 during the first global outbreak (February 2020), several alleged therapies and preventive measures have emerged, although most have not been scientifically proven. Because crises such as pandemics usually generate a variety of psychological reactions, it is likely emotions such as fear drive the population to seek alternatives to protect themselves [5]. Misinformation about diseases has been well documented in the literature, usually revolving around causation, transmission, and potential cures of predominantly infectious diseases. This phenomenon has been reported in the past for conditions such as leprosy, tuberculosis, and influenza, among others [6]. Belief in such misinformation can be dangerous because it may reduce the adoption of proven health and hygiene measures, and create a false sense of security. These products may also pose other health risks given the lack of evidence of their safety. Bogus therapies tend to be widely promoted over a short time, and people can be predisposed to following them without questioning their authenticity or whether there is supporting evidence [6]. Some bogus therapies popular during the COVID-19 pandemic include eating garlic, turmeric, and lemon under the assumption that these substances have antimicrobial properties [6].

### Chlorine Dioxide and Misinformation

Chlorine dioxide is a chemical compound commonly used as a bleach and disinfectant in industrial processes and water purification treatment [7,8]. Nevertheless, sellers and distributors have claimed that this substance may serve as treatment for multiple pathologies such as autism, Ebola virus, cancer, hepatitis, diabetes, HIV/AIDS, COVID-19, and even depression [9,10]. The commercialized product containing chlorine dioxide or sodium chlorite for health-related issues is advertised in English as chlorine dioxide solution or miracle mineral solution, while in Spanish, it is known as "Dióxido de cloro" [11,12]. Chlorine dioxide solution was commercialized and used in various countries across Europe and America before the COVID-19 pandemic. These products are promoted as nutritional supplements to bypass the strict approval processes required by law for medicines or health treatments [13,14]. Throughout the pandemic, the demand for chlorine dioxide has increased alarmingly worldwide. Since January 2020, the US Food and Drug Administration (FDA) has received reports of serious adverse events in patients who have consumed this substance [12]. Adverse reactions included respiratory failure, disturbance of the heart's electrical activity, hypotension, acute liver failure, acute kidney injury, hemolytic anemia, vomiting, and severe acute diarrhea [7,15].

Consequently, health agencies, institutions, and organizations worldwide tried to discourage consumption of chlorine dioxide solution by refuting the false claims that painted it as a therapeutic and preventive treatment for COVID-19. In Spain, on May 14, 2010, the Ministry of Health ordered chlorine dioxide solution, which was sold on the internet, to be withdrawn from the market [10]. In the United States, on April 8, 2020, the FDA advised consumers not to buy or ingest any chlorine dioxide–based products because of the lack of scientific evidence of their efficacy or safety [12]. On July 6, 2020, an official statement addressed to health personnel was published on the Mexican government's official website. The document warned medical personnel not to recommend the use of chlorine dioxide. Later, on July 23, 2020, the Mexican regulatory agency "Comisión Federal para la Protección contra Riesgos Sanitarios" (COFEPRIS) released a statement to the Mexican population informing them of the risk of chlorine dioxide solution or miracle mineral solution, emphasizing that its consumption should be stopped immediately, and encouraging the reporting of any adverse reaction related to its use [16]. On August 18, 2020, the Pan American Health Organization published a post on their Facebook page warning about false information about chlorine dioxide solution use [17].

Several reports have been published on the impact of the internet and social media on the population, misinformation about COVID-19, and the quality of information available online. In a study involving a 27-question survey of 1136 students, Chesser et al [18] reported that only 43% had a high literacy level about COVID-19. Most of this sample reported the internet and social



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media as their primary source for COVID-19 information. Cuan-Baltazar et al [19] evaluated the quality and readability of the first 110 English and Spanish website results for the search term “Wuhan coronavirus” appearing in the Google search engine on February 6, 2020. Webpages were evaluated using different instruments for online health information. Most of the sample was considered to be of low quality in terms of the information provided [19]. Roozenbeek et al [20] studied the susceptibility to misinformation about COVID-19. Misinformation was perceived as being the most reliable in Mexico, compared with the United Kingdom, Ireland, the United States, and Spain. When analyzing the predictors of susceptibility to misinformation, being older was associated with a lower risk in all countries, except for Mexico, where it was significantly higher [20]. In another study undertaken in May 2020, the top 75 viewed videos using the word “coronavirus” and “COVID-19” were analyzed, and 27.5% of videos were found to contain nonfactual information that achieved 62,042,609 views in total [21].

### Infodemiology and Google Trends

Infodemiology is the science that studies the distributions and determinants of information shared in electronic media concerning public health [22]. The rapid increase in internet users and information published worldwide enables data collection in almost real time. According to a statement published in May 2020 by the National Institute of Statistics and Geography, 56.4% of Mexican households have internet access, reporting entertainment, obtaining information, and communicating as the main activities performed [23,24].

Google Trends is a platform provided by Google that allows one to assess the search frequency of a specific term during a certain time period. The platform tracks words from search queries that users enter into the Google search engine and presents them according to a specified time period and geographic location. The search volume results are presented as a relative search volume (RSV) index, wherein each data point is divided by the total number of searches performed in a specified geographical region within a given time range to provide relative comparisons [25].

Google Trends has been used as a tool to provide insights into population behavior [26] and has played a role in several distinct types of studies during the COVID-19 pandemic. It has been used to investigate the interest of specific diseases such as Kawasaki disease [27], to evaluate societal interest in pornography during the crisis [28], to find correlations between chest pain search volume and acute coronary syndromes hospital admissions [29], and to compare public awareness on the COVID-19 pandemic across different countries [30], among others. Additionally, Walker et al [31] reported statistically significant correlations between daily searches related to loss of smell and COVID-19 new cases and deaths [31,32]. We found only two articles using infodemiology to study interest in chlorine dioxide in Mexico. Both studies used an international comparative analysis to evaluate differences in search trends for chlorine dioxide solution among countries, in which Mexico stood out as one of the countries with the highest number of searches [33,34].

The primary goal of our study was to investigate changes in interest trends for chlorine dioxide prior to and during the COVID-19 pandemic in Mexico using internet search volume in a popular search engine as a proxy. In the process, we also aimed to determine the impact of official governmental communications deterring from the substance’s consumption on the trend. It is hypothesized that during the pandemic in Mexico, RSVs for chlorine dioxide increased. Additionally, we believe this trend is fueled by social and media interactions, stems from unreliable sources, and is poorly influenced by government public health statements.

## Methods

### Data Extraction

The database was created using the Google Trends platform provided by Google. Data on the RSVs were extracted at the national level and by state during the entire period selected. The location was set to Mexico, the category to “All categories” and “Health,” and the time period was specified to March 3, 2019, to February 21, 2021. The data values ranged between 0 and 100. The terms analyzed were the Spanish translations of chlorine dioxide: “dioxido de cloro” and “dióxido de cloro.” Both terms were included to capture searches without the written accent. Because there is no official registration of this product in the legal market, the commercial name varies depending on the producer and distributor. However, we use this term, as it is the one used by most health institutions’ communications and news releases.

### Data Analysis

The database was downloaded in CSV format in the time period established according to the number of weekly searches and RSV index. Data were exported to RStudio (version 0.97.551; RStudio, PBC) and SPSS (version 21; IBM Corp) for analysis. Multiple seasonal subseries box plots were analyzed to rule out annual or seasonal patterns. The timeline is presented in Figure 1. An analysis was then performed on data from March 1, 2020, to February 27, 2021.


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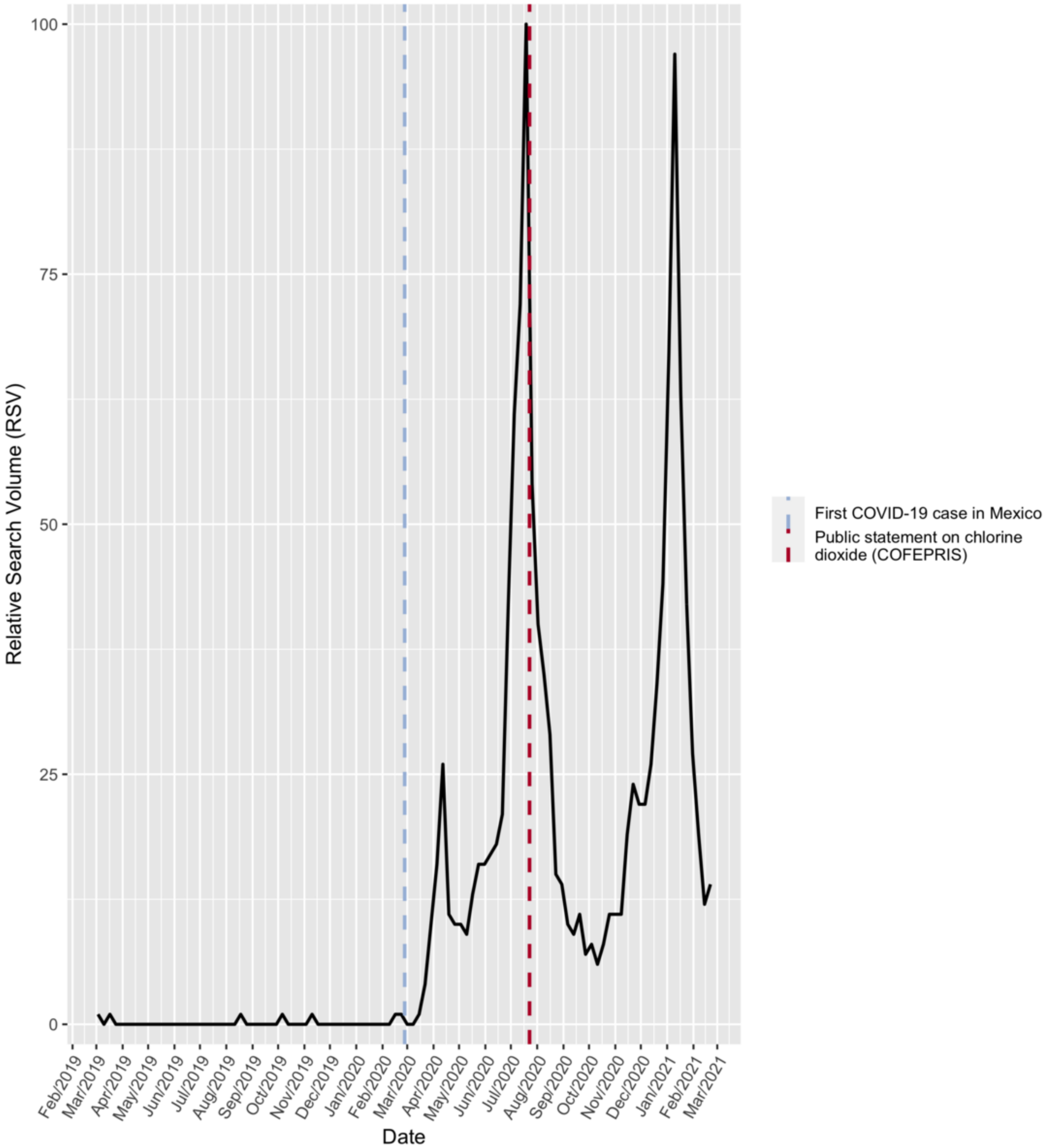
**Figure 1.** Timeline for the relative search volume index for "chlorine dioxide" in Mexico from March 3, 2019, to February 21, 2021. The first confirmed COVID-19 case in Mexico and governmental public statement about this substance are included in the plot. COFEPRIS: Comisión Federal para la Protección contra Riesgos Sanitarios.




From March 1, 2020, to February 27, 2021, we recorded data spanning 52 weeks. Four groups of 13 weeks each were created, as it allowed for easy comparisons and enabled us to divide them into equally sized sets. The Kruskal-Wallis test was used to compare the total number of searches for chlorine dioxide in the four time periods since the first case of COVID-19 in Mexico. The post hoc Dunn test was used to identify differences between means.

## *Results*

The average RSVs for the term chlorine dioxide in Mexico for the first, second, third, and fourth time periods analyzed were 9.69 (SD 7.38), 40.00 (SD 25.79), 11.46 (SD 5.02), and 37.61 (SD 24.83), respectively. Dates, averages, and SEs are shown in Table 1. Visual analysis of the data since 2019 did not show any seasonal or annual patterns. Since the beginning of the pandemic in Mexico, the specified term's popularity has increased, as demonstrated by an upward trend in the number of searches. During the first time period (from early March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2020), the number of searches increased slightly, and the search volume was 26 relative to its maximum popularity (set at 100). During the second time period, this term's highest search volume since 2019 reached 100 in the week of July 19-25, 2020, after which it declined rapidly to 15 on August 23-29. The search volume continued to decline between September and November 2020 during the third period and reached its lowest point (7) on September 27, 2020. At the end of the third period, the volume increased slightly and, during the fourth period, continued in an upward trend that led to a sudden increase to 97 on January 10, 2021. Five weeks later, the volume declined sharply to 12, and the pattern was similar to that in the second time period. A subanalysis was carried out to highlight those states with the greatest search tendency during the aforementioned period. The highest scores were recorded in the following states: Sinaloa (n=100), Aguascalientes (n=96), Querétaro (n=95), Sonora (n=95), and Nuevo León (n=96). No visual geographical relationship was found concerning search trends. The results are presented in Figure 2. The timeline of the search volumes and time periods are shown in Figure 3.

**Table 1.** Time periods analyzed.

| Groups | Time period | Weeks | RSV[a] | | Percentage change (%) |
|---|---|---|---|---|---|
| | | | Mean (SE) | Minimum to maximum | |
| Group 1 | March 1 to May 30, 2020 | 13 | 9.69 (2.04) | 0-26 | N/A[b] |
| Group 2 | May 31 to August 29, 2020 | 13 | 40.00 (7.15) | 15-100 | 312.85 |
| Group 3 | August 30 to November 28, 2020 | 13 | 11.46 (1.39) | 6-24 | –71.35 |
| Group 4 | November 29, 2020, to February 27, 2021 | 13 | 37.61 (6.88) | 12-97 | 228.18 |

[a]RSV: relative search volume.

[b]N/A: not applicable.

**Figure 2.** RSV index by Mexican states from March 3, 2019, to February 21, 2021. RSV: relative search volume.

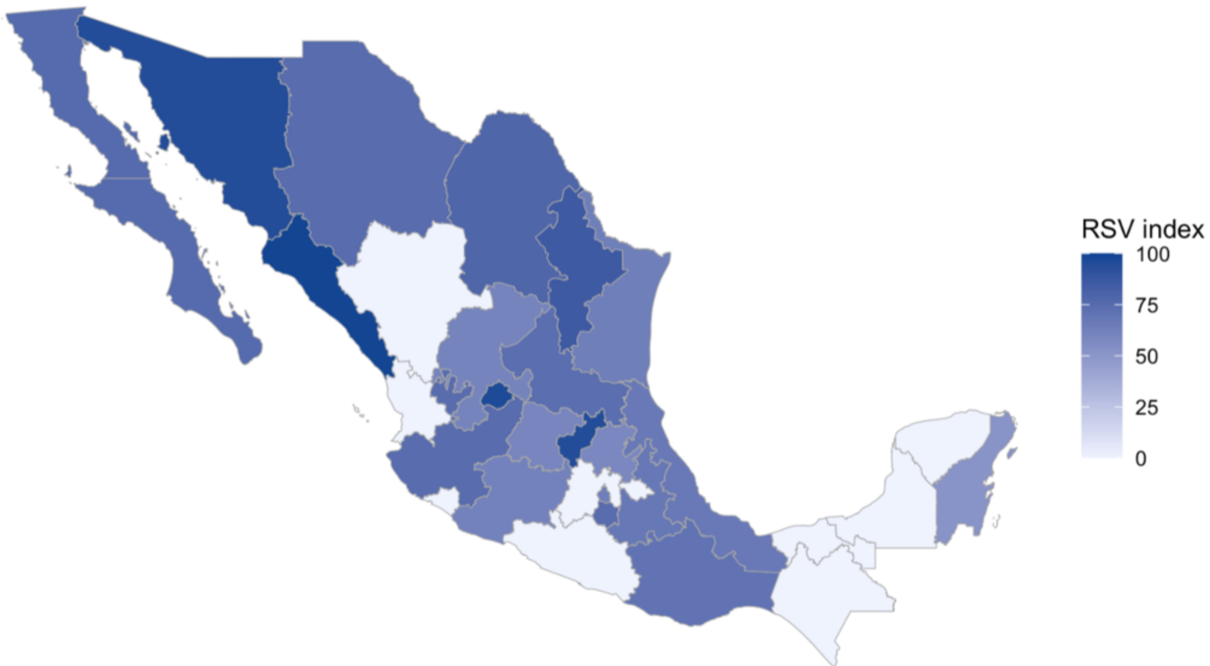




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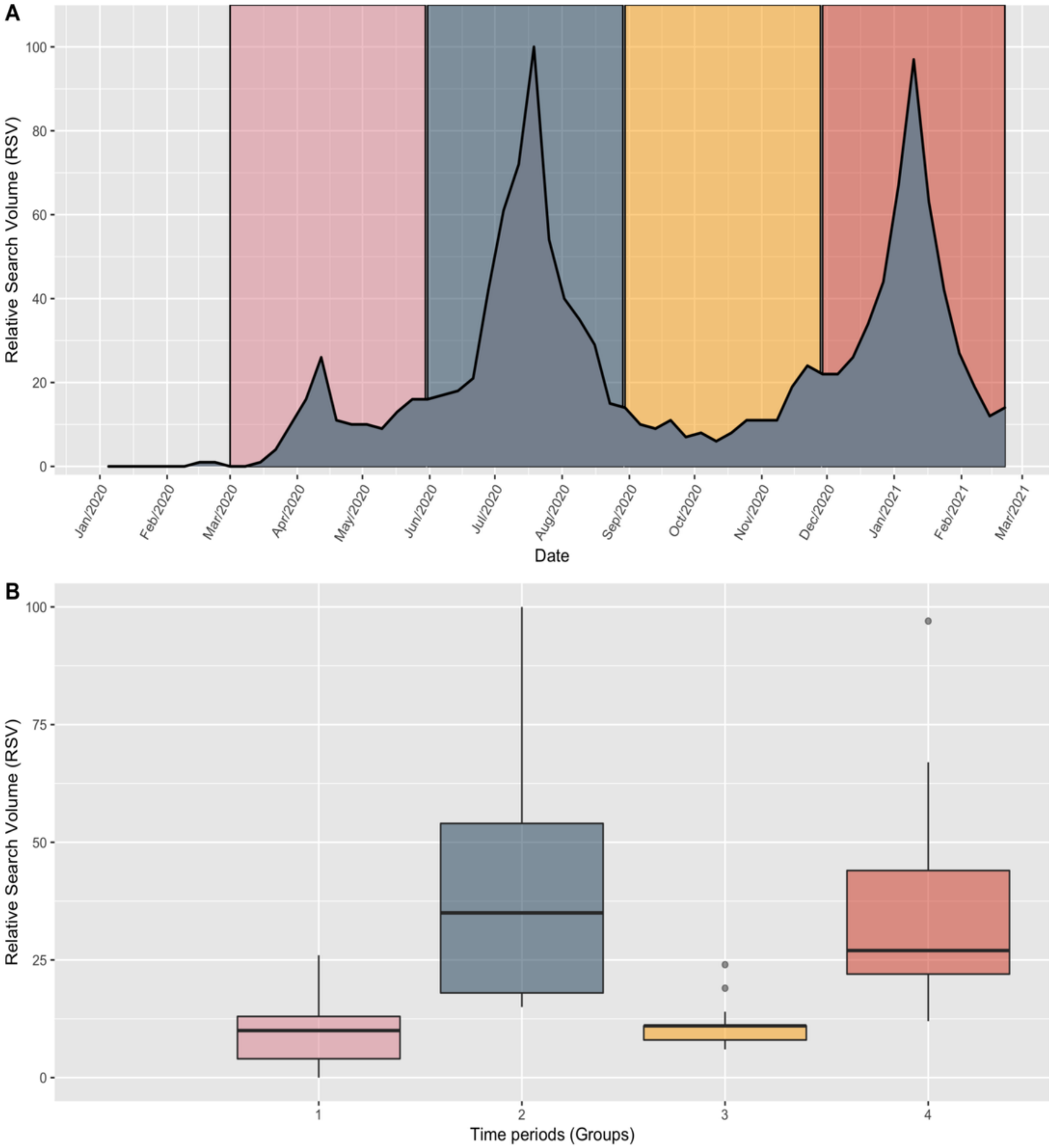
**Figure 3.** A: Timeline of the RSV index for chlorine dioxide in Mexico since the first confirmed COVID-19 case in Mexico shown according to the different time periods analyzed. B: Data distribution of RSV index values by time period. RSV: relative search volume.




The Kruskal-Wallis test results show a statistically significant difference ($P$<.001) between the mean ranks of at least one pair of groups. Pairwise post hoc comparisons using the Dunn test indicated four significant comparisons. The data distributions are presented in Figure 2. The mean search volume was significantly lower in the first time period (9.69) than in the second (40.0) and fourth (37.61) time periods ($P$<.001 for each comparison). The mean volume was significantly higher in the second (40.0) than in the third (11.46; $P$=.001) time periods. The mean volume was significantly lower in the third than in the fourth ($P$=.001) time period. The differences were not significant between time periods 1 and 3 and between 2 and 4 ($P$>.99 for both).

## Discussion

### Principal Results

Interest in chlorine dioxide grew as the pandemic started in Mexico. We found a significant increase in the number of searches for chlorine dioxide at the beginning of the pandemic in February 2020 in Mexico. Two peaks—in July 2020 and January 2021—are of particular public interest. Differences in statistical significance were demonstrated between the four time periods evaluated, suggesting an unknown mechanism that drives public interest. Maximum interest was recorded during June to August 2020 and December through February 2021,



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with previous time periods with significantly lower search volumes. Although chlorine dioxide is an essential ingredient of sanitizers used for surfaces and water, the variable of interest likely responded to searches corresponding to the purported product for COVID-19.

The Mexican regulatory agency COFEPRIS published a statement urging citizens to stop the consumption of this substance on July 23, 2020. Sousa-Pinto et al [35] reported media coverage can have a strong influence on RSVs compared with actual epidemic trends or public behavior. Nevertheless, many of these communication channels do not have the processes in place to filter misinformation related to public health issues. Therefore, the dissemination of information by specialized health institutions through these channels is essential in educating the public. Consistent with the hypothesis, this COFEPRIS public statement did not seem to have an effect on the number of searches, as it was released shortly past the first popularity peak and 3 months before the second peak. We believe this may be indicative of the government's poor ability to disseminate public health information relative to alternative media sources.

Several Latin American artists, singers, and influential people have been reported to promote chlorine dioxide as a protective or therapeutic agent against the disease caused by SARS-CoV-2. Such promotion was carried out through publications on social networks, media interviews, and consumption of chlorine dioxide solution on live television [36-38]. As these communication channels are likely to have had an impact on the population's interest in chlorine dioxide solution, it is essential to research the primary sources used by the population for health-related advice. Based on the different levels of RSV seen across states, we suspect search trends are likely most influenced by the media that is consumed locally, such as local celebrities, social networks, or television shows.

Ensuring public health statements from COFEPRIS are well disseminated and widely consumed is essential. Facing a public health emergency, it is important to measure the effectiveness of such statements as well as evaluating the best timelines and pathways to relay important messages. As experts identify a gradually growing interest toward potentially adverse treatments, major health institutions ought to prioritize informing about the dangers and redirecting toward reliable sources. In this sense, the lack of regulation seen in many of the channels through which untruthful medical information is often shared, compromises a threat to public health.

On September 20, 2020, two months after the aforementioned COFEPRIS statement was released, more than 100 people protested in Mexico City to demand the use of chlorine dioxide solution in hospitals. This group of people, allegedly led by a group of scientists and doctors, also marched against the use of masks and vaccines [37]. Assuming that this trend is influenced by media that promotes consumption through nonfactual information and does not respond to communications created by public health institutions, we believe that changes in search volumes may be at least partially associated with changes in consumption of chlorine dioxide solution. Currently, there are two case reports published of complications after chlorine dioxide solution prophylactic ingestion for COVID-19 in Mexico, an acute kidney injury and an intestinal perforation [39,40].

### Limitations

Multiple limitations should be considered when interpreting these results. Search volumes were used as a proxy to measure population interest in this product and should not be interpreted as indicative of the number of people consuming chlorine dioxide. Additionally, standardization of data by Google does not allow for comparisons between absolute numbers of search volumes.

The results were also limited to the population with internet access (56.4% of Mexican households) and who used Google as their standard search engine [23,24]. Other media sources such as news coverage and word of mouth may have had a more significant impact on misinformation and consumption of chlorine dioxide solution than the internet.

### Comparison With Prior Work

Misinformation has been associated with negative views about public health measures. In two cross-sectional studies, Bertin et al [41] reported that conspiratorial beliefs negatively predicted participants' attitudes of and intentions to be vaccinated against COVID-19. This observation also relates to the views of chloroquine. The use of this drug to prevent severe COVID-19 was controversial at first, and after several studies were published, multiple governments and scientific committees disapproved of its use. Being prochloroquine was associated with a negative attitude about COVID-19 vaccination and a preference for alternative over biomedical therapies [41]. Greater susceptibility to misinformation was associated with reduced compliance with public health guidance and a decreased likelihood of being vaccinated or recommending vaccination [42].

Although disinformation is not a new enemy of public health, the internet and social networks can be powerful sources of misinformation among the general population and can contribute to the undermining of public health policies during a pandemic. Myths have a strong cultural influence that drives social impact [6]. Misinformed beliefs are significantly associated with lower levels of digital health literacy, confidence in government, and trust in scientific institutions [43]. Given that the internet and social media have become new tools for seeking health-related information, misinformation must be addressed by the public health realm. Misleading information has been published about the virus and how it spreads; about how to prevent the infection; about who or what is responsible for it; and in attempt to discredit preventive measures, therapies, and vaccines [20,44-46]. The lack of corroboration of the scientific veracity of what is advertised has allowed companies and individuals to profit from deceiving the consumer into buying products lacking medical evidence or government authorization. There is evidence of misinformation about cancer, Ebola and Zika viruses, smoking, and COVID-19 that has been associated with harmful consequences reported on a global scale [46].

Multiple scientific articles have described approaches in which health institutions can respond to misinformation, which we



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recommend Mexican public health agencies to implement. Strategies such as automatic learning techniques capable of identifying misleading information on the internet; health care institutional use of social media to promote evidence-based information; studies on the dissemination, creation, and consumption of false information on the internet; and the use of infodemiology to analyze trends in population behavior [44-47]. Given that misleading information is distributed among a new generation of social media users, it is time to include infodemiology and internet scientific research in the public health agenda.

## Conclusions

The pandemic stimulated interest in Mexico toward a substance that was previously sold as a prophylaxis or treatment for multiple diseases in other countries without sufficient medical evidence. Multiple potential mechanisms could have been involved in the double peak observed. This interest is likely to influence the level of consumption of this substance; thus, it is necessary to continue investigating its means of dissemination and its impact on the likeliness to believe or propagate more misinformation in Mexico. In addition to collecting data on chlorine dioxide solution consumption, risks, and adverse reactions, future research should study in-depth the effects of misinformation and the role Mexican culture has played in its uptake. We assume that social networks play an essential role in disseminating this data, given the evidence of the medium as a propagator of disinformation. It is crucial to continue analyzing the role these new media platforms play regarding health decisions as well as evaluating the quality of the information available.

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## Authors' Contributions

JMCC, ADPG, and JPMH were responsible for the study design. All authors wrote and approved the final manuscript.

## Conflicts of Interest

None declared.

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## Abbreviations

**COFEPRIS:** Comisión Federal para la Protección contra Riesgos Sanitarios
**FDA:** Food and Drug Administration
**RSV:** relative search volume


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Original Paper

# Constituents' Inferences of Local Governments' Goals and the Relationship Between Political Party and Belief in COVID-19 Misinformation: Cross-sectional Survey of Twitter Followers of State Public Health Departments

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## Abstract

**Background:** Amid the COVID-19 pandemic, social media have influenced the circulation of health information. Public health agencies often use Twitter to disseminate and amplify the propagation of such information. Still, exposure to local government–endorsed COVID-19 public health information does not make one immune to believing misinformation. Moreover, not all health information on Twitter is accurate, and some users may believe misinformation and disinformation just as much as those who endorse more accurate information. This situation is complicated, given that elected officials may pursue a political agenda of re-election by downplaying the need for COVID-19 restrictions. The politically polarized nature of information and misinformation on social media in the United States has fueled a COVID-19 infodemic. Because pre-existing political beliefs can both facilitate and hinder persuasion, Twitter users' belief in COVID-19 misinformation is likely a function of their goal inferences about their local government agencies' motives for addressing the COVID-19 pandemic.

**Objective:** We shed light on the cognitive processes of goal understanding that underlie the relationship between partisanship and belief in health misinformation. We investigate how the valence of Twitter users' goal inferences of local governments' COVID-19 efforts predicts their belief in COVID-19 misinformation as a function of their political party affiliation.

**Methods:** We conducted a web-based cross-sectional survey of US Twitter users who followed their state's official Department of Public Health Twitter account (n=258) between August 10 and December 23, 2020. Inferences about local governments' goals, demographics, and belief in COVID-19 misinformation were measured. State political affiliation was controlled.

**Results:** Participants from all 50 states were included in the sample. An interaction emerged between political party affiliation and goal inference valence for belief in COVID-19 misinformation ($\Delta R^2$=0.04; $F_{8,249}$=4.78; $P$<.001); positive goal inference valence predicted increased belief in COVID-19 misinformation among Republicans (β=.47; $t_{249}$=2.59; $P$=.01) but not among Democrats (β=.07; $t_{249}$=0.84; $P$=.40).

**Conclusions:** Our results reveal that favorable inferences about local governments' COVID-19 efforts can accelerate belief in misinformation among Republican-identifying constituents. In other words, accurate COVID-19 transmission knowledge is a function of constituents' sentiment toward politicians rather than science, which has significant implications on public health efforts for minimizing the spread of the disease, as convincing misinformed constituents to practice safety measures might be a political issue just as much as it is a health one. Our work suggests that goal understanding processes matter for misinformation about COVID-19 among Republicans. Those responsible for future COVID-19 public health messaging aimed at increasing belief



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in valid information about COVID-19 should recognize the need to test persuasive appeals that address partisans' pre-existing political views in order to prevent individuals' goal inferences from interfering with public health messaging.

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**KEYWORDS**

COVID-19; outbreak; mass communication; Twitter; goal inferences; political agendas; misinformation; infodemic; partisanship; health information

## Introduction

### Background

Amid the widespread global COVID-19 pandemic, social media have exacerbated the spread of health misinformation and disinformation [1]; belief in false health information is, at times, just as common as the endorsement of accurate information [2]. The politicized and polarized state of information surrounding COVID-19 in the United States has fueled a concomitant infodemic on social media, where "facts" are subjective depending on one's political agenda [3-7].

Public health agencies often use Twitter as a tool to disseminate and amplify the propagation of COVID-19 information [8,9], but exposure to local government–endorsed public health information via Twitter does not make one immune to believing COVID-19 misinformation. Whereas public health agencies, via their Twitter accounts, can share valid information and details of their concerted efforts to protect constituents, politicians are equally likely at times to distribute misinformation via tweets to pursue political agendas that could harm their constituents [10,11]. In fact, incongruencies in tweets exist in COVID-19 messaging across unique state public health agencies' and individual stakeholders' Twitter accounts [8].

Whereas conservative rhetoric connected to Republican politicians is associated with more misinformation, democratic rhetoric is more consistent with guidelines from public health officials [2,12,13]. As a result, US partisan affiliation is a stronger predictor of COVID-19 beliefs than local infection rates or demographics (eg, health status and age) [14]. Yet, the relationship between Republican partisanship and COVID-19 misinformation is nuanced when considering the potential goal understanding processes at work. Despite the high levels of COVID-19 misinformation, red state partisans are largely dissatisfied with their state government's management of the pandemic; this low approval of their state politicians' efforts is even more depressed for politicians who have been resistant to implementing business closures as a safety measure [14]. Thus, many Republicans with red viewpoints are unhappy with what their state government has done to effectively manage the pandemic. However, the goal understanding processes that facilitate belief in COVID-19 misinformation are unclear.

### Theoretical Framework

Pre-existing political beliefs can influence the endorsement of misinformation [3,15-17]. In the context of the COVID-19 pandemic, politicians from the Republican Party and right-leaning media figures downplayed the threat of COVID-19 in comparison to Democratic politicians and left-leaning media figures while focusing on the economic damages resulting from widespread business closures and the threat to individuals' personal liberties [18,19]. As a result, media and political figures' attitudes toward the COVID-19 pandemic cascaded to Republican supporters, affecting individuals' compliance with public health guidelines, including mask wearing and social distancing [3,19-21]. Given that extant research suggests that Republicans are exposed to more persuasive messages containing misinformation from their party leaders compared to Democrats [3,17-21], we posit the following hypothesis: Republicans endorse greater levels of COVID-19 misinformation than Democrats (hypothesis 1 [H1]).

When Republicans experience discontent with their local government's public health efforts however, their endorsement of COVID-19 misinformation is reduced. If Republicans think that their local government is not doing a good job and perhaps think that the government is serving a less prosocial agenda, then they will believe less misinformation about COVID-19. According to goal understanding theory, the goal inferences that people make about others have spillover effects or consequences beyond merely endorsing a goal inference [22]. We theorize that the association between increased discontent and the decreased endorsement of misinformation occurs because Republicans are likely relatively more critical of their government and its efforts when their goal inferences are negatively valenced. This spillover effect for Republicans' inferences of their local government's goals results in the more systematic processing of relevant persuasive messages promoting misinformation about COVID-19 and thus reduces their endorsement of such beliefs spread by party leaders. On the other hand, when Republicans think that their local government is doing well and they have positive sentiments toward their government's agenda, they tend to endorse more COVID-19 misinformation, given the conservative ideologies related to COVID-19. However, we do not expect to find this same spillover effect for Democrats' goal understanding processes because of the reduced likelihood that they endorse misinformation on COVID-19, given the focus on science-based practices associated with liberal political beliefs regarding the pandemic. In other words, political affiliation likely interacts with goal inference valence in ways that matter for belief in misinformation, as we predict herein: Republican Twitter users' positive goal inference valence for their local government's COVID-19 efforts predicts heightened belief in COVID-19 misinformation, whereas this outcome is not the case for Democrats (hypothesis 2 [H2]).

We are uncertain about the relationship between goal inference valence for government COVID-19 efforts and belief in misinformation about SARS-CoV-2 for independents or those without a political affiliation. Indeed, independent voters



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generally lean toward 1 of the 2 major partisan ideologies; 48% of independents leaned Democrat and 54% leaned Republican as of 2019 [23]. Americans who do not lean toward a particular party are less politically informed [23]. Thus, individuals who do not identify with a party may not be influenced by mediated messages from politicians to the same extent as partisans. Similarly, independents have more negative sentiments toward political parties and politicians [23]. As such, they may be less susceptible to believing politicized misinformation. Yet, we refrain from generating predictions and propose the following research question: what is the relationship between the goal inference valence for local governments' COVID-19 efforts among independent Twitter users and those with other or no party affiliations and their belief in COVID-19 misinformation?

## Methods

### Study Design

We conducted a web-based cross-sectional survey of US Twitter users (n=258) who followed their state's official Department of Public Health Twitter account between August 10 and December 23, 2020. The valence of inferences about local governments' goals, demographics, and belief in COVID-19 misinformation were measured. We controlled for state political affiliation based on the 2020 presidential election outcome. We conducted a linear regression analysis to assess whether political party and the valence of inferences about state governments' goals significantly predicted belief in COVID-19 misinformation while controlling for state party affiliation. The institutional review board of University of California, Davis (protocol number: 1502267-5), approved all study materials and procedures prior to data collection.

### Recruitment

We took a random sample of Twitter users who follow their state's official Department of Public Health Twitter account (eg, California Department of Public Health, Oregon Department of Public Health, etc). Each state's Department of Public Health has an official Twitter account. These Twitter accounts received an influx of social media engagement in 2020, which was likely due to concern regarding COVID-19. Consequently, it is likely that each state's followers were impacted by COVID-19 social distancing measures and that users are following their state's Department of Public Health because they are interested in information about COVID-19 for the state in which they reside.

We randomly selected the final sample of 200 participants from each of the 50 states (200 × 50 = 10,000) from a shuffled list of all followers from each state's Department of Public Health. Then, we distributed the hyperlink to the survey to each follower in our sampling frame (n=10,000) through Twitter and asked our sample of participants to respond. Of the 10,000 members of our sample, 532 (5.3%) responded to our direct message. This nonresponse level was expected; whereas research shows that traditional telephone response rates are low (<10%), response rates in web-based communities are reported to be even lower (<6%) [24,25].

### Survey Development

This cross-sectional survey consisted of demographic questions, measures of COVID-19 knowledge, questions related to political party affiliation, and an open-ended question asking participants about their local government's crisis response goals. COVID-19 misinformation items were selected by comparing the Centers for Disease Control and Prevention guidelines for slowing the spread of COVID-19 with common, prevalent COVID-19 myths [26-28]. Multimedia Appendix 1 contains details for the open-ended goal inference measure and the misinformation items. Qualtrics programming software (Qualtrics International Inc) was used to host the survey. Prior to data collection, an expert in survey design reviewed all measures for their effectiveness, and we made adjustments based on the expert's feedback.

### Procedure

We sent (ie, via direct message) our sampling frame an invitation to participate in the survey. Participants who clicked the survey link were directed to an electronic consent form. Of the 10,000 followers messaged, 532 participants consented to participate.

Participants were asked a series of questions about their inferences of their local government's goals, demographics, political party identification (Democrat, Republican, independent, or other), and COVID-19 misinformation (Multimedia Appendix 1). State political affiliation was controlled. Of the 532 participants who consented, 274 were excluded from the final analysis because they did not complete more than 1 item; 258 participants were retained.

### Statistical Analysis

#### COVID-19 Misinformation Computation

We computed the endorsement of COVID-19 misinformation by calculating the sum of the number of myths (5 myths in total) that each participant endorsed and the sum of the number of truths (5 truths in total) about SARS-CoV-2 that they did not endorse. Each myth and truth was effectively coded as "1" for having a false belief or as "0" for having an accurate belief. In other words, if people believed all 5 falsehoods about COVID-19 and rejected all 5 truths, then their score would be 10, which is the theoretical maximum, whereas those rejecting all falsehoods and accepting all truths would yield a score of 0—the theoretical minimum. On average, participants believed 1.27 (SD 1.21, SE 0.08; minimum=0; maximum=5.00; skewness=1.01; kurtosis=0.64) myths.

#### Valence of Inferences About Local Governments' Goals

Participants' open-ended textual inferences of their government's goals were processed through the Linguistic Inquiry and Word Count (LIWC) computerized text analysis tool [29] to quantify the emotional valence of each participant's open-ended goal inference [22]. LIWC uses raw word counts to assign scores to texts in psychology-relevant categories, including scores for the emotional tone (ie, valence) of a text, and it has been used in recent medical internet research to measure emotion in textual responses, including sentiment toward the COVID-19 pandemic [30-35]. LIWC assigns each text an emotional valence score based on the percentage of words used in the text by comparing


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the text to a dictionary of words in relevant categories. LIWC has been used in hundreds of studies and has been extensively validated (ie, via a word selection stage, an assessment of the base rate of the frequency of words, and a phase in which human judges cross-validated the prior stages). Further, the program's capabilities have undergone over 10 years of refinement [36]. LIWC emotional tone scores range from 1 to 100; a score of 100 indicates maximally positive emotional valence, and a score below 50 indicates more negative emotional valence. Participants' average inference valence was negative, as their average tone score was 38.86 (SD 35.20, SE 2.19; minimum=1.00; maximum=99.00; skewness=0.86; kurtosis=−0.80).

### State Partisan Affiliation

Participants from all 50 states were retained and included in our study. Between 1 to 15 participants came from each of the 50 states; Louisiana and Massachusetts had the most participants, with 13 (13/258, 5%) and 15 (15/258, 5.8%) participants, respectively. Each participant's self-reported state of residence was aggregated with the state's partisan leaning during the 2016 presidential election [37]. Slightly over half of participants lived in red states (143/258, 55%).

## Results

The majority of participants were female (157/258, 60.9%), were White (212/258, 82.2%), and identified as a Democrat (129/258, 50%) or a Republican (66/258, 25.6%). The most frequently observed education level was a bachelor's degree from a college (81/258, 31.4%). The average participant age was 44.17 (SD 12.21, SE 0.76; minimum=19.00; maximum=75.00; skewness=0.11; kurtosis=−0.66) years.

The linear regression results for H1 revealed that while controlling for state political leaning, party affiliation was not a significant predictor of belief in COVID-19 misinformation ($P$=.66). Whereas the average score for belief in misinformation for Democrats was 1.11 (SD 1.17, SE 0.10; minimum=0; maximum=5.00; skewness=1.15; kurtosis=1.03), this value was twice as high for Republicans (mean 2.15, SD 1.37, SE 0.24; minimum=0; maximum=5.00; skewness=0.46; kurtosis=−0.55) and was in the expected direction. For independents, the average score for belief in misinformation was 1.21 (SD 1.12, SE 0.14; minimum=0; maximum=5.00; skewness=1.11; kurtosis=1.23); the average score for belief in misinformation for participants who reported another or no party affiliation was 1.13 (SD 1.07, SE 0.20; minimum=0; maximum=4.00; skewness=0.75; kurtosis=0.01). Overall, these results are inconsistent with H1.

When testing H2, the results revealed an interaction between political party affiliation and goal inference valence ($\Delta R^2$=0.04; $F_{8,249}$=4.78; $P$<.001). More positively valenced inferences of the government's COVID-19 goals strengthened the relationship between party affiliation and belief in COVID-19 misinformation among Republicans when compared to that among Democrats (B=0.01; $t_{249}$=2.03; $P$=.04), as predicted. Positive goal inference valence predicted increased belief in COVID-19 misinformation for Republicans (β=.47; $t_{249}$=2.59; $P$=.01) but not for Democrats (β=.07; $t_{249}$=0.84; $P$=.40).

With regard to the research question, the relationship between goal inference valence and belief in misinformation is not significant for independents (β=−.19; $t_{249}$=1.56; $P$=.12) and is significant in the positive direction for those with no party affiliation or another affiliation (β=.43; $t_{249}$=2.36; $P$=.02). Table 1 shows the regression table, and Figure 1 shows a representation of the interaction.

**Table 1.** Regression results for political party interacting with goal inference valence to predict belief in COVID-19 misinformation[a,b].

| Variable | B (SE; 90% CI) | β | *t* (*df*) | *P* value |
|---|---|---|---|---|
| Intercept | 0.98 (0.17; 0.70 to 1.25) | 0 | 5.78 (249) | <.001 |
| Blue state | 0.06 (0.15; −0.18 to 0.31) | .03 | 0.44 (249) | .66 |
| Inference valence | 0 (0; 0 to 0.01) | .07 | 0.84 (249) | .40 |
| Independent | 0.44 (0.26; 0.02 to 0.87) | .16 | 1.72 (249) | .09 |
| Other or no party affiliation | −0.40 (0.34; −0.97 to 0.17) | −.11 | −1.15 (249) | .25 |
| Republican | 0.59 (0.33; 0.04 to 1.14) | .16 | 1.77 (249) | .08 |
| Inference valence (independent) | −0.01 (0.01; −0.02 to 0) | −.17 | −1.77 (249) | .08 |
| Inference valence (other or no party affiliation) | 0.01 (0.01; 0 to 0.02) | .17 | 1.82 (249) | .07 |
| Inference valence (Republican) | 0.01 (0.01; 0 to 0.03) | .19 | 2.03 (249) | .04 |

[a] $F_{8,249}$=4.78; $P$<.001; $R^2$=0.13.

[b] Unstandardized Regression Equation: COVID-19 misinformation = 0.98 + 0.06*blue state + 0*inference valence + 0.44*independent − 0.40*no or other party affiliation + 0.59*Republican − 0.01*inference valence (independent) + 0.01*inference valence (no or other party affiliation) + 0.01*inference valence (Republican).


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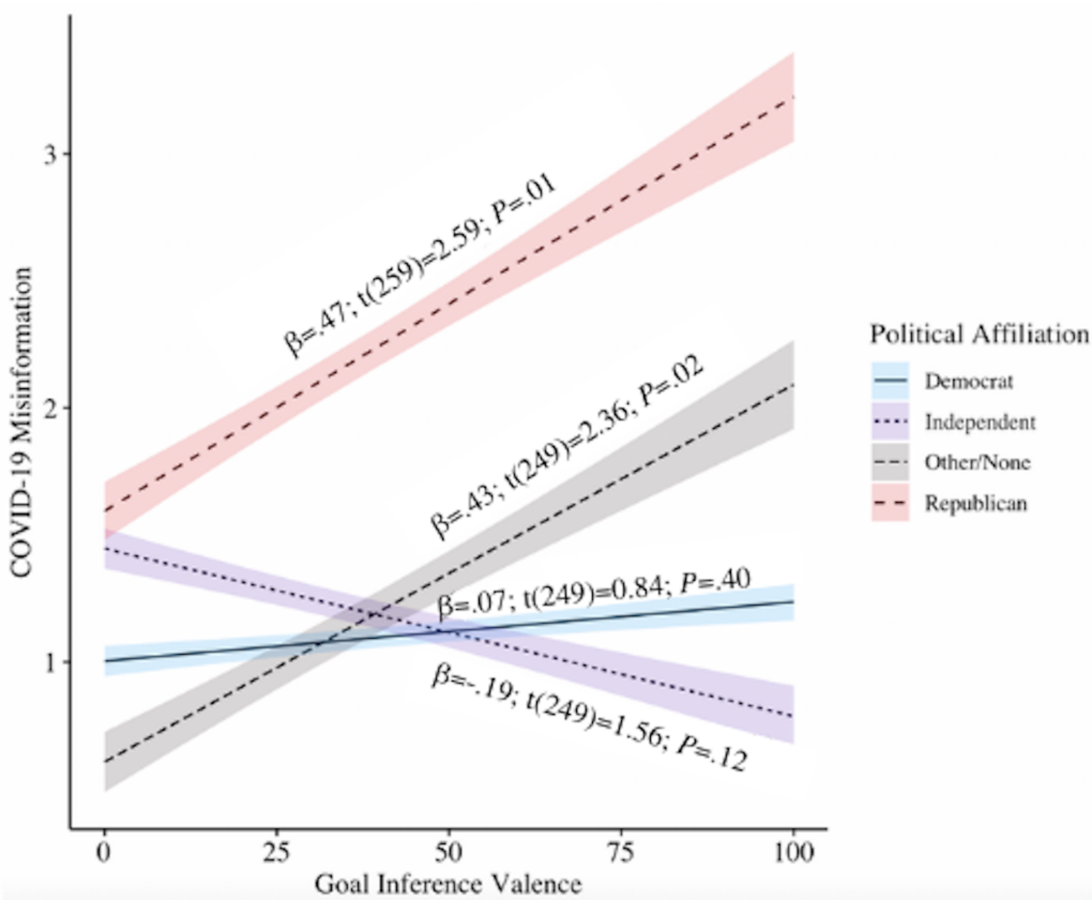
**Figure 1.** Interaction plot.




## Discussion

This project examines the cognitive processes underlying the relationship between partisanship and health misinformation. We investigate how positive sentiment toward local governments' COVID-19 efforts can enable or impede belief in COVID-19 misinformation.

### Principal Results

Our results reveal that even though the overall endorsement of misinformation regarding COVID-19 does not vary across political party affiliations, when considering the valence of goal inferences among Republicans versus those among Democrats, a more complex pattern of results emerges. Republicans' positive inferences about their local government's COVID-19 efforts can accelerate belief in misinformation, given conservatism's reliance on politics rather than science in their pandemic information dissemination efforts [4]. In other words, if Republicans believe that their local government has positive intentions, they may be more vulnerable to believing politically fueled COVID-19 misinformation than Democrats. As a result, accurate COVID-19 transmission knowledge has been driven by politicians' political agendas and state partisan orientations rather than science. This is not the case for Democrats because of the science-based information campaigns of liberal political agendas [3]. Curiously, individuals without a mainstream political affiliation who had positive sentiment about their local government's goals to address COVID-19 tended to endorse more misinformation, which is similar to Republicans. We speculate that this outcome was due to their lack of information. Indeed, US citizens who do not lean toward a particular party are relatively less politically informed [23]. At the same time, we recognize the exploratory nature of our work and understand that confirmatory work in the future is needed, especially when considering that party affiliation is not always associated with conservative views. Indeed, having no party affiliation yielded results consistent with those for Republicans; however, we caution that additional research is needed, as having no affiliation does not mean that one is apolitical.

### Limitations

Our study is subject to a few limitations. As with all cross-sectional studies, we do not have evidence for the direction of causality, even if theory suggests that there is a causal relationship between goal inference valence and the endorsement of misinformation about COVID-19. We also recognize that the goal understanding mechanisms underlying misinformation are likely more complicated, as they involve other constructs of theoretical significance such as rationality, which is an important factor in risk communication [38].

Previous work has also found that the LIWC computerized coding methodology may overidentify emotional expression [39]. Thus, LIWC may have captured extraneous sentiments when quantifying participants' open-ended goal inferences.

Another limitation is participant self-selection, which suggests that participants who volunteered for this study were somehow motivated to share their thoughts about the topic. This makes



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them fundamentally different from those who opted to not participate. Although more Democrats (129/258, 50%) than Republicans (66/258, 25.6%) completed the survey, participants from red states tended to have a higher response rate (143/258, 55.4%) than those from blue states (115/258, 44.6%). This may be because liberals, who are living with stricter COVID-19 public health guidelines than conservatives who are living in red states with more relaxed guidelines, may be especially concerned about COVID-19. Consequently, non-Republicans living in red states may have been more incentivized to participate in this study and overrepresented [3,17]. These concerns are connected to our small sample size and use of Twitter as a recruitment means. Thus, we cannot generalize beyond our sample, especially if one considers participant self-selection to be a potential bias for our sample and findings. Future work is required to gain more confidence in our findings. At the same time, we purposefully recruited participants who follow their local health department's Twitter account because we felt that these people would more likely be affected by partisan agendas than the general population; regardless, our findings should be interpreted with sampling limits in mind.

Although it was not practical to identify all potential confounders, we expect that inference valence varied among participants according to their personality, general trust for governments and their agencies, mental health risk factors, and exposure to COVID-19 information. To reduce bias through methodological triangulation, future work should complement our survey design with experimental data on exposing people to different government campaign messages and assessments of their goal inferences and COVID-19 beliefs and intentions. This may help extrapolate the specific sources of negative inference valence for governments' goals regarding COVID-19 (eg, negatively valenced inferences resulting from mask and vaccine mandates vs less autonomy-restrictive messaging) and the role that goal understanding plays between governments and their constituents.

### Theoretical Implications

Despite these limitations, we find merit in our findings and think that they suggest several meaningful theoretical implications that are consistent with past work [1,7]. Goal understanding theory [22] was supported in the novel context of the government's goal to address the COVID-19 public health crisis. Goal inferences are consequential for what people believe to be true about a global pandemic and how they might protect themselves, similar to how trust in science and politics can influence the measures that people take to protect themselves from SARS-CoV-2 infection [6]. Previously, goal inference mechanisms had only been demonstrated in personal relationships, such as those among friends or classmates, that have been dyadic [22,40]. Moreover, the spillover effects have been limited to more interpersonal processes without public health implications. Our research extends goal understanding spillover effects to the novel, hitherto unexplored context of the politicized endorsement of public health misinformation. Mechanisms that occur at the dyadic level of communication in close relationships likewise manifest in contexts where the agent and its goals function at a more macrosociological level of communication. Future research can expand on these theoretical implications by assessing how people understand the goals of specific politicians or government agencies with larger samples and perhaps expand on other social issues for which misinformation is a concern. Such work would extend the generalizability of our findings and address theoretical concerns of how partisanship and goal inferences work together with other factors to affect what people believe.

### Practical Implications

We also find merit in our results in terms of their implications for theory-based interventions and health practitioners. To our knowledge, we are the first to demonstrate that goal understanding processes matter for misinformation about COVID-19 among Republicans (and those not affiliated with a mainstream party). Those responsible for messages aimed at increasing belief in valid information about COVID-19 should recognize the need to address individuals' pre-existing political views in order to prevent them from interpreting public health information as a political issue.

Exposure to attitudinally incongruent political information can elicit a type of biased information processing known as *motivated skepticism* [41]. If COVID-19 health information is viewed as a political issue, social media public health campaigns have the capacity to reinforce a pre-existing belief in misinformation rather than educating the public. Thus, future social media campaigns aimed at reducing the endorsement of misinformation should take into account the sentiments of their target audience's inferences regarding their local government's goals.

### Conclusions

A deeper understanding of the relationship among partisanship, goal understanding, and other cognitive processes would prove fruitful for our knowledge regarding how people process and endorse health misinformation. Such work would facilitate the development of effective social media public health interventions during the COVID-19 infodemic, and it would also uncover the mechanisms of goal understanding in message processing beyond interpersonal dyadic contexts.

## Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey items.
[DOCX File , 14 KB - infodemiology_v2i1e29246_app1.docx ]


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## Abbreviations

**H1:** hypothesis 1
**H2:** hypothesis 2
**LIWC:** Linguistic Inquiry and Word Count


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Original Paper

# (Mis)Information on Digital Platforms: Quantitative and Qualitative Analysis of Content From Twitter and Sina Weibo in the COVID-19 Pandemic

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## Abstract

**Background:** Misinformation about COVID-19 on social media has presented challenges to public health authorities during the pandemic. This paper leverages qualitative and quantitative content analysis on cross-platform, cross-national discourse and misinformation in the context of COVID-19. Specifically, we investigated COVID-19-related content on Twitter and Sina Weibo—the largest microblogging sites in the United States and China, respectively.

**Objective:** Using data from 2 prominent microblogging platform, Twitter, based in the United States, and Sina Weibo, based in China, we compared the content and relative prevalence of misinformation to better understand public discourse of public health issues across social media and cultural contexts.

**Methods:** A total of 3,579,575 posts were scraped from both Sina Weibo and Twitter, focusing on content from January 30, 2020, within 24 hours of when WHO declared COVID-19 a “public health emergency of international concern,” and a week later, on February 6, 2020. We examined how the use and engagement measured by keyword frequencies and hashtags differ across the 2 platforms. A 1% random sample of tweets that contained both the English keywords “coronavirus” and “covid-19” and the equivalent Chinese characters was extracted and analyzed based on changes in the frequencies of keywords and hashtags and the Viterbi algorithm. We manually coded a random selection of 5%-7% of the content to identify misinformation on each platform and compared posts using the WHO fact-check page to adjudicate accuracy of content.

**Results:** Both platforms posted about the outbreak and transmission, but posts on Sina Weibo were less likely to reference topics such as WHO, Hong Kong, and death and more likely to cite themes of resisting, fighting, and cheering against coronavirus. Misinformation constituted 1.1% of Twitter content and 0.3% of Sina Weibo content—almost 4 times as much on Twitter compared to Sina Weibo.

**Conclusions:** Quantitative and qualitative analysis of content on both platforms points to lower degrees of misinformation, more content designed to bolster morale, and less reference to topics such as WHO, death, and Hong Kong on Sina Weibo than on Twitter.

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**KEYWORDS**

internet; social media; misinformation; COVID-19; Twitter; Weibo; prevalence; discourse; content; communication; public health; context; content analysis



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## Introduction

As the COVID-19 pandemic began to emerge in the early weeks of January 2020, information about the mechanism, location, and speed of transmission, as well as the array of government actions to stop the spread of the virus, was limited. Individuals worldwide turned to social media for information, spending an average of 82 minutes per day on social media compared to 75 minutes a year earlier. Twitter, as 1 observer put it, “especially shone as a real-time news source” of breaking news and analysis about the virus [1]. In the United States, in the first quarter of 2020, Twitter’s daily user figures were 24% higher than for the same period a year earlier [2]. In China, individuals turned to their equivalent of Twitter, Sina Weibo (referred to here as Weibo), to learn about the virus and exchange concerns.

Although the role of social media, such as Twitter, has received considerable scrutiny in political contexts, such as conflict, revolts, and elections [3], it had, until recently, been less scrutinized in a public health context [4]. Twitter emerged as a platform for discussion about the Ebola virus in 2014 [5], with studies showing that many tweets were inaccurate and wildly speculative compared to those that were scientifically accurate. Individuals also took to Twitter activity in 2015 and 2016 to discuss virus transmission, treatment, and symptoms, providing a measure of public health surveillance to track and predict the Zika virus but also amplifying rumors and misinformation, defined as incorrect information that is not intentionally false [6] about the virus [7]. The proliferation of misinformation, even when harmless, can result in serious social and lethal health consequences in the context of pandemics [8]. As the number of Twitter users has grown in the intervening years since Ebola and Zika, so has the centrality of Twitter in the context of the recent pandemic to the extent that COVID-19 has been referred to as the “Twitter Pandemic” because of its role in distributing medical information and misinformation [9]. For example, a March 12, 2020, tweet falsely claimed that Costco had recalled toilet paper it thought was contaminated with COVID-19, including old video repurposed to support the false claim [10].

Weibo has occupied an analogous space as Twitter in the Chinese context [11]. The Chinese microblogging platform was launched by Sina Corporation in August 2009, after Twitter was blocked in China earlier that year due to anniversary protests at Tiananmen Square [12]. As King et al [13] note, individuals in China have access to a number of different social media platforms, but Weibo is a widely used microblogging platform, with over 430 million monthly active users, a large proportion of China’s population [14], compared to Twitter’s 326 million users a month. The platform has been criticized in Western media outlets for limiting free speech [15]. King et al [16] find a tendency on Chinese social media platforms not necessarily to censor criticism of the government altogether but more to avoid controversial issues that might have an unsettling impact on social order and to steer toward more benign topics less likely to stir the public. Alternatively, and in the particular context of COVID-19 content, Lu et al [17] suggest that China permitted criticism of the regime but that those criticisms were matched by statements of support for the progress and positive outcomes associated with the epidemic. Indeed, criticisms “targeted at the government for perceived lack of action, incompetence, and wrongdoing” [17] were complemented almost exactly proportionately with bursts of support for the regime. Thus, previous research suggests the possibility that there will be a relative dearth of subjects on Weibo that might rouse the public, favoring instead either anodyne content or a complementarity intending to balance criticisms with support.

Further, research has provided evidence in other public health contexts about the comparatively higher amounts of misinformation on Twitter compared to Weibo. In a study of misinformation surrounding the Ebola epidemic in 2014-2015 comparing Weibo and Twitter, Fung et al [18] found that the amount of misinformation is low for each platform and does not exhibit meaningful differences across platforms. Relatedly, the authors found that most content focuses on outbreak-related news, Ebola health communication, and responses on both social media platforms. Weibo did, however, emphasize favorable Chinese government behavior—sending relief to Guinea—compared to Twitter. Although a useful comparative study for Ebola, the previous study is unlikely an appropriate analogy for the COVID-19 epidemic because of the coronavirus’s origins in China, which implicated the Chinese government, thereby creating the type of setting where China might have more incentives to shape a particular narrative away from controversial issues [18].

More recently, Rodriguez et al [19] compared COVID-19 misinformation on Weibo and Twitter, although subsetted to a small fraction of total posts by using a keyword search of “coronavirus,” which yielded fewer than 2000 social media posts during their period of study. In addition, the authors extracted an equal number of tweets and Weibo posts, which does not account for the differing sample sizes of users across the 2 platforms. Further, they limited the analysis to just 2 days in February 2020, specifically February 6 and 7, when Dr Li Wenliang, who raised the alarm about coronavirus in China, passed away. The authors did, however, find more misinformation on Twitter than on Weibo. In the following section, we describe our method for studying COVID-19 content across the 2 platforms by way of understanding both the type of discourse and also the potential exposure to misinformation on both Weibo and Twitter. The objective of this study is to compare COVID-19-related information and the relative prevalence of misinformation to further understand public discourse across social media and cultural contexts.

## Methods

### Study Design

To compare content related to COVID-19 on Twitter and Weibo, including misinformation, we studied 3,579,575 posts from both Weibo and Twitter—2,344,332 (65.49%) tweets on Twitter and 1,235,243 (34.51%) posts on Weibo—focusing on content from January 30, 2020, when the World Health Organization (WHO) declared COVID-19 a “public health emergency of international concern,” and February 6, 2020. We then compared top keywords, hashtags, and misinformation (guided by WHO’s COVID-19 misinformation website [8]) for both platforms.



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## Ethics Statement

We registered an academic research application for Twitter's Application Programming Interface (API) in December 2020, which allowed us to search for specific keywords and key dates and obtain Twitter users' publicly available tweets across 2 different batches of posts. Because the posts were made publicly, they were exempt from requiring institutional review board approval. Moreover, our study only included secondary data analysis of publicly available information and deidentified personal individuals' information. The Twitter API allows academic researchers with specific research objectives to obtain precise, complete, and unbiased data, while protecting the security and privacy of people on Twitter and the developer platform.

## Data Collection and Analysis

With respect to Weibo, we used a large-scale COVID-19 social media data set that includes a total of over 40 million Weibo posts [20]. The data set, Weibo-COV, covers posts from December 1, 2019, to April 30, 2020, and contains variables such as location, repost network, post time, and interaction information. To obtain access to the Weibo-COV corpus, we submitted a research application that outlined the objectives of our study to the authors of the data set and received approval. All posts were in Mandarin and therefore accessible to the Mandarin speakers on the research team. Three members of the research team are fluent in reading and speaking Mandarin, 2 of whom are native Mandarin speakers.

Drawing on the approach of Fung et al [21], we compared a 1% random sample of Twitter and Weibo content in the early stages of the pandemic. A random selection of 1%, given the millions of total posts we used, yielded more than 35,000 total posts and is both likely to be representative of content but also manageable from an analysis perspective. The first batch of posts consisted of a 1% random sample of Tweets and Weibo posts created within 24 hours of the WHO declaration that the 2019-SARS-CoV-2 outbreak was a "public health emergency of international concern" (January 30, 2020). The second batch was a 1% random sample of Tweets and Weibo posts created 1 week after the WHO declaration (February 6, 2020), both searching English keywords "coronavirus" and "covid-19" and the Chinese words "新冠," "新型冠状病毒," and "疫情." These 2 windows provide insights into how social media users react, discuss, and interact with content, potentially content that includes purposefully misleading or inadvertently factually incorrect information. Furthermore, the 1-week period allowed us to compare whether there is substantial content moderation on alternative health information across the 2 platforms.

Due to the complexity of the Chinese text, we then segmented the text into phrases using the Viterbi algorithm [18]. The Viterbi algorithm is a dynamic programming algorithm for identifying the most likely sequence of hidden states, otherwise known as the Viterbi path, that results in a sequence of observed events. In this case, the algorithm helped us with segmenting Chinese words and phrases for readability. We recorded the contents and time of posting for each microblog post in a comma-separated file.

We also conducted relative risk (RR) analysis, which emphasized the direction of the relative frequency of keywords and hashtags across the 2 batches. Items that had an RR of greater than 1 were considered trending, whereas a fading item was identified by a number less than 1. To calculate the RR for a keyword or hashtag, we used the following equation:

$$RR_i = P_{iBatch\ 2}/P_{iBatch\ 1}$$

The numerator denotes the probability of tweets/Weibo posts with item i in batch 2, whereas the denominator denotes the probability of tweets/Weibo posts with item i in batch 1.

After computing the RR, we manually coded a random selection of 5%-7% of the social media posts, which comprised the initial 1% random samples, following Fung et al [18]. We then assigned a random number between 0 and 100 for the tweets and posts; if a post was assigned a number of 5 or less, we selected it for manual coding. The proportion of the random numbers was different for each data set, so the manually coded data sets consisted of the following:

- Twitter: batch 1, n=954 (6.1%) of 15,737 tweets; batch 2, n= 448 (5.8%) of 7726 tweets
- Weibo: batch 1, n=279 (5.7%) of 4914 posts; batch 2, n=441 (5.9%) of 7439 posts

Within each selected sample, we categorized the posts into English/Chinese posts and non-English/non-Chinese posts and excluded the latter. Using Fung et al's [21] classification of topics, 3 coders read and classified the content. Each coder first independently reviewed the tweets and Weibo posts and identified them by various categories. After completing this step, the research team then recoded the content to examine and verify whether category decisions aligned across the tweets and posts. Finally, all manual coding efforts were checked by the lead coder for a wide-ranging review and deconfliction. We also included a few unique categories that relate to COVID-19 in our classification, similar to Fung et al's [18] categorization for Ebola-related content (eg, "News of a Case of Someone Spreading Rumor of 'Ebola in Pudong' Being Detained by Police," "Assistance to Guinea-Chinese Medical Team Departure for Guinea"). This decision was made because a portion of the tweets and Weibo posts did not fit into the original categories that Fung et al [18] had designed, but we deemed important, substantial in number, and particular to the COVID-19 situation (eg, "Cheer on," "Dali," "News About Li Wenliang"). In this manner, we provide a comprehensive, multifaceted review of Weibo and Twitter content during these 2 pivotal dates.

In addition, we determined whether tweets and Weibo posts contained sources of misinformation through our manually coding and categorizing of the randomly selected subdata sets. Specifically, we manually categorized microblog contents under different themes to identify the information and misinformation, using the WHO fact-check website to adjudicate accuracy calls [8]. Importantly, WHO has communicated with more than 50 digital companies and social media platforms to safeguard that science-based health messages from the organization or other official sources appear first when individuals search for information concerning COVID-19. Its Mythbusters page


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includes the refutation of falsehoods, such as assertions that water or alcohol can protect against COVID-19 or that the virus cannot spread in humid climates.

## Results

### Data Analysis

Our analysis suggested that Twitter has far more posts centered on the virus, a total of 2,344,322 tweets across the 2 batches, despite the virus being more concentrated in China than in the United States at the time, compared to 1,235,243 Weibo posts across the 2 batches, as illustrated in the number of coronavirus-related posts retrieved shown in Tables 1 and 2. As Table 1 shows in more detail, a number of keywords appear across both Weibo and Twitter batches: "coronavirus," "Wuhan," and even "Li Wenliang." Dr Li Wenliang was a Chinese ophthalmologist known for raising awareness of the early COVID-19 outbreak in Wuhan. Dr Li Wenliang passed away on February 7, 2020, 1 week after the WHO announcement and date of our second batch.

**Table 1.** Top 20 most frequent words on Weibo and Twitter.

| Results[a] | Weibo (N=1,235,243) | | Twitter (N=2,344,322) | |
|---|---|---|---|---|
| | Batch 1 | Batch 2 | Batch 1 | Batch 2 |
| COVID-19 posts/tweets retrieved (raw data), n (%) | 491,353 (39.78) | 743,890 (60.22) | 1,572,928 (67.09) | 771,404 (32.91) |
| Relevant posts/tweets analyzed (1% random sample), n/N | 4914/491,353 | 7439/743,890 | 15,737/1,572,928 | 7726/771,404 |
| Top 20 most frequent keywords | 疫情 (epidemic situation) | 疫情 (epidemic situation) | Coronavirus | Coronavirus |
| | 理由 (justification) | 理由 (justification) | China | China |
| | 肺炎 (pneumonia) | 肺炎 (pneumonia) | Health | Wuhan |
| | 冠状病毒 (coronavirus) | 口罩 (mask) | Virus | Virus |
| | 武汉 (Wuhan) | 大理 (Dali) | Outbreak | Li Wenliang |
| | 新型 (new type) | 加油 (to cheer on) | WHO[b] | Doctor |
| | 口罩 (mask) | 武汉 (Wuhan) | People | Outbreak |
| | 感染 (infect) | 确诊 (diagnose) | Wuhan | People |
| | 加油 (to cheer on) | 物资 (goods and materials) | Emergency | Death |
| | 宠物 (pet) | 求助 (seek help) | Cases | Cases |
| | 确诊 (diagnose) | 冠状病毒 (coronavirus) | Global | Hospital |
| | 医院 (hospital) | 新型 (new type) | Public | News |
| | 病例 (case of illness) | 征用 (expropriate) | World | World |
| | 医生 (doctor) | 防控 (prevent and control) | Confirmed | Public |
| | 抗击 (resist/fight back) | 患者 (sufferer) | Spread | Health |
| | 黄冈市 (Huanggang, prefecture-level city in Hubei) | 李文亮 (Li Wenliang) | Breaking | Disease |
| | 病毒 (virus) | 感染 (infect) | First | Police |
| | 防控 (prevent and control) | 信息 (information) | Illness | Epidemic |
| | 隔离 (quarantine) | 医院 (hospital) | Travel | Media |
| | 卫健委 (National Health Commission) | 抗击 (resist/fight back) | Declared | Infected |

[a]Reflects data from 2 cross-sectional samples of Twitter tweets and Chinese microblogs (Weibo) on COVID-19, January 30-31, 2020 (batch 1), and February 6-7, 2020 (batch 2). Keywords and hashtags are used in Twitter and Chinese microblogs for a number of reasons, such as emphasizing the theme of the post.

[b]WHO: World Health Organization.



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**Table 2.** Top 10 most frequent hashtags on Weibo and Twitter.

| Results[a] | Weibo (N=1,235,243) | | Twitter (N=2,344,322) | |
|---|---|---|---|---|
| | Batch 1 | Batch 2 | Batch 1 | Batch 2 |
| COVID-19 posts/tweets retrieved (raw data), n (%) | 491,353 (39.78) | 743,890 (60.22) | 1,572,928 (67.09) | 771,404 (32.91) |
| Posts/tweets with hashtags (percentage of analyzed posts/tweets, n/N (%) | 3418/4914 (69.55) | 4528/7439 (60.87) | 4982/15,737 (31.66) | 2468/7726 (31.94) |
| Top 10 most frequent hashtags | 共同战役 (Fight the pandemic together.) | 新型肺炎求助通道开启 (new COVID help channel opened) | Coronavirus | Coronavirus |
| | 武汉加油 (Go Wuhan.) | 武汉加油 (Go Wuhan.) | China | China |
| | 最近疫情地图 (latest epidemic map) | 抗疫行动 (fighting COVID movement) | 2019ncov | Wuhan |
| | 世卫组织称无证据显示宠物会感染 (WHO says there is no evidence that pets can get infected.) | 手写加油接力 (Show your support challenge.) | Coronavirusoutbreak | 2019ncov |
| | 抗击新型肺炎我们在行动 (We are acting in the fight against COVID.) | 李文亮医生去世 (Dr Li Wenliang passed away.) | Wuhan | Coronavirusoutbreak |
| | 黄冈疾控负责人一问三不知 (The leader of Huanggang Disease Control doesn't know anything.) | 最新疫情地图 (latest epidemic map) | nCov | wuhancoronavirus |
| | 疫情仍处于扩散阶段 (The epidemic is still in the spreading stage.) | 大理欠理了 (Dali messed up.) | Breaking | Liwenliang |
| | 疫情结束后最想吃的东西 (what you want to eat most after the epidemic is over) | 肺炎患者求助 (COVID patients ask for help.) | WuhanCoronavirus | HongKong |
| | 新型冠状病毒 (novel coronavirus) | 新华锐评 (XinHua/CCP news channel commentary) | PrayforChina | CoronaOutbreak |
| | 河南多地急需医护物资 (Many places in Henan urgently need medical supplies.) | 抗击新型肺炎第一线 (the first line of fighting COVID) | HongKong | CoronavirusChina |

[a]Top hashtags identified in 2 cross-sectional samples of Twitter tweets and Chinese microblogs (Weibo) on COVID-19, January 30-31, 2020 (batch 1), and February 6-7, 2020 (batch 2).

Despite high areas of overlap between the 2 platforms' content, Weibo's content entirely omitted several references that were present on Twitter, including WHO and death. The only reference of WHO on Weibo related to a popular hashtag that underscores the message that pets cannot get infected with COVID-19. In that period, people were not dying in the Twitter-using world, suggesting that individuals writing about death in the Twitter context were referencing the situation in China, and yet "death" was absent from the top words used on Weibo. Weibo instead appeared to reference "pneumonia," a less acute and potentially survivable medical condition. In particular, we saw that Dali, a city in Southwest China's Yunnan Province, was also a popular keyword and hashtag in the Weibo analysis due to the public's reaction over a large controversy [22]. During the 1-week period, Dali intercepted a shipment of masks that was meant for the Chongqing municipality and Huangshi in Central China's Hubei Province, which was the epicenter of the outbreak. As a result, many Weibo users were angry at the city of Dali for intercepting a shipment of surgical masks that had only 8 confirmed cases of COVID-19, whereas the hard-hit Chongqing municipality had 400 cases. Moreover, the government of Dali had already distributed the boxes of surgical masks and could not retrieve them after Chongqing demanded for the shipment [23]. As for the Twitter analysis, we learned that users are interested in the "global" effects of COVID-19 through posts on travel restrictions, Hong Kong, the overall spread, and WHO.

Beyond excluding some topics, such as WHO, that were common on Twitter, while including topics, such as Dali, that



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were critical of government officials, the Weibo content also included whole categories of posts that pushed positive themes and were intended to be reassuring compared to the absence of those types of themes being prevalent on Twitter. Keywords from the Weibo content focused on more positive and encouraging messages or themes (eg, “to cheer on” or the hashtag “pray for China”) or empathy (“sufferer”) compared to Twitter keywords (eg, “death”), which did not appear in the Weibo list. Generally, we found that the Weibo analysis included a substantial amount of unified support in “fighting” the COVID-19 pandemic and for health care workers. For example, 1 Weibo post read, “#2020好起来# #抗疫行动# 勤洗手 戴口罩 2020一定会好起来的 加油！！！ 绿洲 刘宪华Henry-Lau的微博视频 转发理由:转发微博 (English Translation: #2020 #Wash your hands frequently and wear a mask. 2020 will definitely get better! Come on!!! ”

Table 2 summarizes the top 10 hashtags for each microblogging platform. To the extent that hashtags connect social media to a topic and make it easier to discover posts on a particular topic, these provided yet another indication of where the conversation on social media was directed during that period. Similar to the most frequent words, the hashtags largely converged, although they emphasized themes intended to bolster and galvanize the public’s fight against the virus. Further, although Twitter highlighted Hong Kong, in reference to the prodemocracy protests, Weibo hashtags did not register the topic in its top 10.

Next, we addressed the RR based on the prevalence of topics between the 2 platforms, showing the frequency of posts on the pandemic over the 1-week period. Although our research design could not address self-moderation that likely occurs, in part, because individuals anticipate that certain posts will be removed and choose not to post certain material at all, it did at least gauge the moderation that took place over the week under study. Figures 1-8 show the RR computation for the top 20 most frequent keywords and the top 10 most frequent hashtags on both platforms across the 2 batches (January 30-31, 2020, and February 6-7, 2020). We found that the keyword with the highest RR (trending) was Li Wenliang for Twitter and Dali for Weibo.

**Figure 1.** RR of Twitter hashtags (batch 1). RR: relative risk.

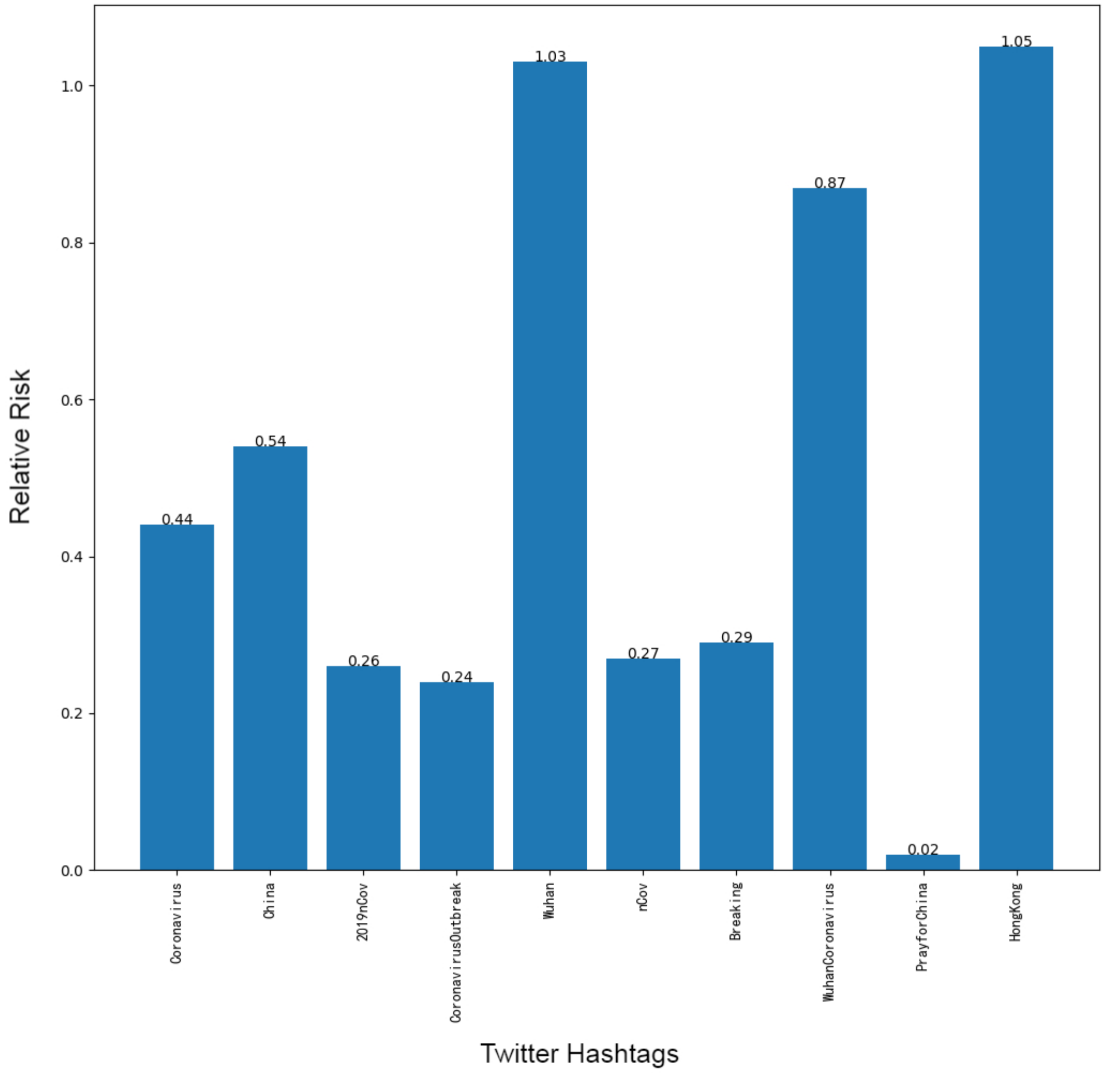



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**Figure 2.** RR of Twitter hashtags (batch 2). RR: relative risk.

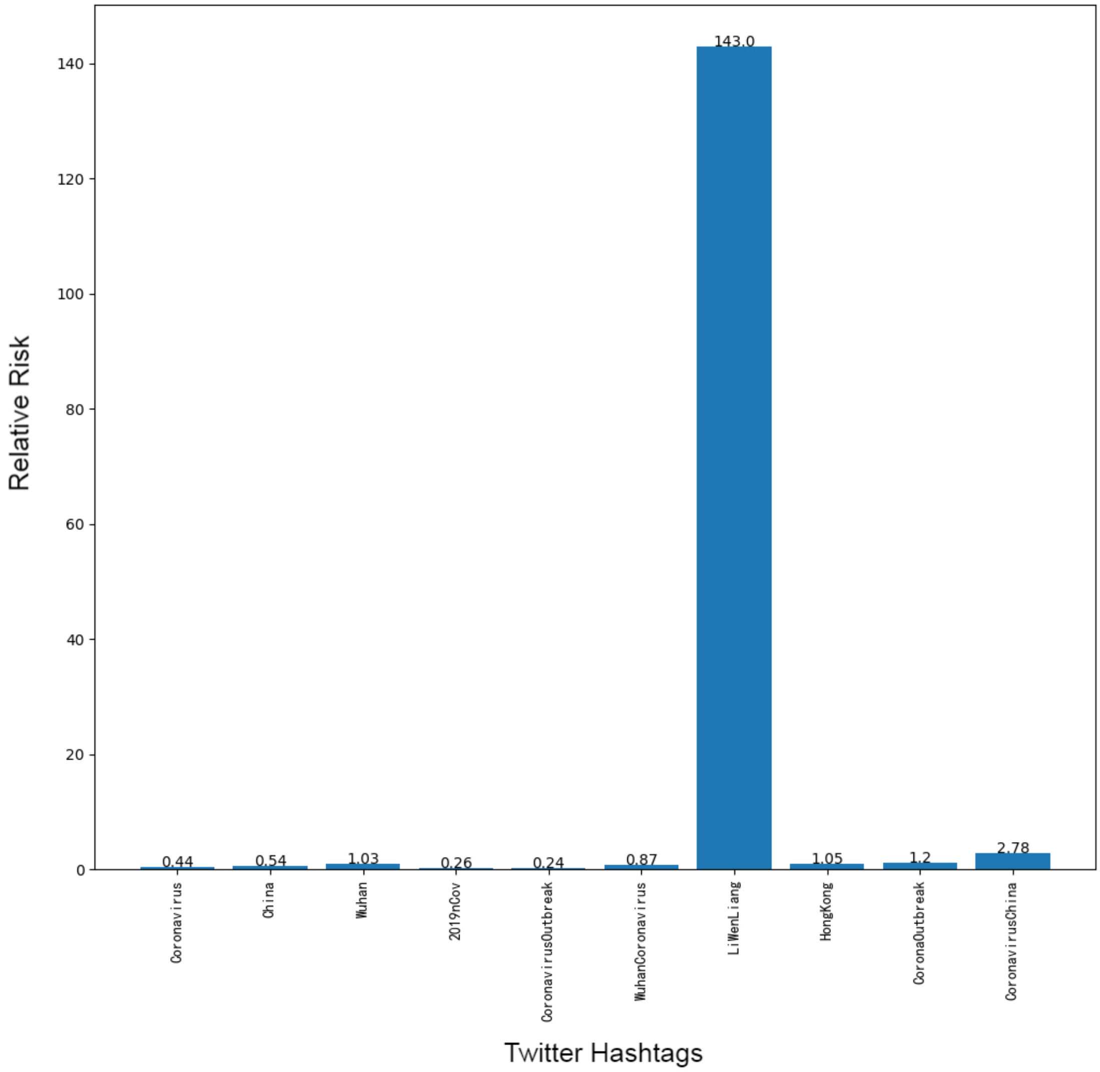




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**Figure 3.** RR of Twitter keywords (batch 1). RR: relative risk.

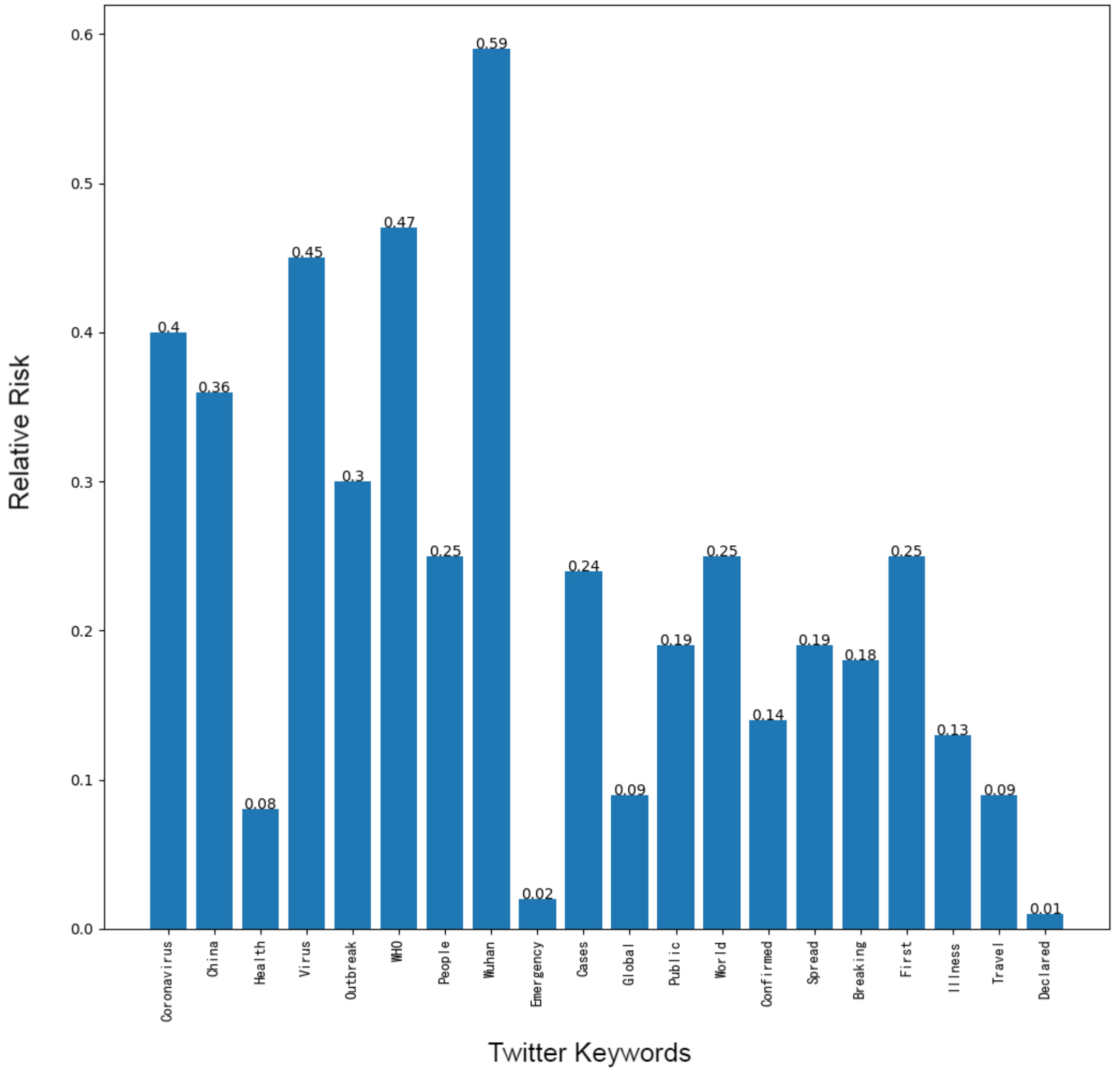




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**Figure 4.** RR of Twitter keywords (batch 2). RR: relative risk.

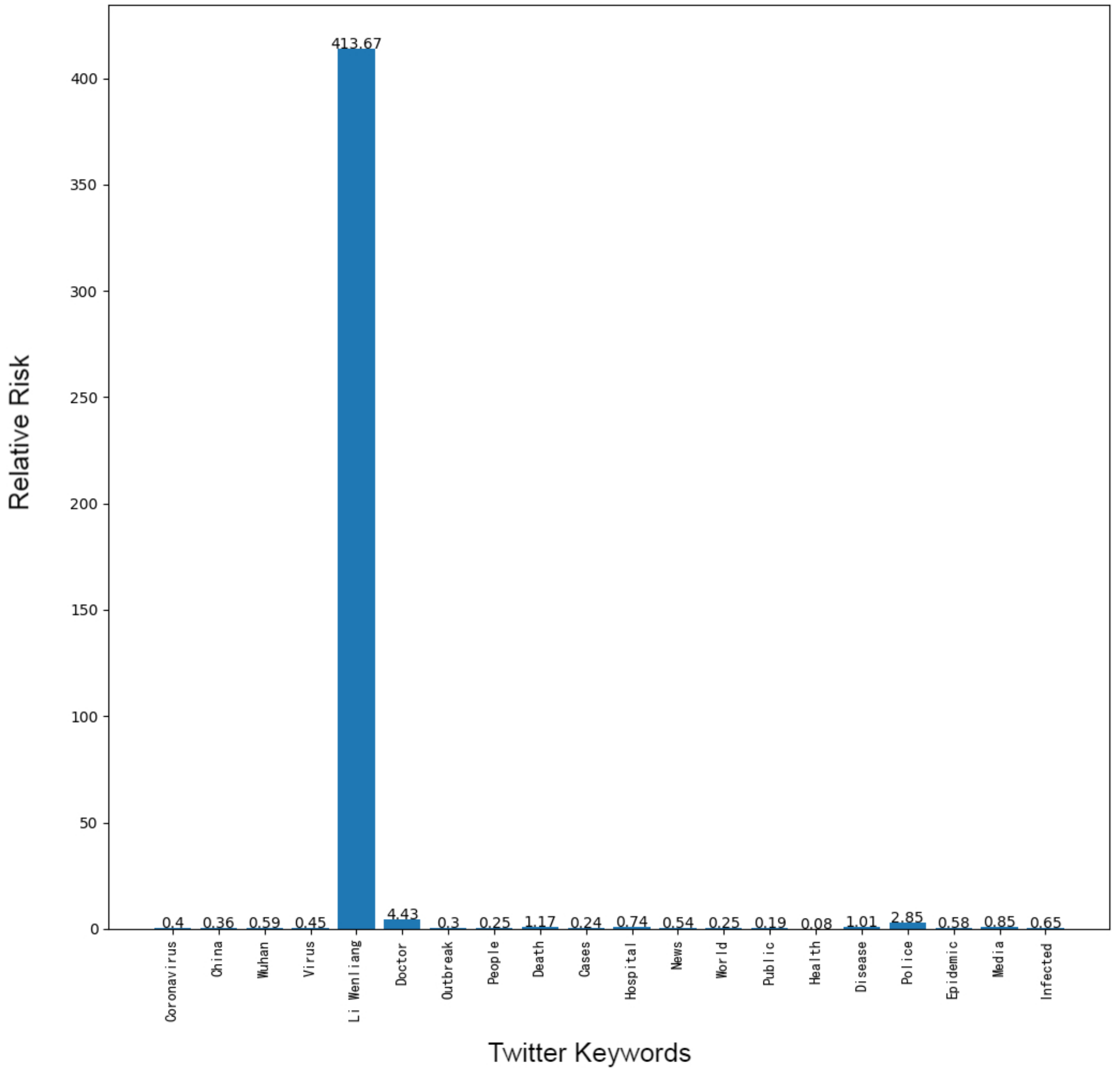




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**Figure 5.** RR of Weibo hashtags (batch 1). RR: relative risk.

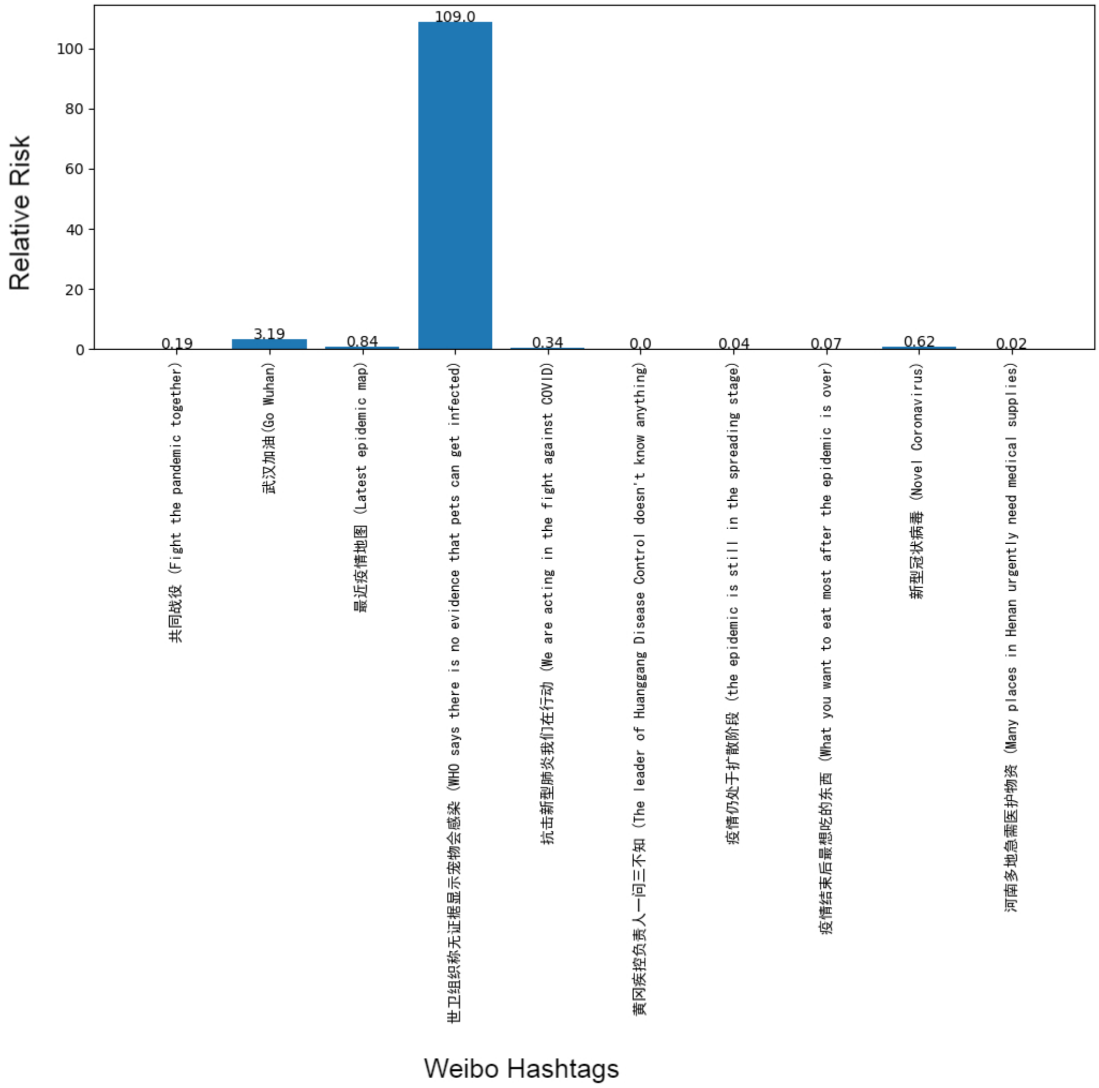



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**Figure 6.** RR of Weibo hashtags (batch 2). RR: relative risk.

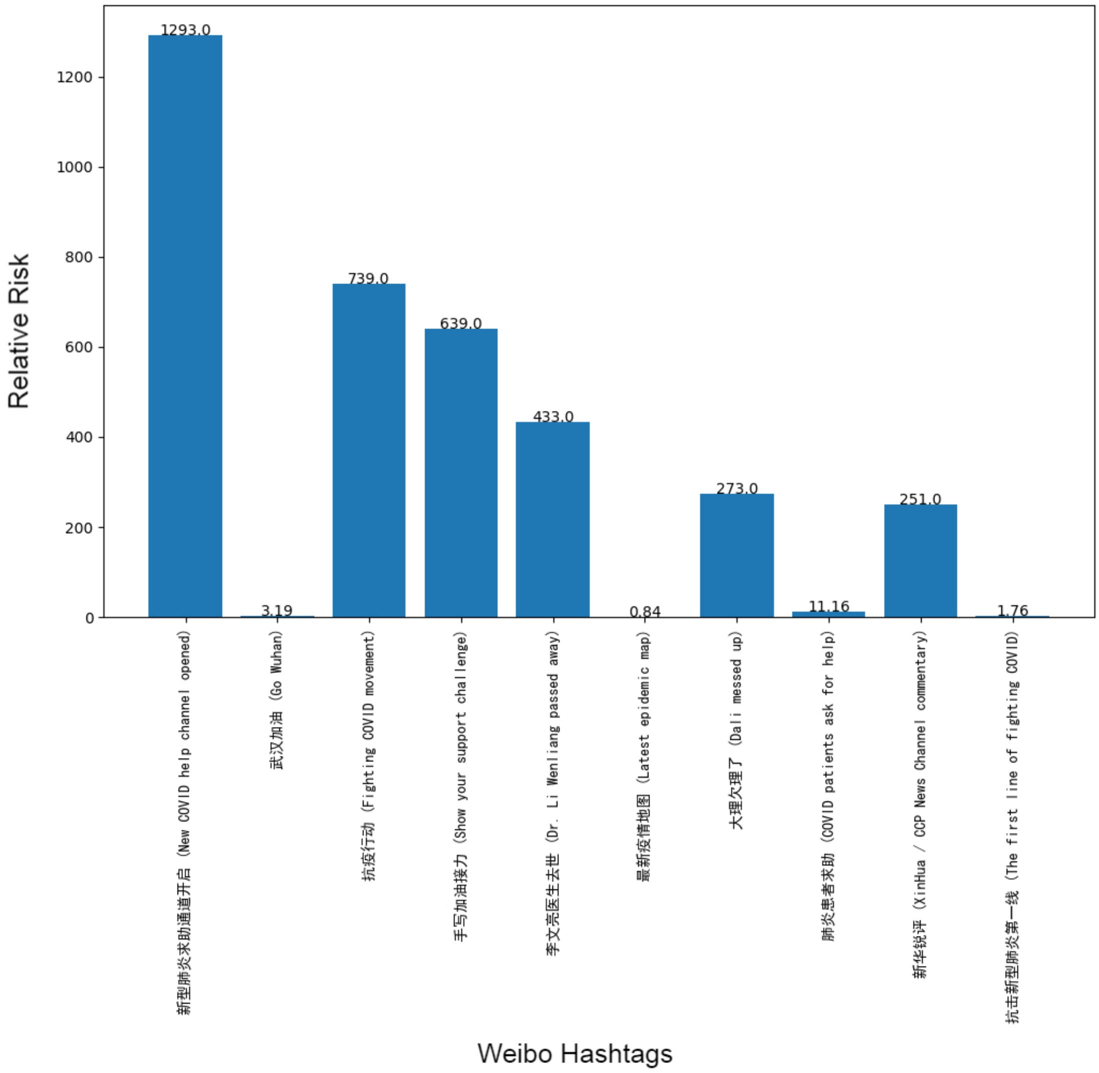




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**Figure 7.** RR of Weibo keywords (batch 1). RR: relative risk.

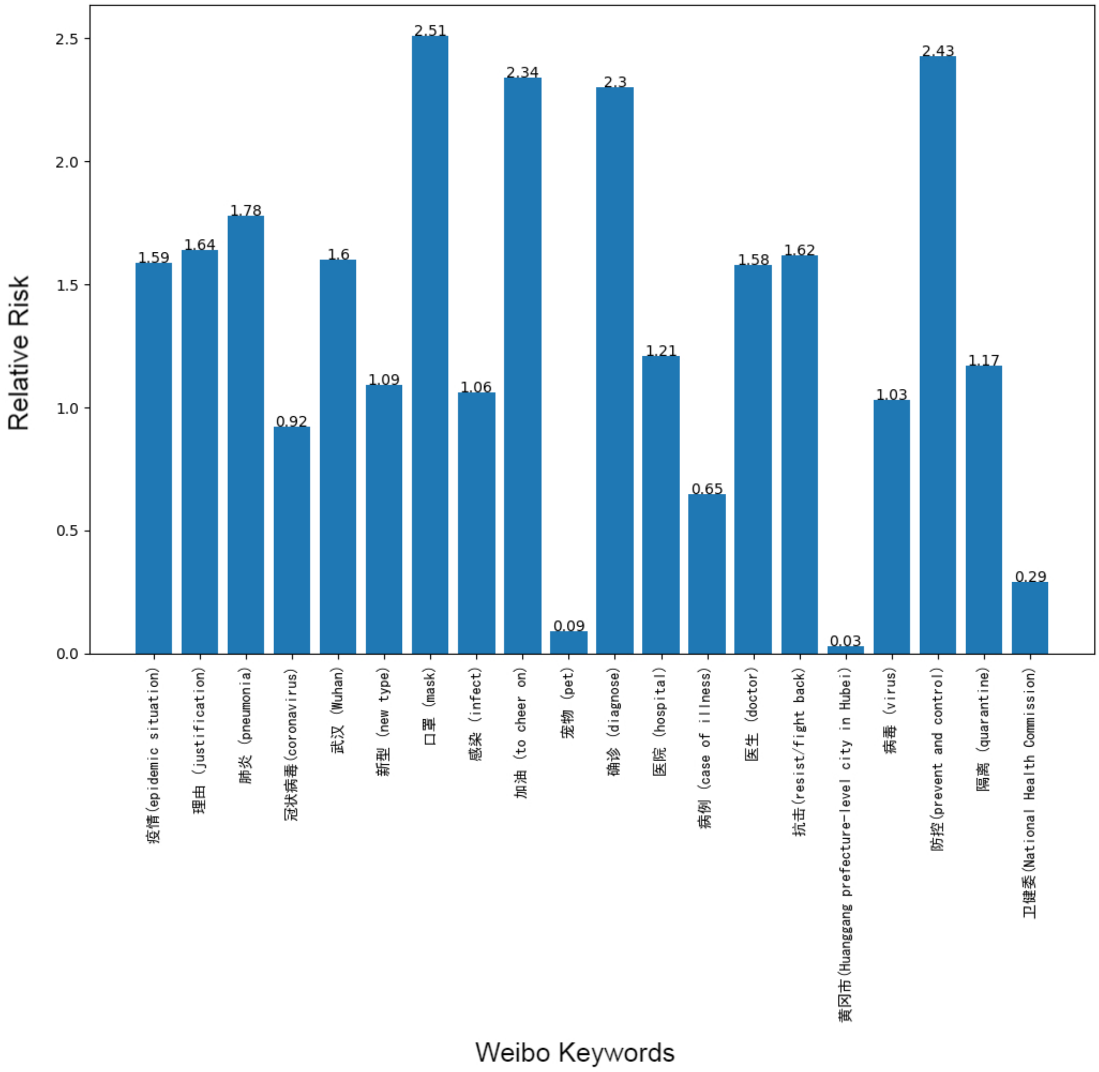



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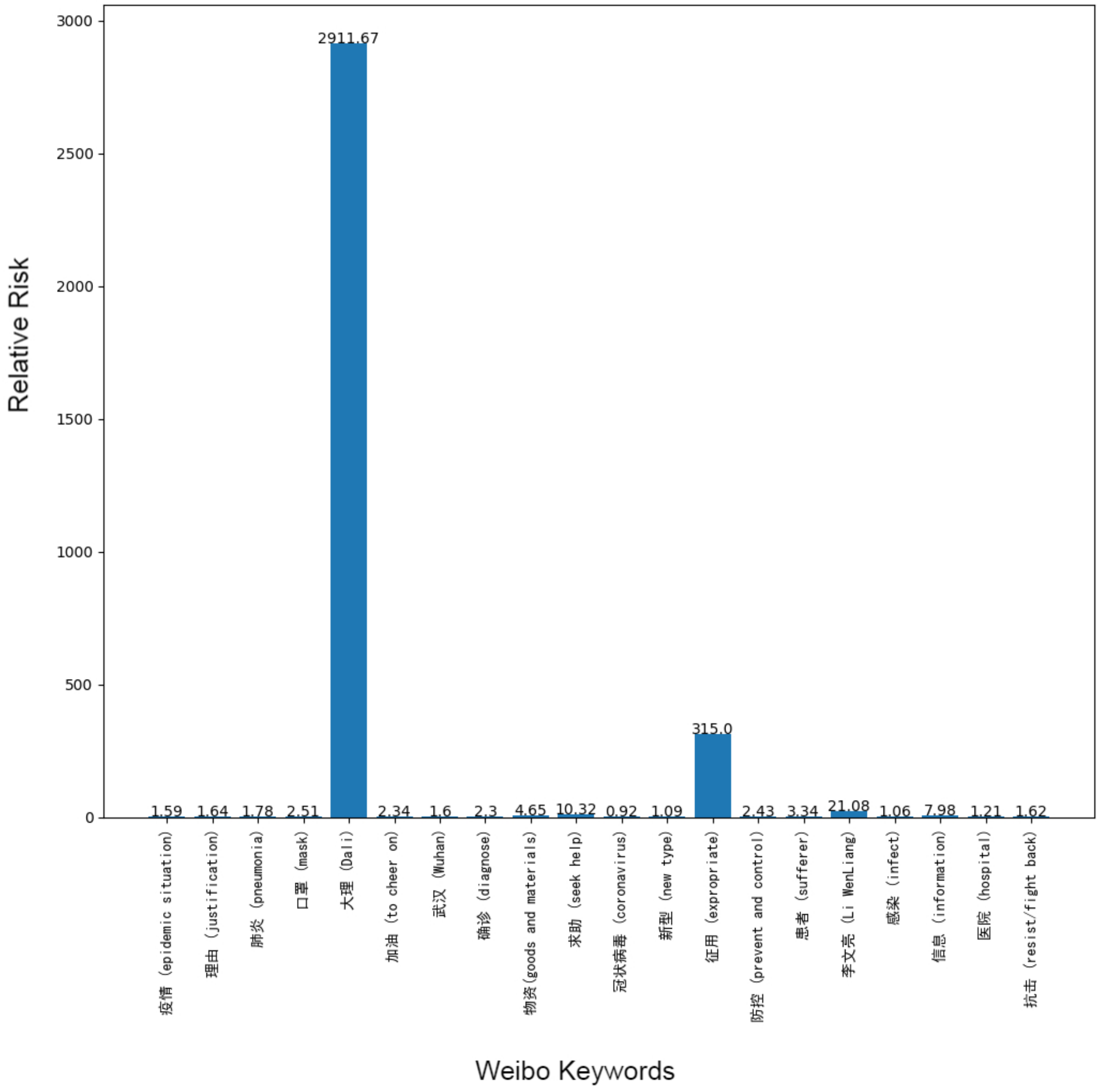
**Figure 8.** RR of Weibo keywords (batch 2). RR: relative risk.




Based on the random selection of 5%-7% of tweets that we manually coded, we found that most content focused news of the outbreak around the world and a growing number of COVID-19 cases across both batches. One representative tweet stated, “Breaking: There are 6 cases of coronavirus in the U.S., says @cdcgov. 1 person to person case has been confirmed in Chicago. CDC says this is a ‘very serious public health situation.’ They expect more cases. CDC is not recommending the general public wear face masks, as of now.” Misinformation was low on both sites, although it was comparatively higher on Twitter than on Weibo. We found that 1.1% of tweets from Twitter contained misinformation on COVID-19, with 5 (0.7%) of 746 tweets after discarding non-English posts in batch 1 and 6 (2.8%) of 211 tweets after discarding non-English posts in batch 2, compared to 0.3% on Weibo, with 1 (0.4%) of 279 posts in batch 1 and 1 (0.2%) of 441 posts in batch 2—a higher level of misinformation by a factor of almost 4 in the 1-week period on Twitter compared to Weibo.

By comparison with misinformation outside the domain of public health, Twitter reported that 0.3% of election-related tweets were flagged as misinformation [24]. Given the large volume of tweets posted on these topics, whether the election or coronavirus), and the tendency of users to engage with misinformation tweets more than accurate ones [25], the rate is notable. Textbox 1 outlines the various tweets that include misinformation found in both batches, and Figure 9 shows a screenshot illustrating an example of Twitter misinformation.

Misinformation was comparatively lower on Weibo, as seen in Table 3. Figure 10 shows an illustrative case of misinformation on the site. Of course, we cannot eliminate the possibility that more misinformation existed but was just removed quickly. Indeed, tweets themselves pointed to evidence of active moderation on Weibo, with 1 tweet stating that “the two trending topics censored by Weibo tonight: #wuhan government owes Dr. Li Wenliang an apology #we want freedom of speech #both had tens of thousands of views before disappearing into this dark night.”



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**Textbox 1.** Misinformation tweets.

**Batch 1 (5 tweets)**

- "#coronavirus possibilities:
  - it is fear porn
  - this is a vaccine scam
  - this is a bio weapon leaked out but will be contained with a vaccine scam
  - the chinese lab fucked up and let a bio weapon out they cannot stop now
  - this is an illuminati depopulation plot
- "given that it's a global problem, the fact that the coronavirus only has around 10k confirmed cases and a 2% fatality rate means that you are more likely to get into a car accident than ever being influenced by this. despite that, the number of anti-chinese comments is crazy."
- "deeply ridiculous: 'indian government slammed for recommending homeopathy for coronavirus prevention' https://t.co/stxcir5n2v what is the harm of tolerating pseudoscience? sigh."
- "here we go, this will be trump's fault because of 'climate change' u.n. agency declares global emergency over virus from china: https://t.co/dyyedmdthr via @aol"
- "conspiracy theories surrounding #coronavirus as a lab made bioweapon somehow reminded me of commercial classic #7aumarivu of 2011 . this was reminded again by a friend during a conversation today. #arm was a visionary director indeed! #suriya https://t.co/vbiptn4wto"

**Batch 2 (6 tweets)**

- "islamic cleric discovers a cure for #coronavirus by mixing fresh camel piss and cow's milk and drinking it straight while its desert warm. #coronavirusoutbreak https://t.co/gypis0z1wf"
- "made in china to destroy canada"
- "something tells us, if anyone wants to find out #whatreallycaused the coronavirus pandemic that has infected thousands of people in china and around the globe, they should probably pay dr. peng a visit. dr peng can be reached at peng.zhou@wh.iov.cn, his phone# is 87197311 zh https://t.co/kzhlotnyjl"
- "cave full of bats in china identified as source of virus almost identical to the one killing hundreds today"
- "worst part about coronavirus is how it makes you super-paranoid when you get sick yrself. i'm clearly coming down w/a sinus infection, and obviously it has nothing to do w/that but man...on the other hand, i wonder if that chinese wuhan bat soup i had last week was a bad idea."
- "sf officials urge public to attend lunar new year celebration, say there's no coronavirus threat. story by"

*Note*: Misinformation was coded based on a 5%-7% random sample of the initial 1% random sample, yielding 746 tweets for batch 1 and 211 tweets for batch 2.

**Figure 9.** Screenshot of a public tweet that contains COVID-19 misinformation from batch 2.




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**Table 3.** Misinformation posts (Weibo)a.

| Language | Batch 1 (1 Weibo post) | Batch 2 (1 Weibo post) |
|---|---|---|
| Chinese | 免疫力。近期的新型冠状病毒引起了社会的广泛关注，人们普遍认为抵抗力好的人，被传染的机率就小，而这与免疫力有很大的关系。免疫力是人体自身的防御机制，是人体识别和消灭外来侵入的任何异物（病毒、细菌等）、处理衰老、损伤、死亡、变性的自身细胞以及识别和处理体内突变细胞和病毒感染细胞的能力。中医认为所有的好的东西，比如人们常说的免疫力、抵抗力都称之为“正气”，一切导致疾病的因素，称为“邪气”。当人的正气充足的时候，就不被邪气所侵犯，所以《黄帝内经》曰：“正气内存，邪不可干，邪之所凑，其气必虚” 。也就是说，当你正气充足的时候，一切致病因素的邪气就拿你没办法，不可能侵犯你。而你得病的时候，一定是正气虚的时候。因此，中医强调正气一定要充足，那么免疫力就会比其他人好，患病的几率也会下降很多 | 最新报道，《健康报》记者采访仝小林院士。要点一：医院病人来源于发热门诊，发热门诊病人来自于社区，因此中医药要早期介入，全面覆盖，下沉到社区。要点二：武汉抗疫1号方，以及根据症状侧重拟订的甲乙丙丁4个加减方，2月4号起就已经在临床用了，工作人员都在加班加点发放给患者，一个患者发3天的量，然后再调整，某知名女财经人士讽刺的中医抗疫方是“花架子”，没落实，对不起，打脸了！要点三：辨证论治，一人一方，最为理想，但大疫当前，资源紧张，无法从容优雅，借鉴以往中医治疗瘟疫的经验，采取“通用方+加减法”模式，是目前最可行的方法，只能退而求其次，请中医同道同心同德。要点四：方舱医院患者也有望用上中药，中医药人一直在努力。仝院士辛苦了转发理由:转发微博 |
| English translation | Immunity. The recent novel coronavirus has aroused widespread concern in society. It is generally believed that people with good resistance have a smaller chance of being infected, and this has a lot to do with immunity. Immunity is the body's own defense mechanism. It is the body's ability to recognize and eliminate any foreign objects (viruses, bacteria, etc.) that invade from the outside, deal with aging, damage, death, and degeneration of its own cells, as well as recognize and process mutant cells and virus-infected cells in the body. Chinese medicine believes that all good things, such as immunity and resistance, are called “zhengqi”(positive energy), and all factors that cause diseases are called “xieqi” (evil energy). When a person's zhengqi is sufficient, he will not be invaded by evil spirits, so the “Huangdi Neijing” (this is a traditional Chinese medicine book) says: “If there is a zhengqi (positive energy), xieqi (evil energy) can not interfere, if evil is combined, its energy will be empty.” In other words, when your zhengqi is sufficient, all the xieqi of the pathogenic factors can do nothing, and it is impossible to invade you. And when you get sick, it must be a time of deficiency of zhengqi. Therefore, Chinese medicine emphasizes that there must be sufficient zhengqi, then the immunity will be better than other people, and the chance of illness will be much lower. | The latest report, a reporter from “Health Daily” interviewed Academician Tong Xiaolin. Key point 1: Hospital patients come from fever clinics, and fever clinic patients come from the community. Therefore, Chinese medicine should intervene early, fully cover, and sink into the community. Point # 2: No. 1 party Wuhan fight against SARS, according to the symptoms and focus on ABC D plus or minus four parties prepared, February 4 onwards has been in clinical use, and the staff are issued to patients in overtime, made a 3 patients The amount of the day, and then adjust, a well-known female financial person ridiculed the traditional Chinese medicine anti-epidemic prescription is “flowery”, not implemented, sorry, face! Point 3: Syndrome differentiation and treatment, one person for one party is the most ideal. However, the current pandemic, resources are tight, and it is impossible to be calm and elegant. Learning from the past experience of Chinese medicine in treating plagues, adopting the “general prescription + addition and subtraction” model is the most feasible method at present Can retreat to the second best, please Chinese medicine fellows with one heart and one mind. Point 4: Patients in Fangcang shelter hospitals are also expected to use Chinese medicine. Chinese medicine practitioners have been working hard. The same academician worked hard. Reason for forwarding: forward Weibo |

[a]Misinformation was coded based on a 5%-7% random sample of the initial 1% random sample, yielding 279 posts for batch 1 and 441 posts for batch 2. Weibo increased the post text limit to 2000 characters. However, posts longer than 140 characters are truncated on the platform, but users can click a “see entire” text button to unfold the rest of the post.



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**Figure 10.** Screenshot of a public Weibo post that contains COVID-19 misinformation from batch 2. This post specifically discusses an "antiepidemic" prescription in treating those infected with COVID-19.


## Discussion

### Principal Findings

We found that across 2 widely used platforms in and outside China, Weibo and Twitter, the nature of discourse converges to a considerable degree, with the platforms both being used to exchange information about the transmission, prevention, and impacts of the COVID-19 pandemic. Similar to Wang et al [26], however, we found far more of a positive, cheerleading valence on Weibo compared to Twitter, with the Chinese microblogging site frequently emphasizing the community fight against the virus in ways that are not observable on Twitter. Correspondingly, as with Lu et al [17], we did see the presence of topics that might be seen as implicating the regime in a negative light, such as the references to the whistleblower doctor, but those were balanced out with the supportive content referenced above. Twitter users, corroborating the finding of Deng et al [27], were attentive to economic implications of the pandemic compared to the virtual nonexistence on Weibo. In terms of misinformation, Weibo had comparatively less misinformation than Twitter, which corroborates a previous analysis of relative cross-platform differences in the context of Ebola that showed less misinformation on the Chinese site [18].

Taken together, our research makes several contributions to the understanding of cross-platform, cross-national content exchange and misinformation across in the context of COVID-19. First, although scholars have studied misinformation in a political context [28], in previous medical epidemics [29], and increasingly in the COVID-19 context [30], comparative study is more limited. Second, a better understanding of misinformation matters in a public health context because it has implications for whether individuals can make meaningful choices about policies, for example, the risks and benefits of complying with public health guidance [6]. Third, the dissemination of misinformation—because of its connection with a range of behaviors such as anxiety, self-prescription of medication and treatments, erosion of trust in government authorities [31], and lower compliance rates on public health measures such as social distancing measures [32]—foreshadows likely public health outcomes. Thus, a closer scrutiny of both patterns of discussion on social media and the presence of misinformation has important implications for anticipating the


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future course of a virus that has claimed millions of lives. Finally, understanding COVID-19 content in a cross-national context helps shed additional light on differences in algorithms and interventions that Weibo versus Twitter use to structure content [15], while also informing potential countermeasures for online misinformation, such as flagging, correcting, or removing online content [10].

### Limitations

Our study does have limitations. First, we note that our results are not generalizable due to the small sample size of tweets and posts that were reviewed, which was based on a 1% random sample of content. Second, we compared posts on Weibo and Twitter at the same point in time in the interest of internal validity, based on WHO's declaration of a global health emergency, which provided a common baseline. We recognize, however, that the arc of COVID-19 was different in China (expressed on Weibo) than outside China (Twitter), which may have affected the nature of posts and the public interest or tolerance for posting misinformation. On January 23, 2020, for example, Wuhan's 11 million residents had been cordoned off from the rest of the country, speaking to the intensity of the virus already by the time of the WHO declaration. By contrast, the first COVID-19 death in Europe was not reported until February 12 and, New York City schools closed on March 15 [33]. Future research should compare potential levels of misinformation at various points during the pandemic in different countries beyond the 1-week mark of the WHO announcement.

Although there were only a few posts containing misinformation across the Twitter and Weibo batches in our study, we acknowledge that misinformation comprises a small percentage of the overall content based on our manual coding. For reference, Fung et al [18] identified 6 tweets and 2 tweets in batch 1 and batch 2, respectively, as alternative health information on Twitter, and 11 posts and 3 posts in batch 1 and batch 2, respectively, on Weibo. These are not large numbers by any means for both platforms, which is similar to our study's single-digit posts, which we identified as misinformation. The 1% random samples of tweets and Weibo posts facilitates a fair way of assessing the representative content based on various categories and minimizes biases. This study's findings are mostly explanatory in nature regarding the level of misinformation found on both platforms during the 1-week period. However, additional research could replicate our study with different 1% random samples of tweets and Weibo posts and examine whether there is consensus or contrasting findings.

Further, although our analysis was agnostic about the position of WHO, social media platforms, and the Centers for Disease Control and Prevention (CDC) that more aggressive moderation was warranted, given the public health crisis, we acknowledge the possibility of overreach. Future studies might also engage with normative questions about the potential for overreach when it comes to content moderation, considerations about whether organizations such as WHO should be endorsing control of information, comparison of COVID-19 content on both platforms with longer periods, and the inverse of our study, which is to analyze posts or accounts that were removed due to misinformation but ultimately found to be accurate and permissible.

### Conclusion

In May 2020, WHO observed that "managing the infodemic is a critical part of controlling the COVID-19 pandemic: it calls on Member States to provide reliable COVID-19 content, take measures to counter mis- and disinformation and leverage digital technologies across the response" [34]. We showed that Twitter and Weibo, the 2 most widely used microblogging platforms in the United States and China, respectively, have carried out information management in different ways. Perhaps most notable is not the reliability of content—both had low levels of misinformation—but rather the absence of certain topics, such as WHO, Hong Kong, and death, as well as the tendency of Weibo posts to provide societal cheerleading, a phenomenon absent on the US-based equivalent. One limitation of our study is the small sample size of the overall COVID-19 content on Twitter and Weibo during this 1-week period. However, we invite and encourage future research to incorporate a larger sample size of tweets and posts and examine longer periods on this important topic.

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## Conflicts of Interest

None declared.

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## Abbreviations

**API:** Application Programming Interface
**RR:** relative risk
**WHO:** World Health Organization


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Original Paper

# COVID-19 and Vitamin D Misinformation on YouTube: Content Analysis

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## Abstract

**Background:** The "infodemic" accompanying the SARS-CoV-2 virus pandemic has the potential to increase avoidable spread as well as engagement in risky health behaviors. Although social media platforms, such as YouTube, can be an inexpensive and effective method of sharing accurate health information, inaccurate and misleading information shared on YouTube can be dangerous for viewers. The confusing nature of data and claims surrounding the benefits of vitamin D, particularly in the prevention or cure of COVID-19, influences both viewers and the general "immune boosting" commercial interest.

**Objective:** The aim of this study was to ascertain how information on vitamin D and COVID-19 was presented on YouTube in 2020.

**Methods:** YouTube video results for the search terms "COVID," "coronavirus," and "vitamin D" were collected and analyzed for content themes and deemed useful or misleading based on the accuracy or inaccuracy of the content. Qualitative content analysis and simple statistical analysis were used to determine the prevalence and frequency of concerning content, such as confusing correlation with causation regarding vitamin D benefits.

**Results:** In total, 77 videos with a combined 10,225,763 views (at the time of data collection) were included in the analysis, with over three-quarters of them containing misleading content about COVID-19 and vitamin D. In addition, 45 (58%) of the 77 videos confused the relationship between vitamin D and COVID-19, with 46 (85%) of 54 videos stating that vitamin D has preventative or curative abilities. The major contributors to these videos were medical professionals with YouTube accounts. Vitamin D recommendations that do not align with the current literature were frequently suggested, including taking supplementation higher than the recommended safe dosage or seeking intentional solar UV radiation exposure.

**Conclusions:** The spread of misinformation is particularly alarming when spread by medical professionals, and existing data suggesting vitamin D has immune-boosting abilities can add to viewer confusion or mistrust in health information. Further, the suggestions made in the videos may increase the risks of other poor health outcomes, such as skin cancer from solar UV radiation.

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**KEYWORDS**

COVID-19; vitamin D; misinformation; YouTube; content analysis; social media; video; infodemic; risk; prevention; health information; immunity; immune system; supplements; natural medicine

## Introduction

The SARS-CoV-2 virus outbreak is a serious global threat, accompanied by an "infodemic" of health misinformation and disinformation [1]. The difference between misinformation and disinformation is based on the intent of the creator or sharer; misinformation is false but not intended to cause harm, while disinformation is deliberately created or shared to mislead or manipulate its audience [2]. Both can be damaging to public health and trust. Although social media can be a valuable tool to share health messaging for free, where it is widely available worldwide [3,4], the overabundance of both accurate and inaccurate health information available to the general public through mainstream and social media can lead to risky health behaviors and, in some cases, even death [5]. There are many factors that influence the consumption of online health misinformation. For example, a recent work by Scherer et al [6] showed that people who are susceptible to misinformation on 1 topic are more likely to be influenced by a variety of misinformation and that those with less education and health literacy, less trust in the health care system, and more positive views toward alternative medicine are also more susceptible to belief in misinformation.

Research has shown that people go online to investigate and diagnose symptoms, to look up treatments and alternative treatments, to research information provided by health care professionals, to research personal as well as public health concerns and topics, to engage with others who have similar health conditions or concerns, and to research and rank health care providers [7,8]. People who use social media for health information face increased exposure to misinformation [9], which in turn can influence their health-related decisions [10]. The explanations of why some are more susceptible to health misinformation are complex, yet research shows that political ideology [11], media use, and trust in government, science, and health authorities can all play influential roles [12].

YouTube is a video-sharing platform visited by approximately 2 billion viewers daily [13]. Over 70% of the videos viewed on YouTube.com are accessed via mobile devices, suggesting that information and entertainment available on the platform are easily accessible in a variety of environments, and YouTube.com is 1 of the most accessed websites [14,15]. In a survey conducted by the Health Information National Trend Survey (HINTS), 8 of 10 people seek health information on the internet [14,16]. Evidence suggests that people use social media to access health information because it can supplement information provided by their health care providers and provide social supports [17].

Despite being a potentially positive source of health information for many, misinformation and disinformation are prevalent on YouTube [15,18]. Currently, YouTube has practices in place to prevent the spread of harmful misinformation [19], though clearly not enough [20]. Health information may be presented in a way that makes it challenging to differentiate the accurate from the inaccurate or to identify misleading statements [21]. Some health professionals take part in spreading misleading opinions and misinformation, adding to the difficulty viewers can experience navigating accurate versus inaccurate health information online [22].

SARS-CoV-2 and the disease it causes (COVID-19) have had an impact on day-to-day life, employment, health care, and general sanitation practices [23]. By April 4, 2020, more than 1 million cases of COVID-19 were confirmed worldwide [24]. At 2 years into the pandemic (as of December 13, 2021), cases had risen to 270 million, accounting for over 5 million deaths. The World Health Organization has provided recommendations for staying healthy and preventing the spread of the virus [25]. Several vaccines are now available in many countries, and efforts to vaccinate large proportions of the population are of paramount importance to curbing the spread of COVID-19, but as of the date of this publication, there is no known cure for COVID-19 [26]. Despite this, there has been an influx of social media posts claiming that an array of substances have preventative or curative properties against COVID-19 and selling dubious "immune boosting" kits, home test kits, and personal protective equipment [27]. Examples of the fake prevention and treatment products promoted on Twitter and Instagram include a mix of so-called immune-boosting supplements (eg, essential oils, some foods, colloidal silver) and unproven pharmaceutical treatments (eg, hydroxychloroquine, remdesivir) [27].

One frequently amplified dietary supplement (during the pandemic but certainly not a new trend) is vitamin D, available through consumption of naturally occurring or fortified foods, supplementation, and synthesized naturally in the skin after UV radiation exposure [28]. The current understanding of the important functions of vitamin D in the body include regulation of serum calcium and phosphate homeostasis, which aids in the maintenance and development of bones. Foods naturally containing vitamin D include fatty fish, fish liver oil, and egg yolks, while other common foods often fortified with synthetic vitamin D include milk, margarine, bread, and orange juice [29]. The fortification is done to prevent vitamin D deficiency, which can lead to rickets. Beginning in the early 2000s, an increasing number of studies investigated vitamin D as a preventive or curative agent for a wide variety of ailments and this has only increased over the past 20 years (Figure 1, data from PubMed), with an evident spike in 2020-2021. Even though it has been extensively studied as a potential preventive agent for a variety of cancers and other chronic and infectious diseases, evidence for the benefits of supplementation have largely failed to show appreciable beneficial effects on human health (besides in cases of extreme deficiency) [29-31]. Early in the COVID-19 pandemic, a correlation between lower vitamin D levels and severity of outcomes was reported across many studies, which led to the idea that supplementation (either preinfection as a preventive agent or postinfection to support treatment) may play a role in pandemic control [32,33]. The most recent



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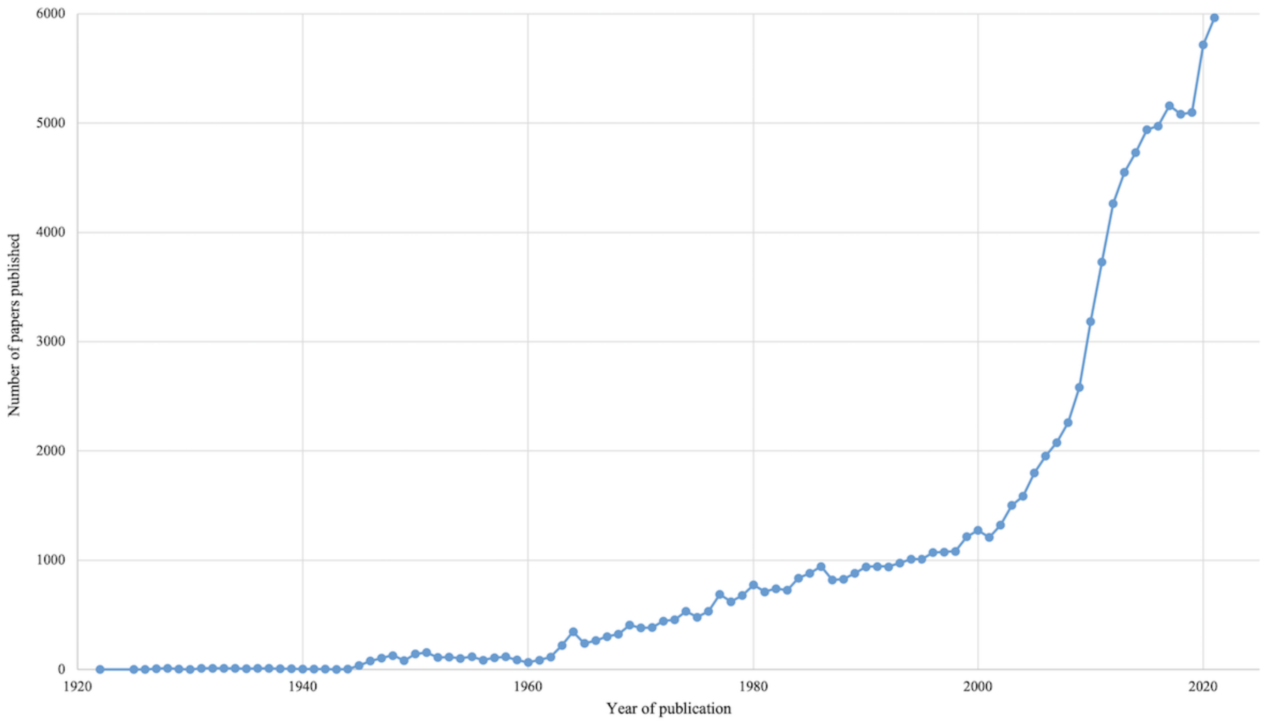
meta-analysis on the topic concluded that vitamin D deficiency can increase the susceptibility to severe COVID-19, but noted that the included studies suffered from high risk of bias and significant heterogeneity and that several of the randomized control trials were too widely heterogenous to include in meta-analysis [34].

**Figure 1.** Number of publications over time in PubMed for 'vitamin D', 1922-2021.




Recommended daily supplementation doses of vitamin D range from 400 IU to 800 IU, depending on the age and condition of the individual, and consuming excess of 4000 IU is generally not recommended as safe [28]. Several companies have advertised supplements (including ones that contain vitamin D) as having immune-boosting properties and thus are potentially profiting from the misinformation infodemic accompanying the COVID-19 pandemic [35]. Recommendations to take a supplement without adequate medical reference or advice may be harmful to the individual and can lead to hypercalcemia and even death in rare cases [36].

The aim of this study was to qualitatively analyze how vitamin D was presented in association with COVID-19 in YouTube videos shared in 2020. Inaccurate or inappropriate messaging regarding vitamin D and COVID-19 may be problematic for a host of reasons, including causing people to take supplements to feel that they are safe from a highly infectious disease that requires vigilant public health behaviors and vaccination. In addition, it may help to drive and legitimize scientifically inaccurate conceptions of immune boosting.

## Methods

### Data Collection

We searched YouTube.com for the keywords “COVID,” “coronavirus,” and “vitamin D” on June 10, 2020, and again on December 7, 2020. We used the Google Chrome web browser, and to limit bias associated with a personal Google.ca account or prior search history, an incognito web browser was used, and no Google account was linked to the search. Browser history was also erased, including cookies and cache, prior to conducting each search. Default search filters were not modified to present the findings in the most common search order, in order of relevance, as it would appear when a person usually searches for a video on YouTube. During each data collection event, search results were collected from the first 3 pages of results, or 60 videos, as previous studies have suggested that most individuals do not view results past the third page [37]. URLs from the first 60 posts of search results were transferred to Microsoft Excel, along with descriptive characteristics, such as the result number, post title, account name, date posted, engagement (thumbs up, thumbs down, and number of comments) on the date of data collection, and type of account.

Only English YouTube videos that discussed COVID-19 *and* vitamin D were included. Videos were excluded if they discussed only 1 of the 2 information categories (ie, COVID-19 or vitamin D). Duplicate videos were also removed.

### Content Analysis

Content analysis is a method of taking valid and replicable inferences from a group of texts for the purpose of specific research context, as used in previous studies [38]. The posts were analyzed using a coding framework (Multimedia Appendix 1) similar to previous social media content analysis studies conducted by our team [39-41] and a codebook developed a priori that was based on COVID-19 themes seen in previous studies and vitamin D–specific themes. Audio and visual content was coded together to ensure the unique impact of YouTube videos was coded appropriately. During each data collection event, a team of 2 coders (authors SF/EQ, SLF/CFS) used the



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code book to code all videos for useful (all accurate information) or misleading (any inaccurate or misleading content) COVID-19 and vitamin D information, unsafe sun exposure recommendations, and confusing correlation with causation. In particular, videos were tagged as misleading if they included information that vitamin D prevents or cures COVID-19, which is a statement that is not in line with the current evidence base, which presently only concludes a correlation between the 2 [34]. The video content was then recorded for areas of interest described in the codebook: a set of codes and inclusion criteria/descriptions developed a priori. If differences in coding results could not be resolved through a consensus-driven discussion between coders, the senior author (CP) was used as a third reviewer to reach consensus. During analysis, the account holder was investigated to determine the type of user (medical professionals included users who stated on their account that they are qualified and work in a medical field; this excluded chiropractors and naturopaths).

### Statistical Analysis

In addition to qualitative content analysis, we calculated simple descriptive statistics to investigate the prevalence of misinformation in our collected videos, as well as whether engagement metrics differed by video accuracy. Bivariate analyses were conducted using various video metrics and parameters to assess potential associations and patterns in the collected data. These analyses consist of generating 2-way tables that describe the relationship between multiple pairs of individual metrics. Chi-square or Fisher exact tests were conducted depending on the appropriateness of the cell size to assess associations between metrics, where strengths of association are represented using *P* values [42].

## Results

### Data Collection

In total, 77 (64.2%) of 120 YouTube videos screened were included in our analysis. We excluded 27 (22.5%) YouTube videos as they did not present information on vitamin D *and* COVID-19 (ie, the videos only discussed 1 of the 2 topics of interest). Videos were also excluded due to duplication (n=13, 10.8%), non-English language (n=2, 1.7%), or blocking by YouTube on copyright grounds (n=1, 0.8%).

The 77 videos included in our study had a total of 10,225,763 views at the time of our analysis. Videos posted by medical professionals accounted for the majority of the videos (n=34, 44%) included in our analysis, followed by "other," for example, personal (n=24, 31%), and news (n=19, 25%) account types.

### Accuracy and Engagement Metrics

Nearly three-quarters (57/77, 74%) of the videos contained at least some misleading information about COVID-19, and 60 (78%) contained misleading information about vitamin D (Table 1, Figure 2). Indeed, most videos (55, 71%) contained at least some misleading information about *both* COVID-19 and vitamin D, and only 15 (19%) videos were accurate in their statements about vitamin D and COVID-19. A minority of videos provided a mix of useful and misleading information across the 2 topics (Table 1). For further analysis on accuracy, we classified the videos as misleading if they had misleading information on vitamin D, COVID-19, or both (ie, 7 [9%] videos with some useful and some misleading information were labeled as misleading overall).

When examining accuracy by account type, we found that most of the useful videos were shared by medical professional accounts (12/15, 80%). The remaining few useful videos were shared by either news organizations or the "other" type (Table 2). Interestingly, medical professionals also shared over three-quarters of the misleading videos (22/62, 35%), although the "other" account type shared the most misleading videos (23/62, 37%) of all misleading videos. There was a statistically significant difference (*P*=.01) between the types of accounts sharing misleading versus useful videos, with medical professionals more likely to share useful information, but medical professionals still mostly shared misleading information on COVID-19 or vitamin D (Table 2).

The number of views, comments, and thumbs up/thumbs down are summarized by overall video accuracy in Table 3. A comparison of mean values suggests that YouTube videos containing useful vitamin D information had greater viewer engagement overall, including a greater number of views; however, the video with the single greatest number of views (1,895,430) was misleading about both COVID-19 and vitamin D. These differences, however, were not statistically significant.

**Table 1.** Accuracy of vitamin D information vs accuracy of COVID-19 information (N=77).

| Misleading/useful information[a] | Misleading COVID-19 information, n (%) | Useful COVID-19 information, n (%) | Total, n (%) |
|---|---|---|---|
| Misleading vitamin D information | 55 (96) | 5 (25) | 60 |
| Useful vitamin D information | 2 (4) | 15 (75) | 17 |
| Total, n (%) | 57 (100) | 20 (100) | 77 (100) |

[a]Fisher exact test: *P*<.001.



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**Figure 2.** Attributes and frequency of appearance in videos coded as misleading (n=62).

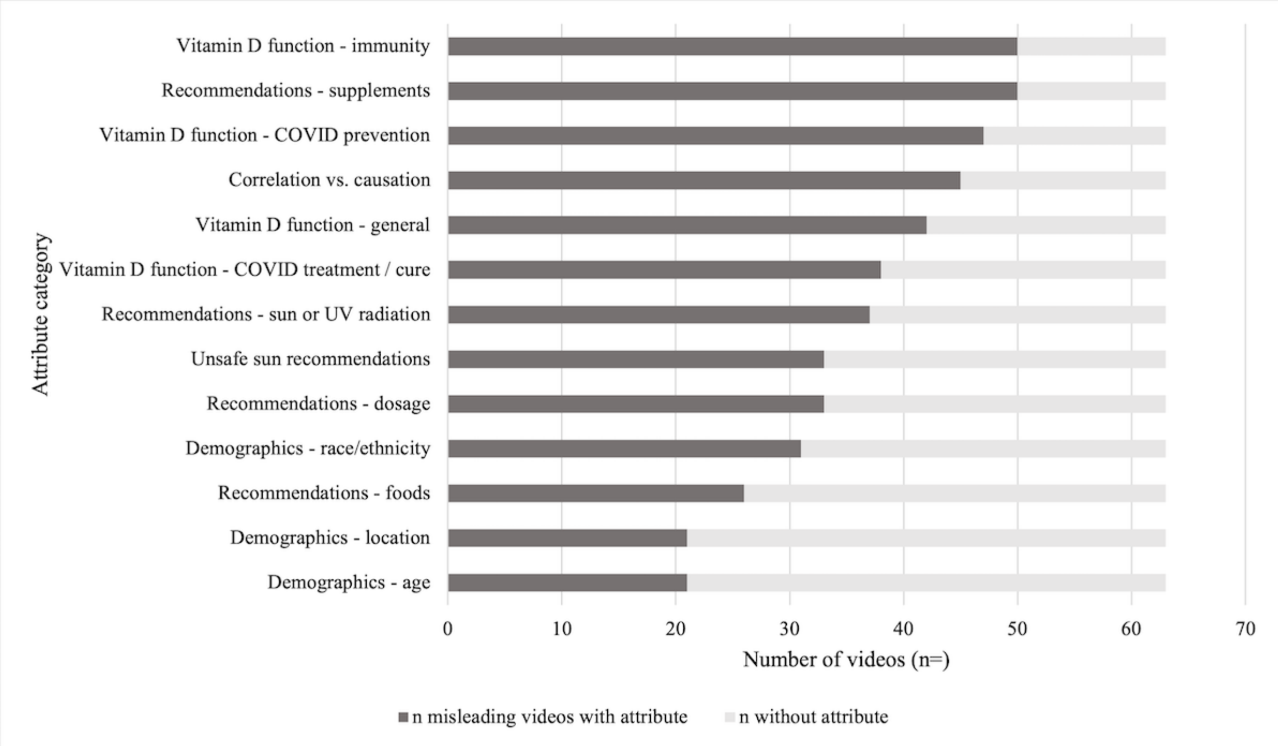


**Table 2.** Accuracy of information by account type (N=77).

| Account type | Misleading information, n (%) | Useful information, n (%) | Total, n (%) | *P* value |
|---|---|---|---|---|
| Medical professional | 22 (35) | 12 (80) | 34 | .01 |
| News | 17 (27) | 2 (13) | 19 | .01 |
| Other | 23 (37) | 1 (7) | 24 | .01 |
| Total | 62 (100) | 15 (100) | 77 (100) | .01 |

**Table 3.** Overall accuracy by engagement metric (N=77).

| Engagement metric[a] | Misleading information | | | Useful information | | | *P* value |
|---|---|---|---|---|---|---|---|
| | n | Mean (SD) | Range | n | Mean (SD) | Range | |
| Views | 62 | 108,436 (278,604) | 8-1,895,430 | 15 | 242,846 (470,504) | 62-1,786, 066 | .21 |
| Comments | 62 | 603 (1397) | 0-8711 | 15 | 1702 (2992) | 2-10,760 | .15 |
| Thumbs up | 62 | 2639 (6212) | 0-40,000 | 15 | 6153 (11,774) | 0-48,000 | .24 |
| Thumbs down | 62 | 64 (154) | 0-1000 | 15 | 272 (710) | 0-2800 | .08 |

[a]At the time of data collection.

## Attributes and Themes

The number of videos per attribute category demonstrated the overall themes shared by the content creators (Figure 3), as well as a sample coding system (Figure 4). Approximately half (37/77, 48%) of the videos recommended that people engage in unsafe sun (does not fit within recommendations [43]) or UV-related behaviors in an effort to improve their vitamin D status (eg, "It's free; just go out in the sun"). Intentional (unprotected) sun exposure was recommended in videos, including the idea to "seek direct sun exposure for 20-60 minutes with minimal clothing," as well as the suggestion that those who have higher levels of melanin in their skin increase their sun exposure, even extremes such as "Stand naked in direct sunlight for a minimum of 20 minutes" or "Never use sunblock." Sunlight was occasionally presented as the "only" or "best" source of vitamin D, recommending "exposure during peak UV hours for optimal absorption." Such information was coded as misleading due to the contrasting statements made by sun safety organizations and existing literature recommendations, such as (but not limited to) avoiding direct unprotected sun exposure of over 15 minutes, avoiding exposure during peak UV hours, and wearing (and reapplying) sunscreen and protective clothing when sun exposure is unavoidable [43]. Many videos did, however, provide recommendations on how to safely generate


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vitamin D from the sun (eg, minimizing exposure with the use of sunscreen, clothing, or seeking shade).

**Figure 3.** Data inclusion and exclusion criteria.

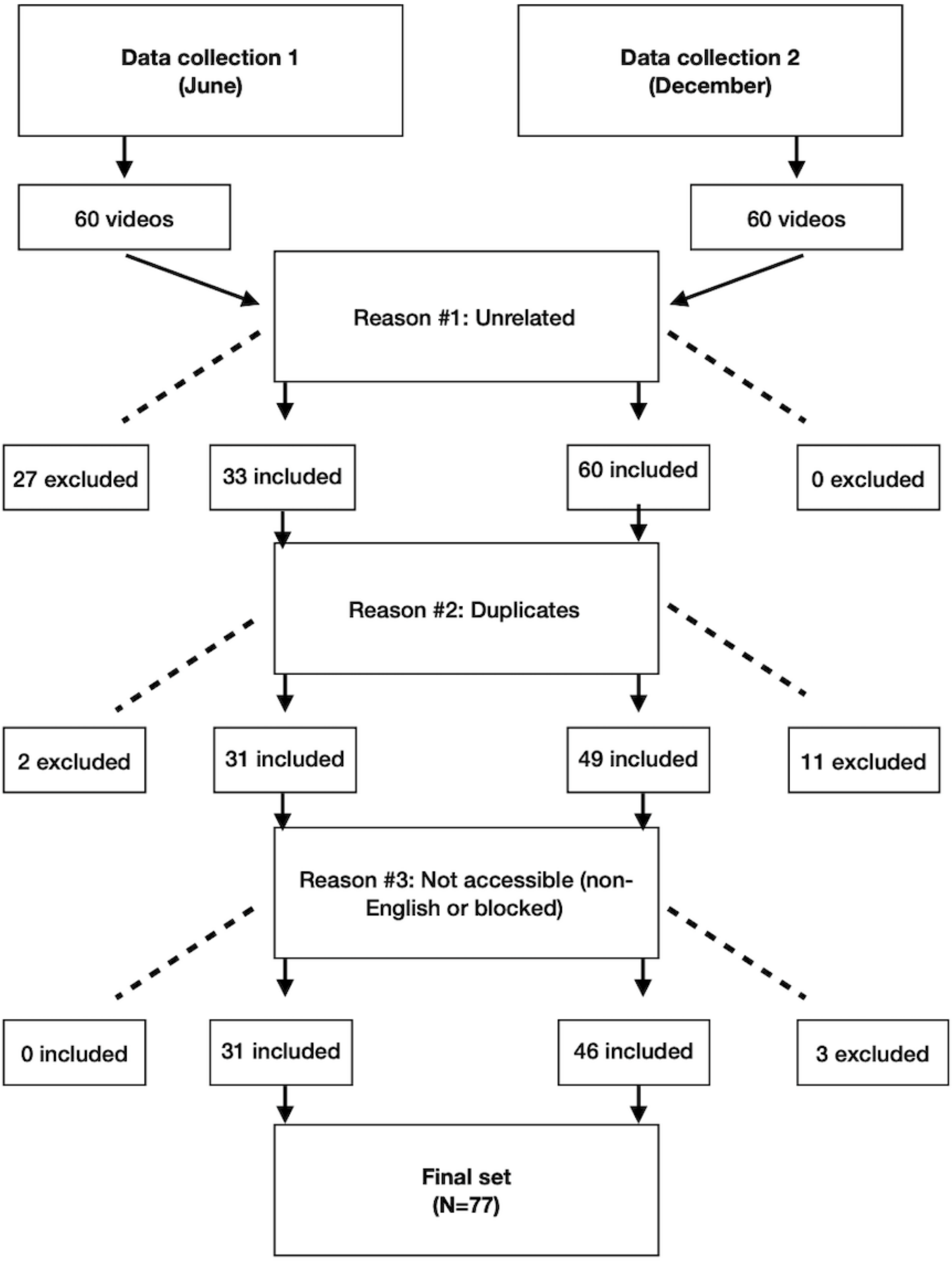




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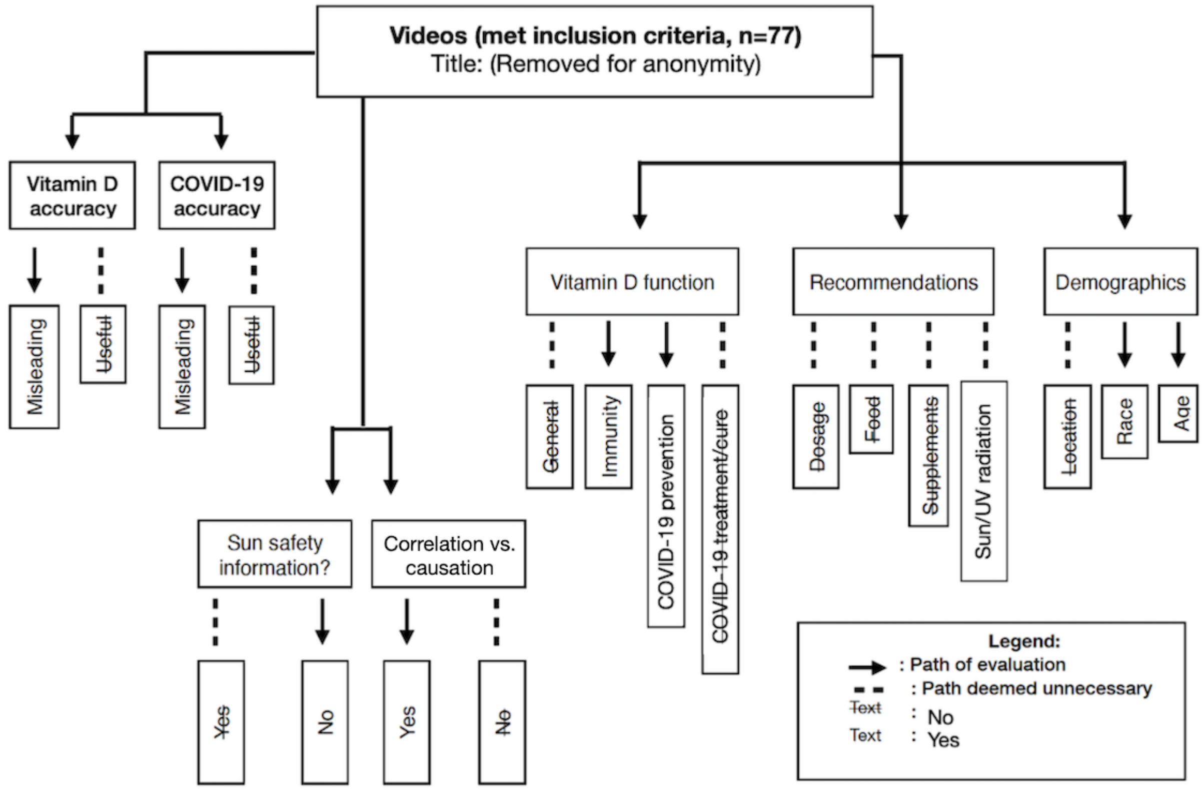
**Figure 4.** Sample of coding system.




Of additional concern, a total of 45 (58%) of 77 videos confused correlation with causation either directly or implicitly. Relevant statements included suggestions that the global COVID-19 pandemic is actually a "pandemic of insufficient vitamin D levels." Concerning statements were also made regarding the state of the scientific evidence between vitamin D levels and COVID-19, suggesting that the "evidence is now so strong" and "overwhelming." Videos also suggested that "every public health official should be recommending it [vitamin D for COVID-19]," and doing so "could save the lives of millions." The notion that "there is no harm in adding a vitamin D supplement to your daily routine" was found in several videos, despite evidence in the literature that demonstrates an overdose of vitamin D can be harmful [36]. Overall, the suggestion of vitamin D supplements being a safe and easy way to "boost immunity" was a common thread in many videos.

Videos commonly discussed the general function of vitamin D (55/77, 71%) and how vitamin D functions in overall immunity (62/77, 80%). Many videos highlighted that vitamin D is known as the "sunshine vitamin" and stated that a considerable proportion of the global population is vitamin D insufficient or deficient. Some videos also included in-depth scientifically supported details regarding vitamin D production, metabolism, and associated mechanisms of action.

Most of the videos (54/77, 70%) explicitly discussed vitamin D as a COVID-19 primary prevention method or to prevent more severe outcomes. Although not all these videos provided misleading information on these topics, the majority (46/54, 85%) of videos including these topics did directly state or imply that vitamin D can prevent or cure COVID-19, which is not supported by current scientific evidence and is thus misleading. Further, 41 (53%) of the 77 videos included comments on the ability of vitamin D to treat or cure COVID-19, and 37 (90%) of these contained misleading information on this topic. Examples of the types of misleading messages included that vitamin D is an "effective treatment" for COVID-19 and could be "lifesaving" and suggested that physicians should provide it to patients infected with COVID-19.

The 8 (10%) of the 77 videos that contained useful information about the potential for vitamin D to prevent COVID-19 or reduce severe disease generally informed viewers that ongoing studies were investigating the theory of vitamin D preventing COVID-19 and outlined proposed mechanisms of action. Useful videos also noted that the current state of the science "does not prove" that vitamin D deficiency increases susceptibility to COVID-19 infection. In comparison, misleading videos encouraged individuals to increase their vitamin D intake to "reduce their likelihood of catching it (COVID-19)" because there is a "strong relationship" between vitamin D status and COVID-19 infection rates. The 4 (10%) of 41 videos that contained useful information about the potential for vitamin D to help treat or cure individuals included similar messages as the useful videos about vitamin D being a potential preventative agent against COVID-19. Useful videos discussed how some hospital-based pilot studies are including vitamin D (or calcifediol) as part of experimental treatment protocols for COVID-19 patients.

Generally, there was a mix of useful information (eg, recommendations to "discuss supplementation and dosage with your physician") concerning vitamin D recommendations,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particularly regarding supplementation (eg, “immune boosting” to preventing COVID-19) and “prescription level” dosage (eg, up to 60,000 IU a day). Several videos stated that “vitamin D supplements amplify immune function” or provide a “boost” to the body in fighting off the virus. A common supporting theory to the claims of vitamin D having a protective factor was that supplement use will “reduce inflammation in the body.” Several videos did suggest consulting with a physician prior to taking supplements, while others suggested starting at a base dosage of 2500 IU daily. We also analyzed the videos for the theme of vitamin D recommendations related to the subthemes of vitamin D dosage, supplements, food sources, and sun or UV radiation exposure. Many of the videos did provide a recommendation (or recommendations) to viewers, with vitamin D supplements (59/77, 77%) being the most common, followed by sun or UV radiation exposure (42/77, 55%), vitamin D dosage (41/77, 53%), and food sources (31/77, 40%).

The videos also discussed the theme of demographics and risk, including aspects of ethnicity, location, and age in relation to vitamin D and COVID-19. Ethnicity was discussed in approximately half of the videos. This content typically focused on how darker-skinned individuals may be more susceptible to vitamin D deficiency and this could support the understanding of racial (and ethnic) differences in severe COVID-19 outcomes. Videos that discussed location in relation to vitamin D and COVID-19 (28/77, 36%) commonly described the increased risk of vitamin D deficiency in northern latitudes or a hypothesized COVID-19 “latitude gradient.” Lastly, videos that had a theme of age (also 28 [36%] videos) generally described how older individuals (ie, greater than 60 years old) may be more susceptible to vitamin D deficiency and, therefore, COVID-19.

## Discussion

### Principal Findings

Our results provide evidence that videos available on YouTube contribute to the infodemic, which may lead to misunderstanding and confusion among viewers. Overall, the results of our study indicated that the majority of videos contain misleading information about both COVID-19 *and* vitamin D, frequently implying in a causal manner that vitamin D supplementation reduces COVID-19 incidence. This type of misinformation is particularly concerning from a public health perspective, given the audience and its susceptibility to be influenced by health information [44]. Although some videos were careful to explicitly state the difference between correlation and causation, others went on to state a direct association between vitamin D and COVID-19, despite the lack of reliable data [30].

Misleading videos generally overstated our current understanding of the relationship between vitamin D and COVID-19 or presented a 1-sided view of the current research (ie, strictly sharing research in support of an association between vitamin D status and COVID-19 outcomes). In addition to sharing selective and misleading messages, the available information was frequently confusing by stating that vitamin D has preventative or has curative abilities against the COVID-19 virus. Of great concern, misleading videos also suggested or directly stated there was no evidence to support COVID-19 public health prevention measures (eg, masks, social distancing, lockdowns) despite the mounting evidence supporting decreased transmission rates with the preventative measures [25]. The most recent meta-analysis on vitamin D as a preventive or curative treatment for COVID-19 did report correlations between levels of vitamin D and COVID-19 outcomes, but the authors were careful to note that the available studies had a high risk of bias and heterogeneity [34]. One bias of particular concern was related to the timing of vitamin D ascertainment, which in many studies was done at the time of diagnosis or hospital admission, which obscures the ability to determine causation (as compared to correlation). A further complication is that we know that circulating vitamin D concentration decreases in times of acute illness or inflammation [45]. This means that given the types of studies available, it is impossible to ascertain whether having higher vitamin D prevents COVID-19 (or severe outcomes), whether COVID-19 inflammation causes lower vitamin D levels, or that vitamin D is a marker of the underlying health status—or indeed some combination of all 3 scenarios.

Vitamin D supplementation recommendations were made in many of the videos that inappropriately associated vitamin D supplementation with reduced risk of contracting COVID-19, often suggesting a dosage higher than standard guidelines [28] or not recommending inquiring about vitamin D recommendations from a family physician (such as based on a confirmed, clinically relevant deficiency). Dietary sources of vitamin D were discussed; however, they were often deemed less valuable than a supplement or solar UV source. Encouraging members of the public to purchase supplements or engage in risky health behaviors for unproven benefits is concerning to public health researchers, tying together health risks and poor health outcomes, such as skin cancer, with the COVID-19 pandemic [46,47]. Several misleading videos also suggested that all individuals should take a vitamin D supplement as they are without risk, readily available, and cheap, or even suggested the use of an extremely high-dose [28] or “prescription level” vitamin D regimen (eg, 60,000 IU/day) to prevent COVID-19 illness and to “boost the immune system.” These videos also commonly described the global population as being vitamin D deficient/insufficient and claim that this is the “real root cause” of the pandemic.

Unsafe sun exposure was a common recommendation in order to increase vitamin D levels, with claims that intentional sun exposure was the “best” option for increasing immunity. Recommending unsafe exposure to UV radiation is alarming, particularly when it is classified by the International Agency for Research on Cancer (IARC) as a known skin carcinogen [48] with other well-documented negative health effects [49]. Although sunlight is a known source of vitamin D [50], studies have shown that the DNA damage and elevated skin cancer risk associated with direct sun exposure outweigh the vitamin D status, particularly when replaceable by diet or supplements [51].

Medical professionals have a highly influential position on online platforms due to the assumption they are sharing accurate and reliable information learned through their professional


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education [52]. Although COVID-19 is a relatively new area of research, it is not encouraging to observe accredited medical professionals sharing potentially dangerous health misinformation, including suggesting individuals overdose on a vitamin or seek intentional risky sun exposure, in turn increasing their risk of skin cancer or other poor health outcomes [20,53,54]. It would be advisable for medical professionals making informational videos on YouTube that they use their platform to share only reliable and accurate information [52], rather than speculative claims for holistic measures (particularly when for personal financial gain), as it has been demonstrated that consumers of social media place more trust in these professionals [52]. Although financial gain (eg, from supplement sales) is 1 reason that some health professionals may share misinformation, this is unlikely to cover all situations. Indeed, physicians and other health care professionals can be susceptible to believing ideas that are at least biologically plausible or where they have trusted colleagues who share in the belief [55]. Additionally, these professionals have a strong desire to alleviate suffering and could have a lower threshold for what constitutes "evidence" in the prevention or treatment of a novel virus [56,57]. It is assumed or expected by many viewers that a medical professional would only share reliable and accurate information [52], although from our results, it is clear that this is not always the case. This could alter the public's sense of medical knowledge and potentially lead to doubt in the health system.

Not all information within the YouTube videos analyzed included misinformation; some of the videos were useful and could provide viewers with valuable information pertaining to their health. Overall, we found useful information was also shared, including guidance on the potential benefits and risks associated with vitamin D intake and the current epidemiology of COVID-19. Other useful videos shared several studies that both supported *and* refuted an association between vitamin D and COVID-19. The videos containing useful information were also found to describe the state of current science, the limitations of current research studies, and the need for additional research before making any supplement or other recommendations. Social media can be a valuable and inexpensive method of sharing health information widely with the public, as long as it is clear and accurate [46].

Despite some of the videos containing useful information, the overall recommendation of supplements contributes to the concerning theories of "immune boosting" holistic approaches to health. This is a dangerous place that lacks sufficient scientific evidence to support the claims [53,54]. The pandemic has lead wellness influencers and companies promoting "immune boosting" products to capitalize on the vulnerability of the unprecedented times of the pandemic. Commercial interest in the "immune boosting" products, as noted in the study by Wagner et al [47], was present with most "immune boosting" posts on Instagram. Similarly, among general Google searches, evidence-based claims were paired with "immune boosting" theories, inadvertently legitimizing the concepts [35]. In the case of medical professionals with YouTube accounts, their position of authority may be inadvertently legitimizing the claims stated about vitamin D *and* COVID-19, simply because viewers assume a medical professional would only share accurate reliable information [52].

## Limitations

This study had some important limitations that should be mentioned. First, we designed our study to collect 60 videos at 2 separate time points, for a total of 120 videos, but many of the videos captured by our search strategy only included information on 1 of our topics of interest (eg, either COVID-19 or vitamin D but not both). This created a smaller data set in our sample than we anticipated. However, 1 of the main drivers of our inquiry was how members of the general population interface with YouTube and what videos they would be likely to see based on simple searches, not to find every video possible using more complex Boolean strings. Therefore, we are confident that the sample of videos we collected was representative of real-world information that is easily accessible to an average user. We also had 2 separate coding teams for the 2 time points of our study, which could have introduced differences in coding across the time points. However, all coders were central members of an experienced team working on similar topics and from the same codebook, led by the same senior scientist, who also carefully reviewed all videos and coding to ensure consistent approaches across the phases.

## Conclusion

In conclusion, the results of our study suggest that confusing messaging about vitamin D as having preventative or curative abilities against/for COVID-19 is prevalent on social media and is dominating the online narrative. Concerns surrounding the type of individuals spreading this type of health misinformation are unique in the unprecedented times of a global pandemic, where the public may be anxiously seeking advice about how to remain healthy [3,58]. Easily accessible online platforms hold the potential to decrease the spread of SARS-CoV-2; however, if misinformation is shared publicly, it can lead to increased viral spread or the increased presence of other poor health outcomes either immediately or in the future (such as skin cancer from intentional UV radiation exposures) [59]. This study is an important contribution for public health, as it demonstrated that health professionals are a significant source of misleading information on the relationship between vitamin D and COVID-19 infection and severity. The practical next steps to address this challenge include the sharing of antimisinformation efforts as well as prebunking or debunking methods to curb risky "immune boosting" behaviors on social media in order to deter the avoidable negative health consequences of unnecessary supplementation [60].


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## Conflicts of Interest

None declared.

Multimedia Appendix 1
Attributes and attribute options, and themes and subthemes.
[DOCX File , 14 KB - infodemiology_v2i1e32452_app1.docx ]

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Original Paper

# The Evolution of Public Sentiments During the COVID-19 Pandemic: Case Comparisons of India, Singapore, South Korea, the United Kingdom, and the United States

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## Abstract

**Background:** Public sentiments are an important indicator of crisis response, with the need to balance exigency without adding to panic or projecting overconfidence. Given the rapid spread of the COVID-19 pandemic, governments have enacted various nationwide measures against the disease with social media platforms providing the previously unparalleled communication space for the global populations.

**Objective:** This research aims to examine and provide a macro-level narrative of the evolution of public sentiments on social media at national levels, by comparing Twitter data from India, Singapore, South Korea, the United Kingdom, and the United States during the current pandemic.

**Methods:** A total of 67,363,091 Twitter posts on COVID-19 from January 28, 2020, to April 28, 2021, were analyzed from the 5 countries with "wuhan," "corona," "nCov," and "covid" as search keywords. Change in sentiments ("very negative," "negative," "neutral or mixed," "positive," "very positive") were compared between countries in connection with disease milestones and public health directives.

**Results:** Country-specific assessments show that negative sentiments were predominant across all 5 countries during the initial period of the global pandemic. However, positive sentiments encompassing hope, resilience, and support arose at differing intensities across the 5 countries, particularly in Asian countries. In the next stage of the pandemic, India, Singapore, and South Korea faced escalating waves of COVID-19 cases, resulting in negative sentiments, but positive sentiments appeared simultaneously. In contrast, although negative sentiments in the United Kingdom and the United States increased substantially after the declaration of a national public emergency, strong parallel positive sentiments were slow to surface.

**Conclusions:** Our findings on sentiments across countries facing similar outbreak concerns suggest potential associations between government response actions both in terms of policy and communications, and public sentiment trends. Overall, a more concerted approach to government crisis communication appears to be associated with more stable and less volatile public sentiments over the evolution of the COVID-19 pandemic.

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**KEYWORDS**

COVID-19; public sentiment; Twitter; crisis communication; cross-country comparison; sentiment; social media; communication; public health; health information; emotion; perception; health literacy; information literacy; digital literacy; community health

## *Introduction*

### Background

COVID-19 has infected people from more than 200 countries since it was first reported in late December 2019 [1]. Countries worldwide have put forth various precautionary measures at different time points in response to the rapidly evolving local disease situations [2,3]. With widespread global media coverage of the crisis and differing government approaches to COVID-19, it is important to understand public sentiments toward the pandemic in relation to governmental actions.

The proliferation of information and communications technology has widened the means for crisis communication since the beginning of the 21st century, particularly with the emergence and rapid propagation of the internet. Governments worldwide have used digital media to provide timely dissemination of information and education materials to a large population at low costs. For example, the widespread use of social media has facilitated crisis communication during recent disease outbreaks such as H7N9, Ebola, and Zika [4-6].

Public sentiment refers to the public's opinion or attitude about a situation or something, which can be positive, negative, or neutral. By understanding the frequency of positive and negative public sentiments, policy makers and stakeholders can gain a clear picture of how people experience a given situation or policy and use such information to inform and calibrate how to more effectively communicate with the public to promote desirable behaviors and prevent negative behaviors [4]. The information gathered can also be used for future pandemic preparedness and crisis management.

In the era of social media, the evolution of public sentiments during the COVID-19 pandemic are highly complex and need to be empirically determined [7]. For example, discourse on social media can intensify negative public sentiments because much of what is propagated there is exaggerated, such as the potential threats of the disease [8]. Online fake news and biased comments are also circulated with ease [5,9], biasing public sentiments toward the disease. Moreover, COVID-19 is a fast-spreading disease that is harder to control than normal influenza because transmission can occur before symptom onset [10]. Thus, government communication on COVID-19 may become less effective in containing negative public sentiments, which can create potential situations of public panic that increase negative behaviors such as panic buying, hoarding, and violent political protest.

Several studies have examined public sentiments surrounding COVID-19 on social media for specific countries [11,12] and worldwide [13]. However, exploring the sentiment difference across multiple countries that have put different national measures in place is important for understanding the perceived public sentiments toward the effectiveness of these measures at macro levels. To the best of our knowledge, no study to date has examined the differences in public sentiments across multiple countries, over a longitudinal trajectory of the pandemic. Examining the differences across geographic locations and the trajectory of public sentiment changes is likely to reveal more dynamic insights than simply examining the frequency of positive and negative sentiments for a given specific time point or for a specific country.

This study attempts to close the knowledge gap by examining how positive and negative sentiments surfaced on Twitter in 5 countries since the early phase of the COVID-19 pandemic over 16 months. We purposefully compare data from 5 countries, namely, India, Singapore, South Korea, the United Kingdom, and the United States. The reason for selecting these countries were the existence of a substantial threat and diversity. The magnitude of the threat is detailed in the following section. Diversity concerns not only geographical and cultural diversity but also different disease trajectories and, linked to that, different and changing government stances on the best way to contain the virus. Diversity also referred to different attention to the countries with regard to the COVID-19 situation. Although the share of Twitter users vary within these countries (Singapore 13.6%, South Korea 22.8%, India 3.7%, the United States 10.3%, the United Kingdom 15.2%), they can still provide a snapshot of the discourse surrounding COVID-19 within a diverse group of situations [14]. This research does not include certain countries that were also highly impacted by COVID-19. For example, China, where the disease outbreak began, was omitted, as they have blocked Twitter and use other local social media platforms such as Weibo [15]. We describe the detailed background of the COVID-19 epidemics in the 5 countries in the next section to further elaborate our rationales for the selection of countries.

### COVID-19 in the 5 Countries

The World Health Organization (WHO) declared the disease outbreak as a Public Health Emergency of International Concern (PHEIC) on January 30, 2020, and its risk was upgraded to a "very high" global level on February 28 [16]. Two weeks later, on March 11, the WHO made the assessment that COVID-19 could be characterized as a "pandemic" [17].

The trajectories of COVID-19 in the 5 selected countries demonstrated good diversity (Figure 1). For each country, we show the daily case numbers in the logarithmic function with a base of 10 to clearly present the trend of confirmed cases. The key events are also highlighted in Multimedia Appendix 1. Figure 1 shows that Singapore, as an Asian travel hub, was one of the first countries outside China to face the new threat. The local spread was well controlled throughout February and early March 2020, due to various containment measures. However, the country had an accelerated increase in the number of cases in mid-March due to the upsurge of imported cases and the outbreak in migrant worker dormitories [18]. The number of cases peaked in April and has since had a steady rate of a relatively low number of cases.



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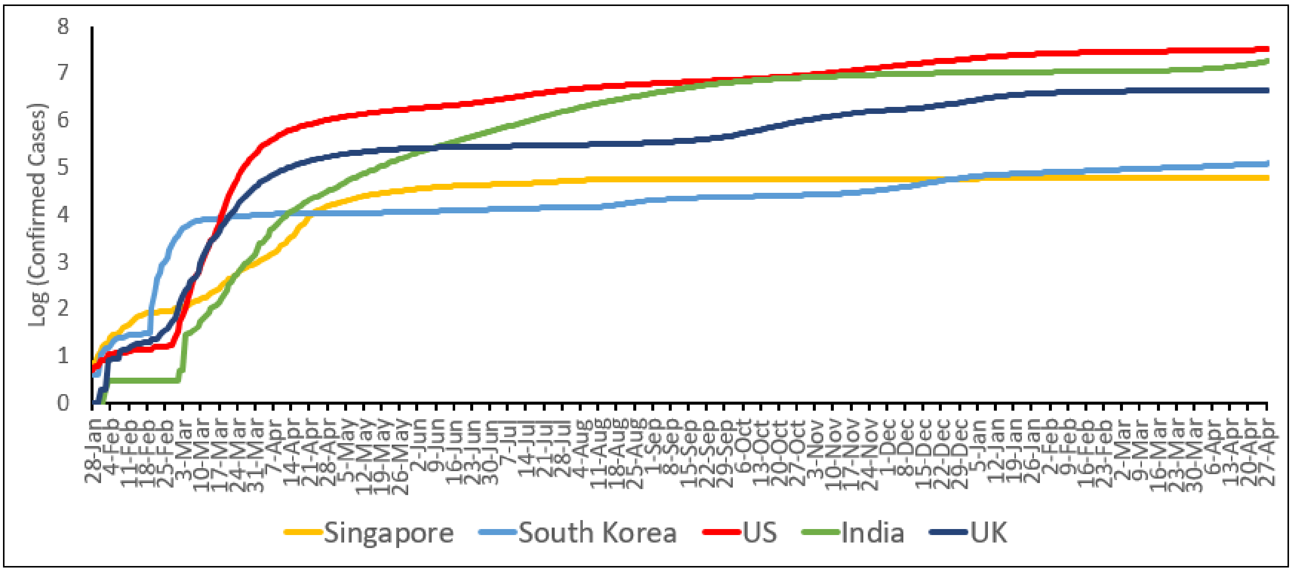
**Figure 1.** Logged numbers of COVID-19 cases in Singapore, South Korea, India, the United Kingdom, and the United States.




In comparison, South Korea witnessed a sudden spread of the disease throughout February until March 10, 2020, after several national measures were implemented to combat the disease, resulting in a plateau [3]. The number of cases remained stable until mid-August when cases began to rise again following another wave of the disease. A third wave also occurred in November 2020. Though numbers remain relatively low compared to other countries worldwide, COVID-19 cases in South Korea surpassed Singapore in late December 2020 [19].

India only had a few confirmed COVID-19 cases until March 2020 when the daily number rapidly increased. The cases remained at a high level and peaked on September 19, 2020. The number of daily cases reduced toward the end of the year and remained relatively constant until early March 2021 when a new wave of a more potent variant of the disease started to spread [20]. As of May 2021, India has become the new epicenter of COVID-19 and has surpassed the United States for the highest number of recorded cases in a day on April 22, 2021 [21].

The number of confirmed cases remained low in the United Kingdom until March 2020 when cases started to rise. The number of daily cases peaked in late April 2020 before falling throughout May and June 2020. It remained relatively steady until September 2020 when the number of cases increased again, surpassing the previous peak in April. The cases currently remain high but stable.

The United States saw an exponential increase in the number of confirmed cases in March 2020, quickly becoming the global epicenter of the disease and surpassing other countries to become the country with the highest number of cases in the world [22]. The number of cases peaked in January 2021, before falling in February 2021. The number of new cases remains steady but relatively high.

In response to the pandemic, the 5 countries have also used diverse strategies in crisis responses and public health communication, the details of which can be found in Multimedia Appendix 1. Singapore and South Korea took unique paths but were similar in terms of decisive actions and regular communication from the governments since their early phases of the epidemic. Both countries enforced some of the toughest measures early on, such as a national lockdown, widespread testing, and extensive contact tracing [3]. Health authorities communicated to the public regularly to address the outbreak, provide advice on preventative measures such as personal hygiene and social distancing, and announce disciplinary actions for people who do not follow the mandatory policies in place [23,24]. However, though Singapore's response continues to receive praise by citizens as cases continue to be low and stable, several waves of cases in South Korea have led to the public criticizing the government for mixed messaging and caused unrest in health care workers [25]. Although the vaccination rollout has been steady and timely in Singapore, the South Korean government has faced backlash from the public for their slow rollout actions [26].

Despite having few cases in early 2020, India implemented a series of COVID-19 regulations early on with travel restrictions, quarantine, and a full lockdown when the number of cases started to rise in March 2020. However, the country was criticized for its lack of COVID-19 testing and delay in providing social support for residents upon enforcing lockdown. Although individual states had varying responses to the pandemic, the number of cases and death rates remained relatively low throughout 2020, and India's strategy garnered praise from its citizens and other countries [27]. This led to an easing of measures, with the allowance of mass gatherings and politicians claiming the country had *beaten the pandemic* [28]. In early 2021, India was also praised for their proactive step toward providing free vaccines to citizens [29]. However, mid-March 2021 saw a second, more virulent wave, leading many to criticize the government's response to the disease [30].

The United Kingdom has seen varying approaches by its constituent countries (England, Scotland, Northern Ireland, and Wales) and has been criticized for its contradictory and indecisive regulations [31,32]. The country delayed its response to the pandemic in March 2020. With the increase of cases, the country went into lockdown at the end of March for which the government was slated due to the late response. As cases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reduced, regulations were loosened, leading to an increase in cases. The government responded with local and tiered restrictions, which were criticized for being complicated and confusing. With a new strain of COVID-19 appearing in the United Kingdom at the end of 2020, the country implemented several restrictions and regional lockdowns to stem further spread of the disease [33]. The lack of forewarning so close to Christmas caused a backlash among the public [34]. The United Kingdom was the first country in the world to initiate a vaccination program in December 2020 with the Pfizer vaccine, and to date, it has the second-highest vaccination rate in the world [35].

Similar to India, the United States has been less centralized in its approach, with many individual states varying in their actions [36,37]. The first case was discovered in late January 2020, and the national response was to reassure the public by downplaying the disease severity. Testing and diagnosis of the disease were slow due to barriers from the US Centers for Disease Control and Prevention (CDC) and Food and Drug Administration [38]. With increasing cases, the government suggested social distancing as a preventative measure. On March 13, 2020, after a substantial increase in cases, the United States declared the pandemic a national emergency, and more states began to implement stay-at-home notices, with differing directives being metered out [39]. Over the coming months, the country was criticized for its mixed and often contradictory messages from health authorities and the president [40,41]. Rather than enforcing countrywide mandates, governors were given a choice to control preventative measures within each state at a county level, leading to varying control measures across the country [42]. With the number of cases remaining stable but still relatively high, many states began to reopen in the summer months, causing a further increase in cases occurring toward the end of 2020, peaking in January 2021. The administering of the COVID-19 vaccines in early 2021 saw a decline in the number of cases, with over 100 million vaccines being administered by March 19, 2021, though mixed messaging and the antivaccination movement has led to varying rates of vaccination among the different states [43].

### Study Focus

With varying key events, regulations, and case numbers within the 5 countries, this paper examines how negative and positive sentiments evolved over the first 16 months of the pandemic for each country. By identifying how events and government crisis response within the pandemic have affected the public perceptions of disease threat across countries, we aim to provide critical case insights for policy makers to create effective response strategies to ensure more stable public sentiments.

## Methods

### Data Source

The study was approved by the Nanyang Technological University Institutional Review Board IR-2020-02-31 and was also reviewed and approved as "Exemption from full A*STAR IRB Review" (institutional review board reference number 2020-258). We used the COVID-19 Twitter Dataset with Latent Topics, Sentiments and Emotions Attributes [44] for our analysis. This data set was collected from Twitter's standard search application programming interface (API) using 4 COVID-19–related search words—"wuhan" (which at the start of the pandemic was commonly used in relation to the virus), "corona," "nCov," and "covid,"—in the English language. For each retrieved record, the API returns a tweet ID, tweet text content, timestamp, a user ID, and a location that is part of the tweet author's public profile, among other attributes. As the "location" attribute is an open-ended field that can contain both geographically meaningful information (eg, "Ontario, Canada" or "London) or otherwise (eg, "online" or "The Entire Universe!"), the country mapping was obtained by having each "location" mapped with a country code using GeoNames cities15000 database [45]. According to Gupta et al [44], the data set has approximately 54% of the collected COVID-19–related tweets associated with meaningful country-identifiable "location" information.

For this study, our analysis comprised 7,814,109 country-identifiable tweets from India; 293,331 from Singapore; 68,903 from South Korea; 12,248,379 from the United Kingdom; and 46,938,369 from the United States. That is, we analyzed a total of over 67,363,091 Twitter posts focusing on the 5 countries of interest covering the 15-month period from January 28, 2020, to April 28, 2021.

In addition to the Twitter data set, for each country, we also collected the key events from the government and health authorities, and plot these events on the pandemic timeline. The composite of Twitter data is then set against the tweet data in each of the countries for detailed analyses.

### Data Processing, Sentiment Classification, and Analysis

The Twitter data were analyzed with an advanced sentiment analytic algorithm, *CrystalFeel*, which has been demonstrated to achieve state-of-the-art measurement accuracy [46] and is available as a complimentary web-based API service for research use [47]. The algorithm was trained and validated using features derived from both pretrained language models, word embedding, and an original handcrafted lexicon. This approach is superior as compared to a traditional bag-of-words approach, which does not have the inherent ability to correctly analyze sentiments from expressions that may or may not contain emotional words per se (eg, "What to do with my life...I have no more choices..."), or expressions with positive/negative words but the sentence-level sentiment is different (eg, "Arrrhhh I hardly feel *happy* any more these day..." or "He *cried* when he heard that his son had been found alive and well"). According to the evaluation study performed [46], CrystalFeel's valence intensity achieved a very high measurement accuracy of 0.816 in terms of Pearson correlation coefficient ($r$) with manually annotated test data provided by a shared task on "affective in tweets," organized at the SemEval 2018–international workshop on semantic evaluation [48]. CrystalFeel's predictive validity was also tested and proven in other natural language processing tasks [49-52].

For a given text message (in this case, a tweet), the CrystalFeel API produces a sentiment score that indicates the intensity of the valence expressed in the text, where the valence intensity score corresponds to the degree of overall unpleasantness and


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pleasantness in the text expression, ranging from 0 (the text expresses extremely negative feelings) to 1 (the text expresses extremely positive feelings). For this study, we used CrystalFeel API service's sentiment labels converted from valence intensity scores for more straightforward interpretation [47], namely, "very negative" (valence intensity ≤0.30), "negative" (valence intensity 0.30-0.48), "neutral or mixed" (valence intensity 0.48-0.52), "positive" (valence intensity 0.52-0.70), and "very positive" (valence intensity ≥0.70).

Based on the sentiment labels, the data for our analysis were then aggregated as the count or volume of "very negative," "negative," "neutral or mixed," "positive," and "very positive" tweets collected for each day.

In addition, as each country has different levels of total tweet volumes, we computed a normalized "positivity" score for each country every day to facilitate cross-country comparisons and understand whether there had been more positive or negative sentiments in each country. This positivity score, expressed as the following formula, was calculated as the difference in the number of positive and negative tweets on a day over the total number of tweets of each of the 5 countries.

Positivity = [(Number of very positive + positive tweets) – (Number of very negative + negative tweets)] / Total number of tweets per day

The higher the normalized positivity scores, the higher the volumes of positive tweets in the discourse. A low score indicates an overwhelming volume of negative public sentiments. A score of zero would indicate an exact balance between positive and negative sentiments.

## Results

### Sentiment Trends in Relation to Key Disease Events and Government Responses

In the following section, we describe the volume of tweets and the normalized positivity score with different qualitative labels of sentiments by each country and key global and local responses. Overall, negative sentiments were expectedly predominant across all countries, especially after the WHO's pandemic declaration on March 11, 2020. Positive sentiments also surfaced in each country after the declaration, more so in Asia than in the west, although to a relatively lesser extent, with "very positive" sentiments being scarce.

#### Singapore

On January 30, 2020, when the WHO declared the disease outbreak as a PHEIC, Singapore witnessed a significant Twitter proliferation of negative sentiments, leading to a low score of positivity at the beginning of the pandemic (Figure 2). There had been several confirmed cases and the declaration heightened the threat of local spread. The frequency of negative tweets decreased in the next week but increased again on February 7 when Singapore raised the outbreak risk assessment to Disease Outbreak Response System Condition (DORSCON) "Orange," meaning the disease was "severe and spread easily, but still contained" [53]. The DORSCON announcement resulted in a balanced sentiment in posts. After that, the negative sentiments were relatively low for a month, corresponding to the containment efforts of local disease spread during this period. Both negative and positive tweets increased after the WHO declaration of COVID-19 as a pandemic, with the positivity score decreasing.

The volume of sentiments peaked after the categorization of COVID-19 as a pandemic and reached its highest level on March 25, 2020, witnessing the second largest dip of the positive score on this day. This concurred with the rapid growth of confirmed cases due to the worsening situation worldwide and tighter measures being implemented in the country, including safe distancing policies requiring at least 1 meter between persons. Although there was a surge of infections in migrant workers living in dormitories, leading to the highest number of cases occurring on April 20, 2020, both negative and positive sentiments decreased in April though they remained relatively high. During this time the government implemented tight regulations such as a "Circuit Breaker" on April 7, requiring citizens to stay at home except for essential trips [18]. They provided regular updates on the number of cases and the methods taken to reduce further spread. The daily volume of sentiments continued to decrease through May and the end of Circuit Breaker on June 1. Thereafter, the overall positivity of tweets remained stable from April 2020 to the end of March 2021. However, there was a spike in the volume of both positive and negative sentiments in October 2020 when the outbreaks at the dormitories finally abated. The highest positivity was witnessed on December 14, 2020, when the Prime Minister addressed the COVID-19 situation and revealed plans to enter "Phase 3" of the pandemic with further loosening of the restrictions due to the low number of cases.

Since March 2021, there has been an increase in negative sentiments, and the positivity score is still on a downward trajectory. This reflects the number of cases increasing and the news that many countries are affected by a third, more virulent wave of the disease.



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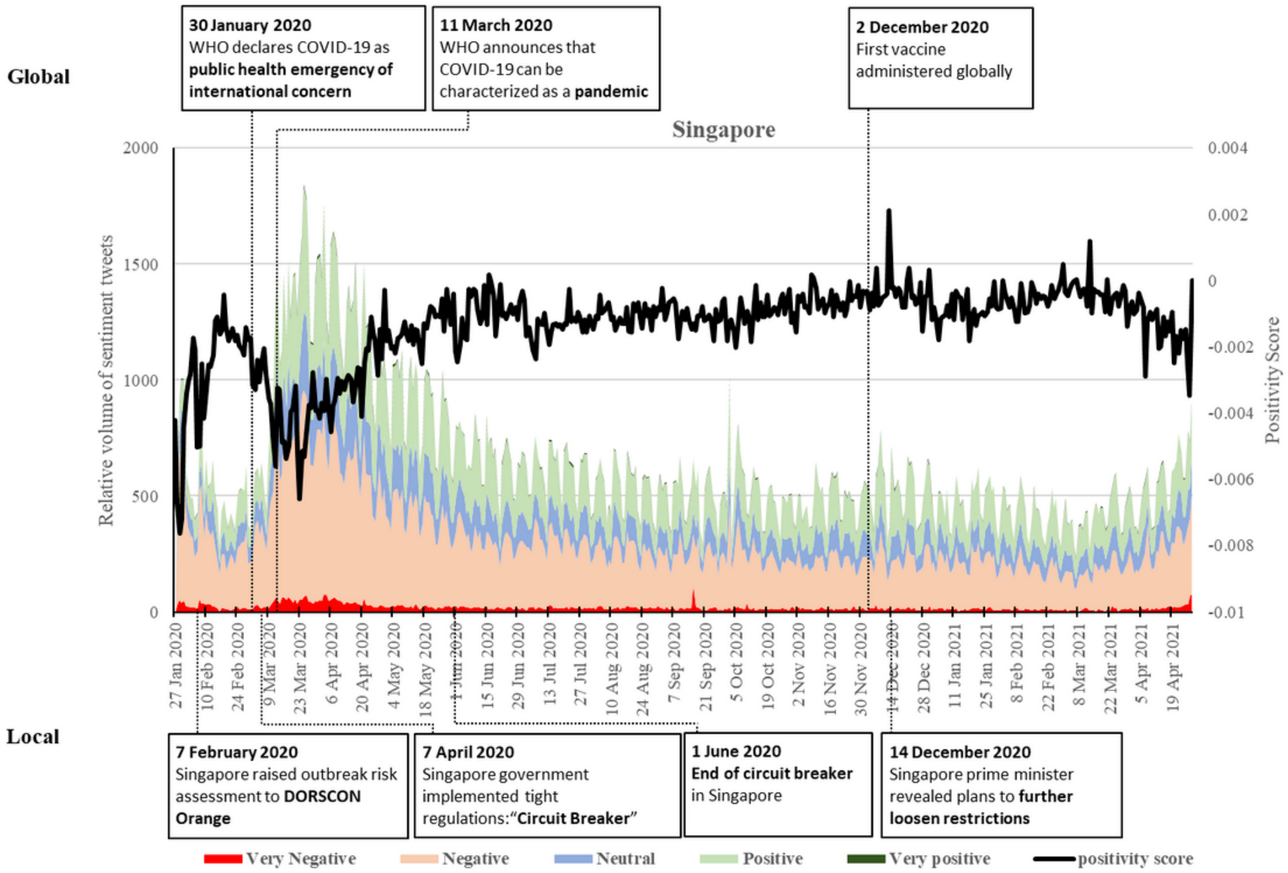
**Figure 2.** Twitter sentiments in Singapore from January 28, 2020, to April 28, 2021. DORSCON: Disease Outbreak Response System Condition; WHO: World Health Organization.




## South Korea

Similar to Singapore, South Korea saw significant fluctuations in sentiments at the start of the pandemic (Figure 3). There was a substantial increase in negative sentiment on January 30, 2020. The frequency of negative tweets decreased in the next 20 days. However, it started increasing on February 18 when the country confirmed its 31st case, who was known as a member of a quasi-Christian cult "Shincheonji" and believed to pass the infection to a number of fellow worshipers at the church located in Daegu, the fourth largest city in South Korea. The number of confirmed cases in the country increased from 30 cases on February 17 to 100 on February 20, swiftly soared to 1000 on February 27, 2000 on February 28, and 3000 on February 29. The number of negative tweets saw its first peak at the end of February, and the negative sentiments overwhelmed the country within this short period. On February 27, South Korea had the second-largest number of confirmed cases in the world. Positive tweets remained at a relatively stable volume during this time with a minor increase during mid-February, when the country started to put control measures into place.

The frequency of negative tweets decreased in late February 2020 and early March, as the country began to implement various measures to fight COVID-19, including drive-through sample collection facilities, mobile phone alerts notifying people of new cases near them, and the "self-quarantine safety protection" app. This smartphone app keeps track of the locations of those who have been ordered not to leave home [54]. This measure is reflected in the increase of positivity in sentiments. The country carried out more than 200,000 tests as of March 11, 2020. The number of new confirmed cases has remained low since then. The number of tweets surged from March 11-13, 2020, after the WHO declared the COVID-19 outbreak a pandemic, with the negative posts roughly doubling the number of previous peaks and more positive sentiments surfacing. Nevertheless, negative comments gradually went down, while the positive sentiments remained high as the country began to flatten the curve, resulting in a relatively high positivity score in the next few months.



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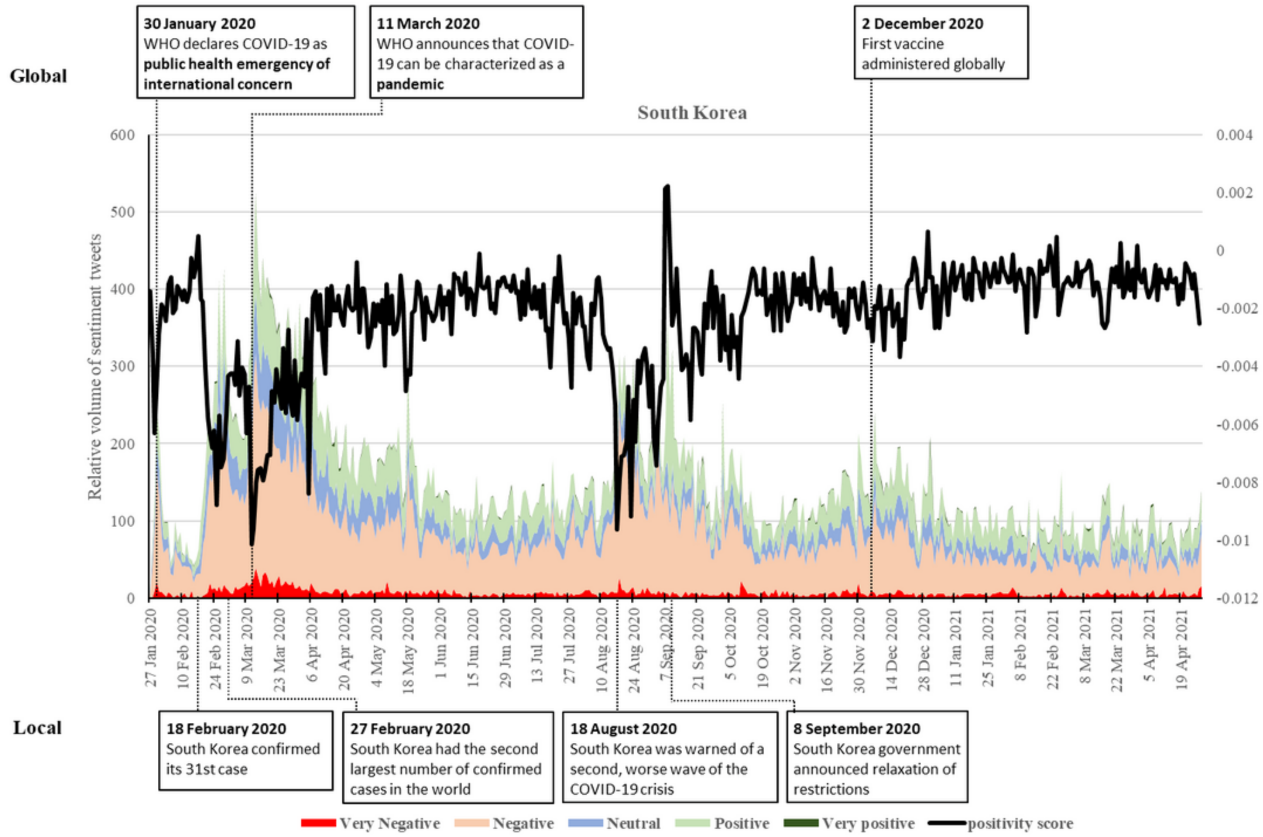
**Figure 3.** Twitter sentiments in South Korea from January 28, 2020, to April 28, 2021. WHO: World Health Organization.




The negative sentiments surged again on August 18, 2020, when the country was warned of a second worse wave of the COVID-19 crisis spreading from Seoul churches. As the number of daily cases reduced and rules began to loosen, sentiments began to balance out. The positivity score increased substantially, with positive sentiments surpassing negative ones in early September, peaking on September 9, 2020, when the government announced a relaxation of restrictions on operations of cafés and bakeries. Concurring with the third wave of COVID-19 outbreak worldwide, South Korea witnessed a surge of negative sentiments in late November and early December, though to a lesser extent than the previous two waves. As the disease curve was flattened, the negative sentiments gradually decreased until the study period. As such, the positivity score remained relatively stable, although slightly more negative with tiny spikes in positivity.

## India

India saw relatively balanced sentiments at the start of the pandemic with a small spike of negative sentiments on February 2, 2020, with the second confirmed case and COVID-19 spreading worldwide (Figure 4). The number of negative posts remained relatively low until March 2020, echoed by the few reported cases within India during this period. After that, sentiments became overwhelmingly negatively skewed except for a spike in positivity on March 22, with the introduction of the “Janata Curfew” [55]. March 26, 2020, saw the lowest positivity score with the first day of the nationwide lockdown. There was an upward trend in positive posts on March 29, 2020, with the government’s introduction of rapid solutions such as new schemes and moratoriums on loan repayments to address public financial concerns [56].


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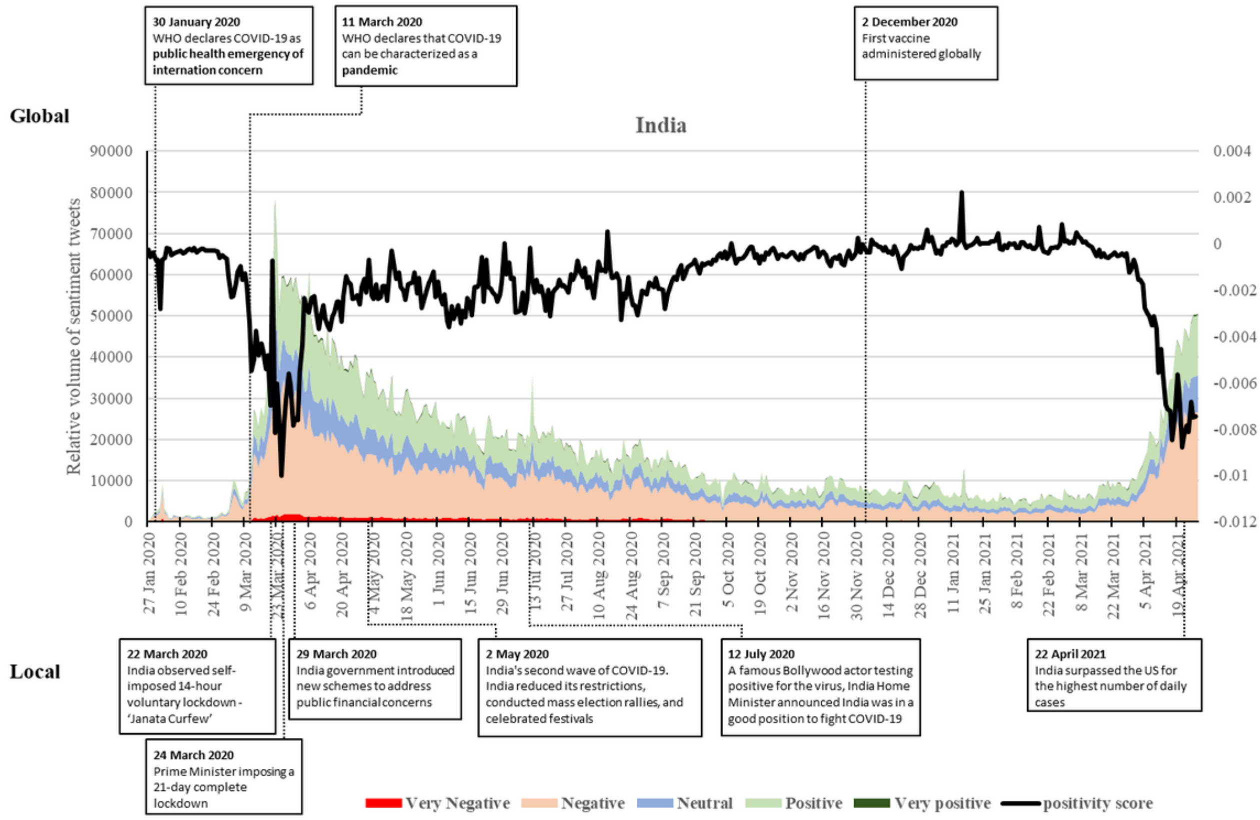
**Figure 4.** Twitter sentiments in India from January 28, 2020, to April 28, 2021. WHO: World Health Organization.




After this peak, the volume of negative and positive tweets started decreasing, particularly the number of negative sentiments. The positivity score increased with sentiments becoming more balanced on April 6, 2020, and remained stable until August. A small spike in the volume of both positive and negative sentiments was seen on July 12, 2020, with the news of a famous Bollywood actor testing positive for the virus and the home minister announcing that India was in a good position to fight COVID-19 [57]. On August 15, 2020, sentiments became more positive than negative on Indian Independence Day. The volume of both negative and positive tweets continued to decrease, and sentiments remained balanced until December 2020, reflecting the decrease in daily COVID-19 cases. On December 31, 2020, there was a slight increase in positive tweets with the end-of-year celebrations.

This balance continued from early January to March 2021, with some small spikes toward more positive sentiments as India announced vaccine maitri (Vaccine friendship) to its neighboring countries [58]. The positivity score became highest on January 16, 2020, with overwhelmingly positive sentiments, as the prime minister launched the world's largest vaccination drive. However, March 2021 saw a sudden downturn in the positivity score, as negative sentiments began to increase back to the March 2020 levels with the new, more deadly wave of cases. Negative tweets reached more than 20,000 by mid-April and peaked on April 27, 2021. India saw the second wave of COVID-19 with exponential increases in infections and death rates. As of May 2, 2021, India reported more than 300,000 cases per day, after the country reduced its restrictions, conducted mass election rallies, and celebrated festivals. As of this writing, sentiments are still highly negative, as the disease continues to affect India.

## United Kingdom

Unlike the Asian countries investigated, the United Kingdom saw only a minor spike of tweets when the WHO declared the COVID-19 as a PHEIC (Figure 5). The tweets began to surge only in late February and early March 2020 when more COVID-19 cases were confirmed. This resulted in little change of the positivity score until early March 2020. The most significant upsurge of the negative sentiments was on March 13, after the WHO's declaration of the pandemic, and major events were canceled.



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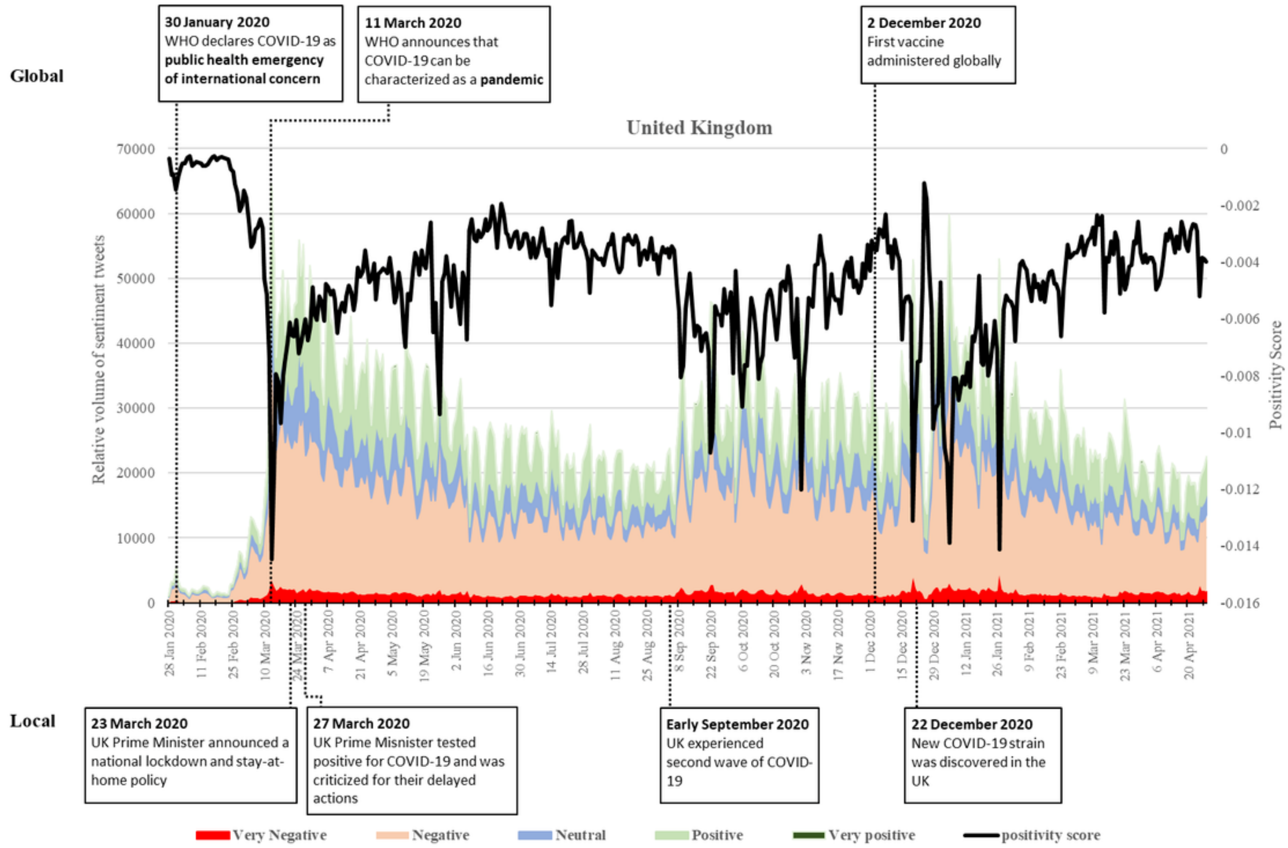
**Figure 5.** Twitter sentiments in the United Kingdom from January 28, 2020, to April 28, 2021. WHO: World Health Organization.




Positive sentiments surged quickly after the UK prime minister delivered a nationwide speech that encouraged the citizens' efficacy in fighting the disease and announced a national lockdown and stay-at-home policy on March 23, 2020. Nevertheless, the surge of positive tweets lasted only for a week and then dipped on March 27 when the prime minister tested positive for the disease. The country was criticized for its delayed actions in preventing the spread of COVID-19 [31,32]. Though the positivity score soon recovered in April, it showed dips in late May and early June when the UK prime minister announced the loosening of the national lockdown while at the same time the country recorded more than 40,000 deaths due to the disease. The positivity score thereafter increased and remained relatively stable during the summertime.

Nevertheless, negative sentiments witnessed significant upsurges again in early September and late December 2020, when the second and the third waves of the disease hit the United Kingdom, resulting in fluctuating and negatively skewed sentiments. Particularly, tiered restrictions were introduced in the UK countries in October. In December, a new COVID-19 variant led to an increase in cases. The United Kingdom witnessed a large dip on December 20 when the prime minister declared, "We cannot continue with Christmas as planned," requiring residents to stay at home during the Christmas holidays [34]. However, a few days later, on December 26, 2020, there was a sudden increase in the positivity score as new restrictions were introduced around the United Kingdom. On January 5 and January 27, 2021, negative tweets increased and reached similar levels early in the pandemic on March 13, 2020, as the prime minister gave statements regarding the COVID-19 situation. Since February 2021, the UK positivity score has increased, with more balanced sentiments as the number of cases remains relatively low and the vaccination has been extensively rolled out. The country has, as of this writing, vaccinated over half of its population. Overall, the United Kingdom did not skew toward positive sentiments during the study period.

## United States

The WHO's declaration of COVID-19 as a PHEIC on January 30, 2020, led to a small spike in the relative volume of negative tweets in the United States, similar to the United Kingdom (Figure 6). The relative volume of both positive and negative tweets remained low until the last week of February. This resulted in little change in sentiments at the start of the pandemic. On February 25, the CDC announced the pandemic was likely to spread to the United States and measures should be put into place to prevent the infection rate from increasing. The announcement coincided with the first major increase of negative tweets. The WHO raised the threat level of the disease to "very high risk" on February 28, the day when the first peak of negative tweets occurs. Few positive tweets were seen at this time. During this period, the positive score gradually became more negative along with the increasing number of cases within the country.



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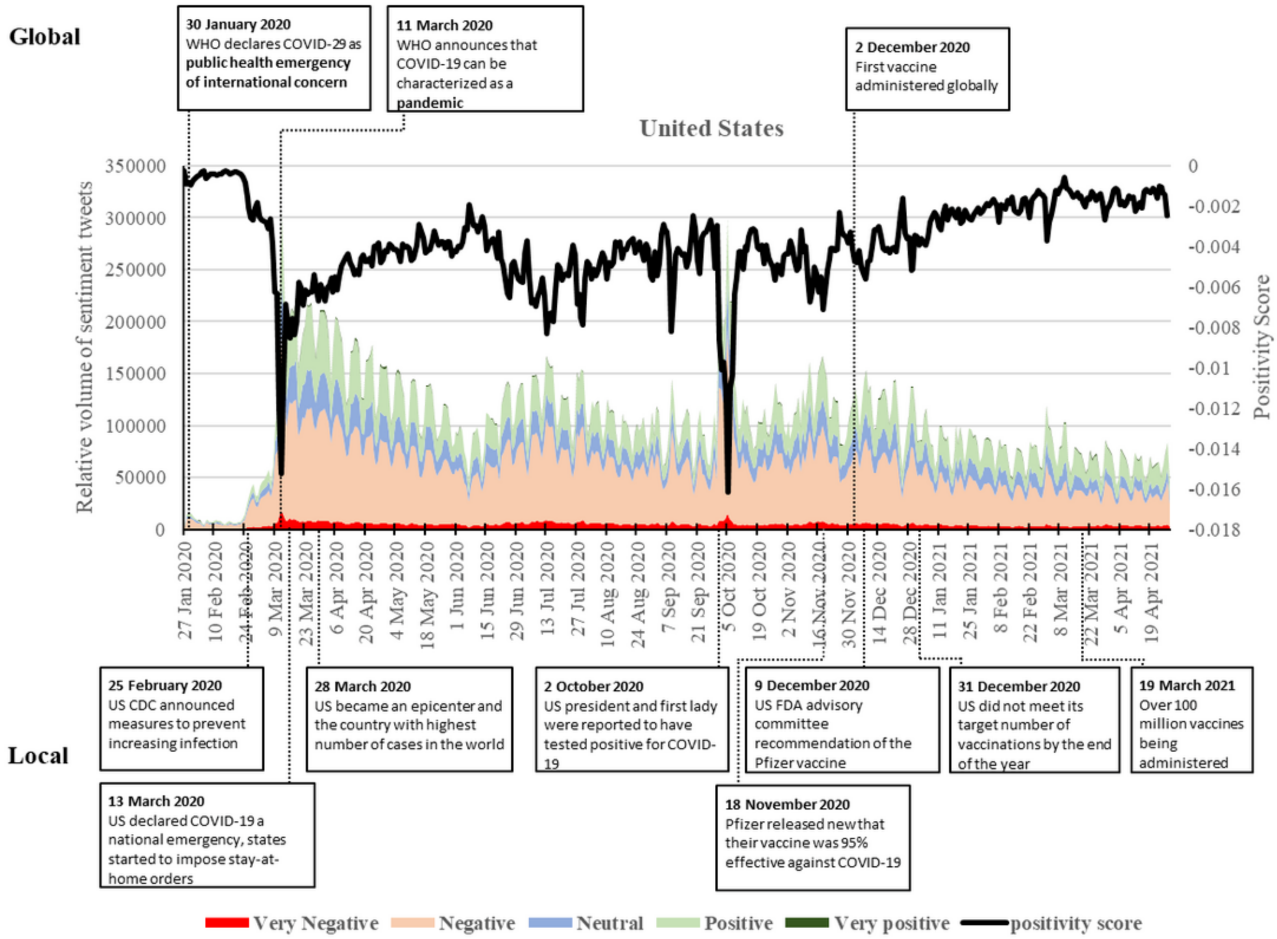
**Figure 6.** Twitter sentiments in the United States from January 28, 2020, to April 28, 2021. CDC: Centers for Disease Control and Prevention; FDA: Food and Drug Administration; WHO: World Health Organization.




The biggest increase in negative tweets, over 30 times more than the peak on January 30 and 5 times than that on February 28, occurred on March 12 and 13, 2020. This increase followed closely upon the announcement on March 11 by the WHO's pandemic declaration and the US's national declaration of emergency on March 13. Meanwhile, the positivity score saw a substantial decrease. However, the dip was much lower than those in the other countries, suggesting an overwhelming number of negative tweets on that day. The reassurance by the government also saw positive sentiment surfacing, leading to an increase in the positivity score.

The volume of both positive and negative sentiments gradually decreased from March 13 to early June 2020 when the number of cases reached 2 million and states started to impose stay-at-home orders. However, the positivity score remained at a negative level, fluctuating in negative sentiments around the summer of 2020 when there was a rise in COVID-19 cases. The number of positive and negative sentiments then began to rise again, with cases increasing rapidly and news of vaccine development and efficacy during trials showing positive results. This increase in tweets culminated in a smaller peak on July 15 as daily cases reached a new high.

Sentiments remained relatively high but stable until October 2, 2020, when negative sentiments rapidly increased as the president and the first lady were reported to have tested positive for COVID-19 [59]. The increase in negative sentiments peaked on October 6—with the president seen discharged from the hospital—and quickly fell back to levels found over the summer. A peak in positive sentiments was found on November 18 as Pfizer released news that their vaccine was 95% effective against COVID-19. However, there was also an increase in negative sentiments as the number of cases surpassed 11 million, and citizens were advised by the CDC to stay home for Thanksgiving. On December 9, 2020, though negative sentiments were still the majority, positive sentiments were found in the tweets with the US Food and Drug Administration advisory committee's recommendation of the Pfizer vaccine, and the world's first COVID-19 vaccine was administered to members of the public in the United Kingdom [35]. On December 22, a small peak in negative sentiments was found as a new strain was discovered in the United Kingdom [33]. On December 31, another slight increase in negative sentiments occurred as reports surfaced that the United States did not meet its target number of vaccinations by the end of the year [60]. Since then, the relative volume of negative tweets remains very high compared to January and February from the previous year.

Though positive sentiments also remain higher than earlier in the pandemic and the positivity score has increasingly become more balanced, the score did not skew toward more positive sentiments than negative within the study period.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## Discussion

### Principal Findings

This study set out to examine the evolution of COVID-19 sentiment trends and the balance of positive and negative public sentiments in 5 countries over the course of the COVID-19 pandemic. The sentiment trajectory of each country within the framework of government actions provides unique implications for considering when and how negative sentiments overwhelm positive sentiments and may cause unanticipated public reactions. The findings of our study present important implications for policy making, as they indicate public perceptions of the disease threat in connection with government health crisis responses, which in turn could lead to large scale public behavior effects.

Our findings clearly demonstrate that Singaporean and South Korean populations showed different perceptions of the disease at the beginning of the COVID-19 pandemic compared to those in the other 3 countries and were immediately active on social media in response to the WHO's declaration of PHEIC in January 2020. This indicates that the 2 countries have been vigilant since the early outbreak, possibly due to perceived closer geographic distance from the initial epicenter (China), higher air travel between the affected countries, and perceived potential disease spread. In addition, both Singapore and South Korea were previously affected by the severe acute respiratory syndrome (SARS) in 2003. They had therefore implemented pandemic preparedness initiatives to improve outbreak preparedness and the rapid handling of novel diseases [23,24]. In contrast, the public in the United States, India, and the United Kingdom demonstrated fewer reactions to the early declaration, suggesting consistency with fewer active cases reported in these countries during early 2020.

Our sentiment analyses also demonstrate a clear contrast between the 2 western countries versus the 3 Asian countries. Over the 16 months, relatively more minor sentiment swings appeared in South Korea, Singapore, and India, but wide swings in negativity were observed in the United States and the United Kingdom. Indeed, the 3 countries in Asia faced escalating waves of cases, which increased expected negative sentiments. However, for all 3 Asian countries, substantial proportions of positive sentiments also surfaced in parallel, balancing the overall negativity of public sentiments. In the United States and the United Kingdom, although negative sentiments increased substantially after the cases began to increase, similar solid positive sentiments were slow to surface, indicating potential public alarm and possibly frustrations within the populations. This could be due to the relatively clearer and stricter regulations implemented by Singapore and Korea upon discovering cases within their nations [3]. Furthermore, although India was slower to act initially upon the WHO declaration, their case-fatality rate remained low throughout 2020, which may have bolstered public positivity toward the pandemic response [27]. In both the United States and the United Kingdom, the initial lack of clarity of COVID-19 responses, along with mixed messaging and contradictory policies appear to have led to a much greater distribution of negative viewpoints from the public over the first 16 months of the disease timeline.

As the pandemic evolved, national-level government crisis responses and local disease developments appear to be strongly associated with the trends and fluctuations of public sentiments in all 5 nations. At a macro level, our findings demonstrate the correspondence between public sentiments and government actions. Overall, negative sentiments surged when local disease threats escalated and with local emergency measures such as the announcement of lockdowns. Conversely, the positive sentiments also increased in line with the government-initiated crisis responses like financial support and vaccination rollout. However, indecisive and contradictory crisis responses, such as those in the United Kingdom and the United States during their early epidemics, seemed to do more harm than good for the public's positive sentiments. Additionally, infections of high-ranking government officials and celebrities induced negative sentiments consistently across countries, possibly because such incidents could amplify the perceived risks and reduce public trust in the government's responses. This implies that governments need to provide initial timely responses to ease the public from the emergent threat during public health crises. Meanwhile, the authorities should also assure the public by maintaining a good impression and considering themselves as role models for the public.

Our findings also suggest that social media play significant roles in public health crisis responses. Overall, echoing previous studies [5-7], this study shows that social media sentiments are sensitive to both global and local crisis milestones. The public's sharing of emotions through social media is an organically developed data source that shows the collective sentiments of the people. The shared positive and negative opinions can reflect the information or situation they face at a point in time. This up-to-date data is a valuable tool to evaluate and understand the emotional well-being of the public, their concerns regarding the new changes, new policy announcements, and the ongoing pandemic itself. This suggests that social media are important data sources for comparisons of local government responses during global public health crises and should be explored further.

### Limitations and Future Research

This research has a number of limitations that warrant future research. First, although our findings clearly showed that the trends of general positive and negative sentiments, and their differences, coincided with government decisions in fighting the disease, our focus is on positive and negative sentiment valences instead of discrete emotions. This choice gives us the advantage of clearly identifying the key differences and trend of change of the focal sentiment construct over a longitudinal scale of 16 months of data and across multiple countries of our analytical interest. In future work, it may be worthwhile to examine more specific shared emotional experiences such as the public's collective fear, anger, happiness, and sadness [46,61,62], and their respective emotion frequency, intensity, and change over time following government measures and communications [7].

Second, the study retrieved and examined tweets in English. English is only one of the common languages in Singapore and


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India, and not widely used in South Korea. Therefore, information on public sentiments in these 3 Asian countries may not be fully captured by our data universe, which is an issue that is faced by many multicountry studies. The data obtained can be used as a general guide with the knowledge that it represents a subset of the population's social media discourse. Nevertheless, future studies should investigate public sentiments with the inclusion of analysis from a broader range of local languages used in each country.

Third, it is useful to note that according to Gupta et al [44], approximately 54.2% of 198,378,184 tweets collected on COVID-19–related keywords have country-identifiable "location" information as declared by the users at their Twitter public profile. Although this is a reasonable representation, we would like to caution toward generalizing the data we used to fully represent the social media population for each country studied in this research.

Fourth, we used Twitter as a proxy for public sentiments on social media. Although Twitter has a high user base in countries such as the United States, India, and the United Kingdom [63], it is only one of many social media platforms and may have less frequent users for other countries, which could lead to selection bias. Future studies should consider expanding the range of platforms used to capture a broader range of social media, such as Reddit and Facebook, and explore the number of unique users posting to capture a wider range of sentiments.

Though these findings demonstrate the association between government and health authorities' crisis responses and evolvement of public sentiments, future research needs to continue across the entire span of the COVID-19 course to attain a fuller understanding of the phenomenon and additionally use more in-depth qualitative methods, including case studies, to further scrutinize the linkages and examine the underlying mechanisms. In addition, specific discourses of public sentiments should be examined to reveal specific public opinion and social media responses toward the government acts and policies.

### Conclusion

This research is an initial attempt to compare long-term public sentiments in different countries, aiming to consider and guide policy implications to manage the unprecedented COVID-19 pandemic and future crises of similar nature. Our findings from longitudinal data over the first 16 months of the COVID-19 trajectory show that India, Singapore, and South Korea have seen relatively stable negative sentiments along with sizable positive sentiments. In contrast, the United States and the United Kingdom witnessed a substantial upsurge of negative sentiments, and parallel positive sentiments were slow to surface. Thus, it appears that concerted early responses to the pandemic are associated with overall positivity reflected in public sentiments. The research findings also suggest that more rigorous and consistent approaches of government crisis communications appear to be associated with more stable and balanced sets of public sentiments during the COVID-19 pandemic.

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## Authors' Contributions

MOL conceptualized, initiated, and led the manuscript; AS and JL drafted the manuscript; PJS, WS, and CP provided discussions surrounding global results; RKG and YY provided data analysis. All authors contributed to the manuscript writing, reviewed the content, and agreed with the submission.

## Conflicts of Interest

RKG and YY are coinventors of the CrystalFeel algorithm. No other conditions or circumstances present a potential conflict of interest for the other authors.

Multimedia Appendix 1
Key COVID-19 events by country between January 28, 2020, and April 28, 2021.
[DOCX File , 26 KB - infodemiology_v2i1e31473_app1.docx ]

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## Abbreviations

**API:** application programming interface
**CDC:** Centers for Disease Control and Prevention
**DORSCON:** Disease Outbreak Response System Condition
**PHEIC:** Public Health Emergency of International Concern
**SARS:** severe acute respiratory syndrome
**WHO:** World Health Organization


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Original Paper

# The Moderating Role of Community Capacity for Age-friendly Communication in Mitigating Anxiety of Older Adults During the COVID-19 Infodemic: Cross-sectional Survey

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## Abstract

**Background:** Older adults were perceived as a vulnerable group during the COVID-19 pandemic due to the health and mental health challenges they faced. The pandemic was accompanied by an “infodemic” of overabundant and questionable information that has affected older adults’ mental health. As the infodemic and ageist narratives were prevalent online, more anxiety symptoms have been induced among older adults who used social media. Age-friendly communication, advocated by the World Health Organization’s Age-friendly City (AFC) guide, could be an antidote by providing tailored information via appropriate channels for older adults.

**Objective:** This study investigated the role of community capacity for age-friendly communication in mitigating anxiety during the pandemic. We hypothesized that age-friendly communication would moderate the effects of infection risks and social media use on anxiety. A double-moderating effect was hypothesized in the context of diminished trust in traditional media.

**Methods:** Data were collected from a cross-sectional telephone survey conducted in Hong Kong in 2020. Older adults (N=3421, age≥60 years) were interviewed about their well-being and daily lives. Community capacity for age-friendly communication was measured in a living district–based evaluation. It had 2 components: the reach of appropriate information to older adults (AFC-Information) and the age-friendliness of communication technologies (AFC-Communication Technology) in the community. We tested the hypothesized moderation and double-moderation effects with ordinary least squares regressions.

**Results:** Perceived COVID-19 infection risk (b=0.002, *P*=.02) and use of social media for COVID-19 information (b=0.08, *P*=.04) were associated with more anxiety symptoms. The effect of using social media was moderated by AFC-Information (b=–0.39, *P*=.002) and AFC-Communication Technology (b=–1.06, *P*<.001), and the effect of perceived COVID-19 infection risk was moderated by AFC-Information (b=–0.03, *P*=.002) and AFC-Communication Technology (b=–0.05, *P*<.001). Lower trust in traditional media exacerbated anxiety symptoms associated with social media use (b=–0.08, *P*=.02). Higher AFC-Information alleviated this moderation effect (AFC-Information × media trust b=–0.65, *P*<.001; AFC-Information × social media use b=–2.18, *P*<.001; 3-way interaction b=0.40, *P*=.003).

**Conclusions:** Our findings highlight the role of community age-friendly communication in mitigating anxiety related to the infodemic. Although using social media may have exacerbated the impact of the infodemic on older adults, it has the potential to deliver timely information for an adequate health response. Although the amplifying effects of low media trust was associated with social media use, age-friendly communication determined its strength. Instead of discouraging the use of digital technologies



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for COVID-19 information, efforts should be made in tailoring information and communication technologies in local communities for older adults.

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**KEYWORDS**

COVID-19; mental health; information technology; media trust; social media; Hong Kong

## Introduction

### Background

The COVID-19 pandemic challenged older adults' health and mental health. The threat of the pandemic may generate mental health challenges, such as anxiety, among the older population. Evidence from different countries suggests that higher COVID-19 death rates in the community are positively associated with distress in the population [1]. Another cross-national study argued that COVID-19-related anxiety is associated with the perceived vulnerability that predicts poorer well-being and increased distress [2]. Because older adults are perceived as a high-risk group, they were advised to stay at home in the early days of the pandemic. Social isolation policies, such as social distancing and lockdown, disproportionally affected the older population by heightening their risks of chronic diseases and mental health challenges [3]. A systematic review and meta-analysis estimated a 25% prevalence of COVID-19-related anxiety among the general population, where negative psychological effects can be attributed to infection risks and quarantine measures [4]. In Hong Kong, about 14% of the population showed symptoms of anxiety during the pandemic in 2020 [5], and older adults exhibited more anxiety symptoms than before the pandemic [6]. Although restrictive social isolation measures were perceived as essential to protect the older population, efforts to mitigate their anxiety were warranted.

The infodemic associated with the COVID-19 pandemic may have aggravated anxiety among older adults. Older adults obtained COVID-19-related information from more diverse sources than younger adults and were driven to worry more about the pandemic [7]. The infodemic could have engendered confusion, undermining public trust and mitigation behaviors [8]. People may panic when information from health communication is too difficult to disambiguate [9]. Conflicting information about the pandemic from media sources may also create uncertainty and stress that contribute to significant psychological issues, such as anxiety [8]. Higher anxiety levels were found among social media users during the pandemic [10,11]. COVID-19-related anxiety in older adults can be further complicated by age-related factors. Ageist views and health worries, both disproportionally affecting older adults, are associated with higher anxiety symptoms [12]. Exposure to negative-age-stereotype messaging could lead to more anxiety and less peacefulness compared to positive-age-stereotype messaging [13]. Studies on social media data suggest the pandemic was often downplayed by messages that emphasized older adults as the main population harmed by COVID-19 and their lives as less valuable [14]. The aggravating effect of the infodemic on anxiety levels can be stronger for older adults who used social media for COVID-19 information [15]. It has become essential to address the anxiety caused by social media use with age-friendly communication solutions.

Experts advocated for better media communication for older adults during the COVID-19 pandemic [16]. As in previous health crises, the public turned to the media as a crucial and reliable source of information [17]. Adequate health communication that delivers accurate information and promotes corresponding health behaviors can mitigate uncertainty and fear [18]. Specifically, effective communication of facts about communicable diseases is the key to an accurate estimation of public risks [19]. Although COVID-19 containment and public health policies may help alleviate pandemic-related mental health challenges [1,20], relevant responses should be appropriately communicated to older adults. This study investigated how the community-level capacity for age-friendly communication may help older adults navigate the pandemic and infodemic and mitigate associated anxiety.

### Community Capacity for Age-friendly Communication

According to the World Health Organization's (WHO) guide on the Age-friendly City (AFC), "information" and "use of communication and digital devices" are 2 subdomains of age-friendly communication and information [21]. A checklist of age-friendly communication and information has been developed based on the views expressed by older people worldwide [21]. In an AFC, information of interest to older people is disseminated regularly in broadcast media and targeted media. Older people can obtain the information, orally or printed using plain language, close to their homes and where they conduct their daily activities, such as public meetings, community centers, and clubs. Volunteer callers and visitors and home support workers are some of the people who may provide information to older people who are at risk of social isolation. Regarding communication and digital devices, electronic equipment, such as mobile telephones and televisions, and automated communication are designed with age-friendly features, such as slow and clear instructions, large buttons, and big lettering. Older people can also have affordable access to computers and the internet in public places, such as community centers and libraries, with tailored instructions or individual assistance.

First, information directed to older adults at the community level may be particularly helpful in enabling them to manage the "new normal" generated by the pandemic. Complementing information on social media, information disseminated by reliable sources through familiar and preferred channels, such as telephone or information stands in the neighborhood [22], can serve as a reference for older adults when evaluating COVID-19 risk and alleviate the anxiety induced by the



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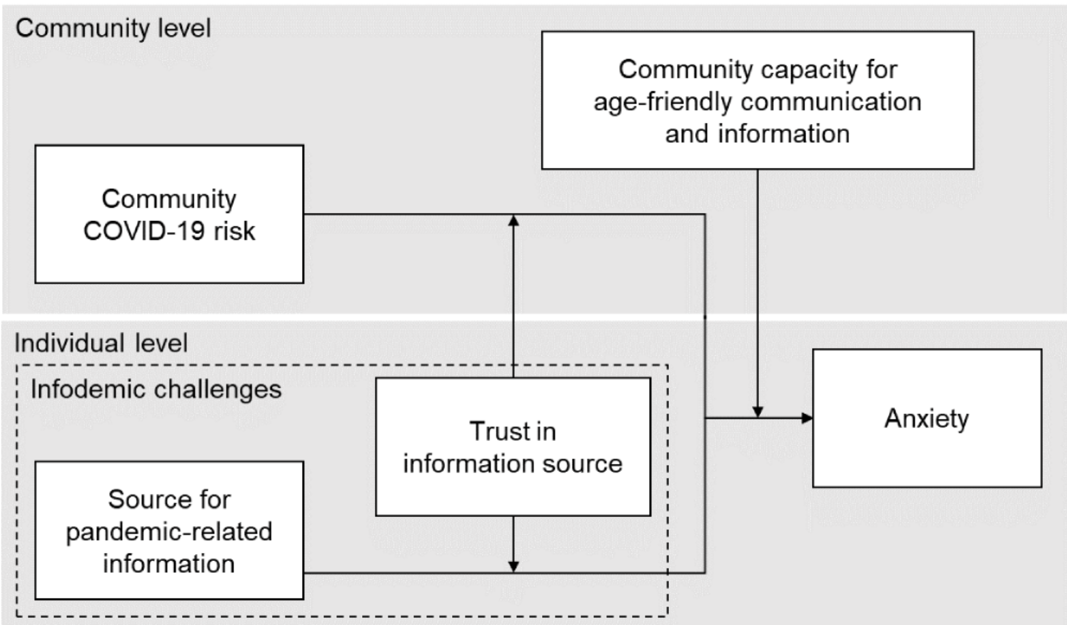
confusing messages on social media about the pandemic. Community information may also communicate appropriate context-specific policy responses, such as responding to local infection cases and resource distribution. Second, user-friendly features on communication and digital devices can enhance older adults' utilization of technologies, which encourage information exchange and have the potential to remediate some of the losses they have experienced and hence maintain a vibrant and supportive community [23]. During the COVID-19 pandemic, older adults may better adapt to digital technologies designed to enhance age-friendliness to compensate for disrupted daily activities. Distributing information via communication channels with which older adults are familiar and in a timely, accessible, and affordable manner is 1 of the core AFC domains in promoting older adults' independence and autonomy [21,24]. As a result, older adults would better mitigate the anxiety induced by COVID-19 infection risk and inconsistent misinformation from social media.

Community capacity for age-friendly communication may buffer the amplified effect of reduced trust in traditional media on infodemic-generated anxiety. In a crisis, insufficient or inconsistent information may lower public trust [25]. During the COVID-19 pandemic, the infodemic of information overabundance and misinformation has undermined public trust toward traditional institutions, including mass media, that could help deliver helpful information for older adults [26]. The prevalence of social media, where health information gains credibility by its rate of dissemination rather than scientific merit, has changed the perceived legitimacy, longstanding trust, and role of the media [27]. A cross-national study found that around 1 in 3 respondents believed the news exaggerated the pandemic [28], and evidence from a German study suggested that nearly half of respondents reported difficulty judging the trustworthiness of media information about COVID-19 [26]. Diminished media trust could undermine the effectiveness of health communication, especially compliance with protective health behaviors [29]. People who reported difficulties in ascertaining reliable guidance to cope with the pandemic exhibited mental health issues, such as anxiety [30]. Since older adults had higher risks of receiving and relaying misinformation [31], stronger efforts should be made to address the challenges they face. Community-level age-friendly communication offers a solution. A trusted information source easily accessible by older adults that can address their questions and confusion may ease their anxiety during the infodemic.

### This Study

Despite the infodemic-amplified anxiety experienced by older adults regarding public health risks during the pandemic, effective age-friendly communication on a community level could ensure they are informed and resilient against problematic information. This study investigated the factors associated with older adults' anxiety levels and the role of age-friendly communication in moderating the effects on anxiety. We hypothesized that the risk of contracting COVID-19 and the use of social media for pandemic-related information would be associated with increased anxiety levels in older adults, where more community-level age-friendly communication could mitigate the associations. The infodemic challenged the trust in traditional media mainly by way of misinformation in social media. We hypothesized that lower trust in the media would exacerbate anxiety symptoms associated with social media use and the risk of contracting COVID-19. Nevertheless, enhancing community capacity for age-friendly communication may help alleviate the negative impact of lowered media trust. We hypothesized that higher community capacity for age-friendly communication would reduce the effect of lower trust in the media on aggravating anxiety symptoms associated with social media use and the risk of contracting COVID-19. Figure 1 illustrates the theoretical framework of this study.

**Figure 1.** Theoretical framework.



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## Methods

### Study Design and Sample

Respondents were recruited to answer a cross-sectional telephone survey aimed to understand the needs and well-being of community-dwelling older adults (age≥60 years) in Hong Kong during the COVID-19 pandemic. The survey protocol is described in a previous study [15]. The survey was administered between May and August 2020 to service users from community centers for older adults and community mental wellness centers. Both centers were membership based and funded by the government. Memberships are free and open to all eligible community members, which include persons aged 60 years or above for community centers for older adults and persons experiencing mental health challenges for community mental wellness centers. Community centers for older adults provide various active aging activities, such as Tai Chi, dancing, music, and computer or mobile phone classes, to their members; community mental health centers provide community health education and social support to their members. Members are eligible to enroll in various activities, usually on the first-come first-serve principle. Survey respondents were existing members of the centers, but it is unknown for how long they have been members or what types of activities they have participated in before the pandemic. The study protocol was designed by qualified clinical psychologists and researchers and pretested by frontline social workers before full-scale implementation. Trained interviewers conducted the interviews using a standardized protocol that enabled social workers to follow up respondents who exhibited mental health challenges. Of the 3550 calls made, 3421 older adults completed the interview, yielding a 96.37% success rate. No respondent had a prior COVID-19 infection history. The Human Research Ethics Committee of the University of Hong Kong approved this study (reference no. EA2003001[A]).

### Measures

#### *Anxiety Symptoms*

Anxiety symptoms were measured using the validated Chinese version of the 2-item Generalized Anxiety Disorder (GAD-2) questionnaire [32]. Scores range from 0 to 6, and higher scores represent more anxiety symptoms; GAD-2 score≥3 suggests the presence of an anxiety disorder [33].

#### *Media Use and Trust*

Respondents were asked to identify their primary source of COVID-19 information from (1) traditional media or (2) social media. The trust levels toward traditional media and social media were measured on a 5-point scale from total distrust (1) to complete trust (5). A "not applicable" option was available for each item for those who did not use the specified media type. The use of social media for COVID-19 information was captured by a 3-point ordinal scale from 0 to 2: 0, no usage (respondents selecting "not applicable" for social media trust level); 1, used social media (respondents with a valid response for social media trust level); and 2, used social media as their primary source of information.

#### *Community COVID-19 Risk*

The local risk of contracting COVID-19 was captured by the number of confirmed cases in the respondent's district of residence during the week of the survey. The survey covered 12 (67%) of the 18 administrative districts in Hong Kong. This measurement was geographically sensitive and reflected the risk of contracting COVID-19 in communities in the survey period. Data were extracted from daily government reports [34].

#### *Community Capacity for Age-friendly Communication*

Data were extracted from assessments by the Jockey Club Age-friendly City Project in Hong Kong (Jockey Club Institute of Ageing of the Chinese University of Hong Kong et al [35]). The assessments investigated the age-friendliness of all 18 administrative districts in Hong Kong with the WHO-suggested AFC guide [21]. The same measurement method was used in previous studies in Hong Kong [36,37]. Within the communication and information domain, the subdomains "information" (AFC-Information) and "use of communication and digital devices" (AFC-Communication Technology) assessed the reach of appropriate information to older adults and the age-friendliness of communication technologies in the community, respectively. For example, the survey asked whether older adults regularly received information they found interesting and relevant to their age group and whether communication devices had large buttons and big font sizes to suit their dexterity and vision. The assessments were conducted between 2017 and 2018 by administering questionnaires with Likert scale survey questions to older adults. Average scores were obtained for each subdomain in each district. Scores ranged from 1 to 6 (1=strongly disagree to 6=strongly agree); a higher index score represented greater age-friendliness of the subdomain in the district. Although the data were obtained before the pandemic, the indexes represented the readily available capacity for age-friendly communication in communities that could be mobilized from the early stages of the pandemic.

#### *Public Health Responses*

Public health responses were measured by the Containment and Health Index from the Oxford COVID-19 Government Response Tracker. The index was calculated daily based on the number and strictness of containment and closure policies, such as canceling public events and stay-home requirements, and health system policies, such as contact tracing and public information campaigns [38]. Scores ranged from 0 to 100; a higher index score indicated that more containment measures were in place. The index score of the interview date was aligned to each respondent to control for its effects on anxiety levels.

#### *Demographic Covariates*

Demographics collected included age in years, gender (0=male, 1=female), district of residence, and service nature. District of residence was not included in the main analysis but was used to match respondents' community COVID-19 risk and AFC indexes. Service nature was indicated by respondents' involvement with either community aged care services or a mental wellness center.


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### Statistical Analysis

Descriptive statistics were computed and appropriately reported. All hypotheses were tested by hierarchical ordinary least squares (OLS) regressions. All models were controlled by the Containment and Health Index and demographic covariates. First, baseline models predicting the GAD-2 score were estimated. Independent variables in the baseline model included community COVID-19 risk and social media use. Since the 2 moderator variables, AFC-Information and AFC-Communication Technology indexes, were substantially correlated (r=0.48, *P*<.001), they were included in 2 baseline models separately. The variance inflation factors of all variables in all baseline models were below 2.0, suggesting low multicollinearity between the variables. Second, 4 OLS regression models examined the mediation effects between the independent variables and moderators. The final set tested for moderation and double-moderation effects with trust in traditional media. Graphs of predicted values are provided to illustrate the moderation effects. The Johnson-Neyman technique was used to identify the range of significant moderation effects [39]. Sensitivity analyses using binary independent variables as social media use measurements, log-transformed GAD-2 score as a dependent variable in OLS regression models, Poisson regressions, and 2-part mixed models yielded similar results. The current set of OLS models is presented for better comprehension and interpretation. Statistical analysis was conducted using R.

## Results

### Demographics

Table 1 shows respondents' (N=3421) demographic characteristics. Their average age was 76 years (SD 8.9), 2549 (74.58%) of 3418 respondents were female, and 2666 (77.93%) of 3421 respondents were members of community centers for older adults. The average Containment and Health Index score was 58.57 (SD 8.80) within the 119-day interview time frame, and there were on average 25.7 (SD 27.5) COVID-19 cases within communities when the survey was conducted. The average GAD-2 score was 0.74 (SD 1.2), where 239 (7.0%) of the 3421 respondents were at risk of anxiety (GAD-2 score≥3), suggesting anxiety symptoms were not prevalent among respondents. Trust in traditional media was moderately high and averaged 4.27 (SD 0.88). Around 1399 (40.89%) of the 3421 respondents used social media and rated their trust in social media, and the average score was 3.18 (SD 1.1); in addition, 203 (5.93%) indicated that social media was their main source of COVID-19 information. The average AFC-Information index was 4.09 (SD 0.21) and the AFC-Communication Technology index 3.96 (SD 0.13).

**Table 1.** Respondents' characteristics (N=3421).

| Variables | Total respondents, N | Respondents, n (%) | Mean (SD) |
|---|---|---|---|
| **Demographics** | | | |
| Age (years) | 3421 | —[a] | 76 (8.9) |
| Gender (female) | 3418 | 2549 (74.58) | — |
| Service nature (community center for older adults) | 3421 | 2666 (77.93) | — |
| Containment Health Index (range 0-100, 119 days) | 3421 | — | 58.5 (8.8) |
| **Psychological distress** | | | |
| GAD-2[b] score (range 0-6) | 3388 | — | 0.74 (1.2) |
| **Community COVID-19 risk** | | | |
| Weekly number of COVID-19 cases in district (range 0-135) | 3421 | — | 25.7 (27.5) |
| **Trust in traditional media (range 1-5)** | 3335 | — | 4.27 (0.88) |
| **Trust in social media (range 1-5)** | 1399 | — | 3.18 (1.1) |
| **Using social media for COVID-19 information** | | | |
| Used social media for COVID-19 information | 3421 | 1399 (40.89) | — |
| Social media as the main source of COVID-19 information | 3421 | 203 (5.93) | — |
| **Community capacity for age-friendly communication (12 districts)** | | | |
| AFC[c]-Information index (range 1-6) | 3421 | — | 4.09 (0.21) |
| AFC-Communication Technology index (range 1-6) | 3421 | — | 3.96 (0.13) |

[a]Not applicable.

[b]GAD-2: 2-item Generalized Anxiety Disorder.

[c]AFC: Age-friendly City.

Table 2 and Table 3 present the associations between anxiety symptoms and the independent variables by OLS regressions. The baseline model shows that the GAD-2 score was positively associated with higher community COVID-19 risk (b=0.002, *P*=.02) and social media use (b=0.08, *P*=.04). A higher Containment and Health Index score, meanwhile, was negatively


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associated with the GAD-2 score (b=–0.02, *P*<.001). Female respondents exhibited more anxiety symptoms (b=0.22, *P*<.001), but those who received service from a community center for older adults showed less anxiety symptoms (b=–0.55, *P*=.001).

The baseline models with AFC indexes suggested a positive association between anxiety symptoms and AFC-Information (b=0.23, *P*=.002) and AFC-Communication Technology (b=0.99, *P*<.001).

**Table 2.** OLS[a] regression results predicting anxiety level moderated by the AFC[b]-Information index (N=3385).

| Variables | Baseline | | With AFC-Information | | Social media use × AFC-Information | | COVID-19 risk × AFC-Information | |
|---|---|---|---|---|---|---|---|---|
| | b | *P* value | b | *P* value | b | *P* value | b | *P* value |
| Age | –0.002 | .39 | –0.001 | .44 | –0.003 | .33 | –0.004 | .11 |
| Gender (female) | 0.22 | <.001 | 0.22 | <.001 | 0.22 | <.001 | 0.22 | <.001 |
| Service nature (aged care) | –0.55 | <.001 | –0.58 | <.001 | –0.59 | <.001 | –0.60 | <.001 |
| Containment Health Index | –0.02 | <.001 | –0.02 | <.001 | –0.02 | <.001 | –0.03 | <.001 |
| Community COVID-19 risk | 0.002 | .02 | 0.001 | .07 | 0.001 | .05 | 0.14 | <.001 |
| Social media use | 0.08 | .04 | 0.08 | .03 | 1.71 | .001 | 0.08 | .03 |
| AFC-Information | —[c] | — | 0.23 | .002 | 0.42 | <.001 | 1.10 | <.001 |
| Social media use × AFC-Information | — | — | — | — | –0.39 | .002 | — | — |
| COVID-19 risk × AFC-Information | — | — | — | — | — | — | –0.03 | <.001 |
| Adjusted $R^2$ | 0.066 | — | 0.069 | — | 0.071 | — | 0.084 | — |

[a]OLS: ordinary least squares.

[b]AFC: Age-friendly City.

[c]Not applicable.

**Table 3.** OLS[a] regression results predicting anxiety level moderated by the AFC[b]-Communication Technology index (N=3385).

| Variables | Baseline | | With AFC-Communication Technology | | Social media use × AFC-Communication Technology | | COVID-19 risk × AFC-Communication Technology | |
|---|---|---|---|---|---|---|---|---|
| | b | *P* value | b | *P* value | b | *P* value | b | *P* value |
| Age | –0.002 | .39 | –0.002 | .33 | –0.003 | .19 | –0.004 | .13 |
| Gender (female) | 0.22 | <.001 | 0.21 | <.001 | 0.22 | <.001 | 0.21 | <.001 |
| Service nature (aged care) | –0.55 | <.001 | –0.63 | <.001 | –0.62 | <.001 | –0.66 | <.001 |
| Containment Health Index | –0.02 | <.001 | –0.03 | <.001 | –0.03 | <.001 | –0.03 | <.001 |
| Community COVID-19 risk | 0.002 | .02 | 0.001 | .10 | 0.001 | .18 | 0.20 | <.001 |
| Social media use | 0.08 | .04 | 0.07 | .06 | 4.31 | <.001 | 0.05 | .16 |
| AFC-Communication Technology | —[c] | — | 0.99 | <.001 | 1.50 | <.001 | 1.81 | <.001 |
| Social media use × AFC-Communication Technology | — | — | — | — | –1.06 | <.001 | — | — |
| COVID-19 risk × AFC-Communication Technology | — | — | — | — | — | — | –0.05 | <.001 |
| Adjusted $R^2$ | 0.066 | — | 0.076 | — | 0.081 | — | 0.088 | — |

[a]OLS: ordinary least squares.

[b]AFC: Age-friendly City.

[c]Not applicable.

Nevertheless, the effects of COVID-19 risk and social media use on anxiety level depended on the age-friendliness of community communication. OLS models with interaction terms suggested significant moderation effects by the AFC-Information index and the AFC-Communication Technology index. The effect of social media use on anxiety symptoms was moderated by AFC-Information (b=–0.39, *P*=.002) and AFC-Communication Technology (b=–1.06, *P*<.001). Figures 2a and 2b illustrate the moderated relationships. The ranges of significant moderation slopes



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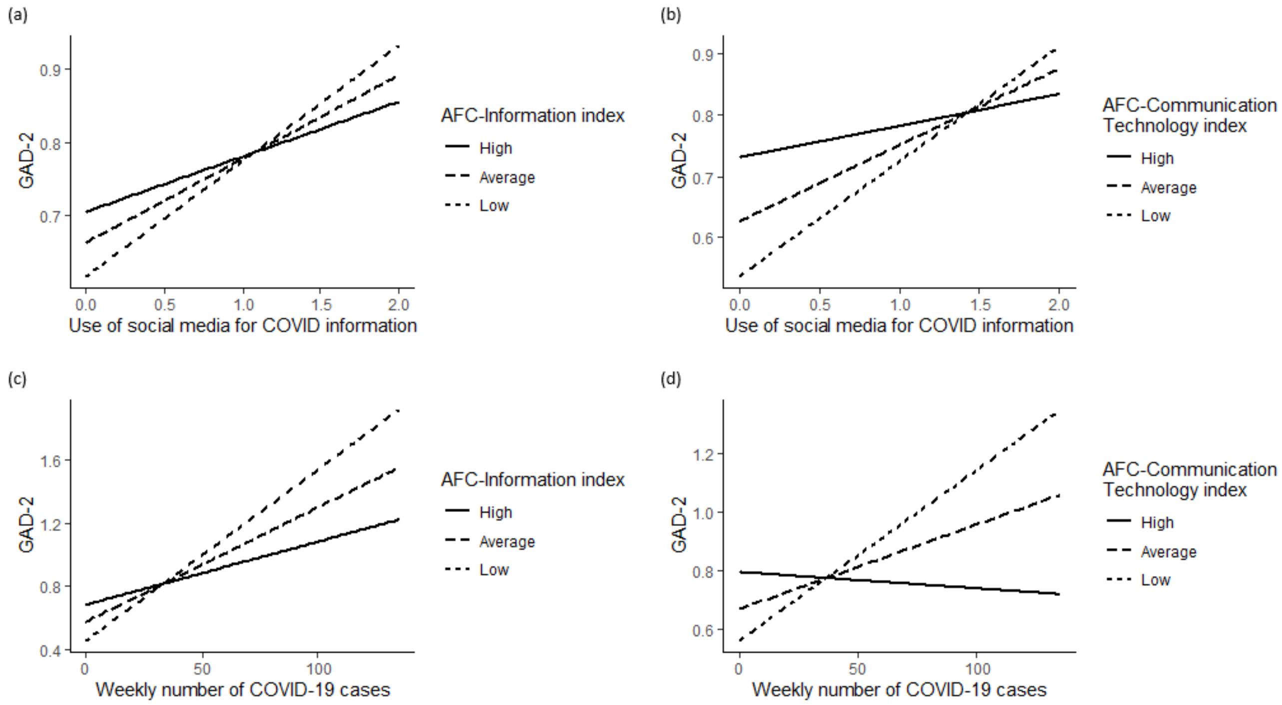
suggested by the Johnson-Neyman technique were AFC-Information<4.20 and AFC-Communication Technology<4.01. The predicted anxiety symptoms of older adults living in a community with high AFC-Information and AFC-Communication Technology indexes were not associated with social media use. More social media use predicted higher GAD-2 scores among older adults living in a community with AFC indexes lower than the thresholds, and the associations were stronger in communities with lower AFC indexes. The effect of community COVID-19 risk was also moderated by AFC-Information (b=–0.03, *P*<.001) and AFC-Communication Technology (b=–0.05, *P*<.001). Figures 2c and 2d illustrate the moderated relationships. Significant ranges of slopes were AFC-Information<4.27 or AFC-Information>4.36 and AFC-Communication Technology<3.99 or AFC-Communication Technology>4.05. Community COVID-19 risk was positively associated with predicted GAD-2 scores in communities with AFC indexes lower than the thresholds, whereas the associations were negative in communities with AFC indexes higher than the thresholds. In general, in districts with a lower capacity for communicating with older adults, more social media use and higher community COVID-19 risk were associated with more anxiety symptoms.

**Figure 2.** Moderation effects of AFC-Information and AFC-Communication Technology indexes. AFC: Age-friendly City; GAD-2: 2-item Generalized Anxiety Disorder.




When trust in traditional media was considered in the moderated relationships, the 3-way-interaction OLS regression models suggested that AFC-Information is the key to moderating the effects on GAD-2 scores but not AFC-Communication Technology. Table 4 presents the moderation effects and the double-moderation effects with trust in traditional media. The single-moderation model suggested trust in traditional media moderates the effects of social media use (b=–0.08, *P*=.02) but not community COVID-19 risk (b=–0.000, *P*=.77). The significant moderation slope range suggested by the Johnson-Neyman technique was trust in traditional media<3.93. For older adults with lower trust in traditional media, using more social media predicted more anxiety symptoms. The double-moderation models are consistent with previous findings. In addition, trust in traditional media and AFC-Information exhibited a double-moderation effect with social media use (3-way interaction b=0.40, *P*=.003) and community COVID-19 risk (3-way interaction b=0.01, *P*=.01). Meanwhile, trust in traditional media and AFC-Communication Technology showed no significant double-moderating effect with social media use (3-way interaction b=0.35, *P*=.14) and community COVID-19 risk (3-way interaction b=–0.004, *P*=.62). Table 5 summarizes the 3-way-interaction effects between AFC-Information, trust for traditional media, social media use, and the weekly number of COVID-19 cases on anxiety.


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**Table 4.** OLS[a] regression results predicting anxiety level, 3-way interaction (N=3300).

| Variables | Baseline | | Social media use × media trust | | COVID-19 risk × media trust | | AFC[b]-Information double moderation | | AFC-Communication Technology double moderation | |
|---|---|---|---|---|---|---|---|---|---|---|
| | b | *P* value | b | *P* value | b | *P* value | b | *P* value | b | *P* value |
| Age | –0.002 | .49 | –0.002 | .43 | –0.002 | .49 | –0.004 | .08 | –0.005 | .08 |
| Gender (female) | 0.20 | <.001 | 0.20 | <.001 | 0.20 | <.001 | 0.20 | <.001 | 0.20 | <.001 |
| Service nature (aged care) | –0.54 | <.001 | –0.54 | <.001 | –0.54 | <.001 | –0.60 | <.001 | –0.63 | <.001 |
| Containment Health Index | –0.02 | <.001 | –0.02 | <.001 | –0.02 | <.001 | –0.02 | <.001 | –0.02 | <.001 |
| Community COVID-19 risk | 0.002 | .02 | 0.002 | .02 | 0.003 | .46 | 0.38 | <.001 | 0.12 | .40 |
| Social media use for COVID-19 information | 0.06 | .11 | 0.40 | .01 | 0.06 | .11 | 9.4 | <.001 | 10.4 | .01 |
| Traditional media trust | –0.04 | .08 | –0.002 | .96 | –0.04 | .24 | 2.7 | <.001 | 0.73 | .46 |
| Social media use × media trust | —[c] | — | –0.08 | .02 | — | — | –1.7 | .002 | –1.5 | .12 |
| COVID-19 risk × media trust | — | — | — | — | –0.000 | .77 | –0.06 | .01 | 0.02 | .64 |
| AFC-Information | — | — | — | — | — | — | 4.0 | <.001 | — | — |
| Social media use × AFC-Information | — | — | — | — | — | — | –2.2 | <.001 | — | — |
| COVID-19 risk × AFC-Information | — | — | — | — | — | — | –0.09 | <.001 | — | — |
| Social media use × media trust × AFC-Information | — | — | — | — | — | — | 0.40 | .003 | — | — |
| COVID-19 risk × media trust × AFC-Information | — | — | — | — | — | — | 0.01 | .01 | — | — |
| AFC-Communication Technology | — | — | — | — | — | — | — | — | 3.0 | .004 |
| Social media use × AFC-Communication Technology | — | — | — | — | — | — | — | — | –2.5 | .01 |
| COVID-19 risk × AFC-Communication Technology | — | — | — | — | — | — | — | — | –0.03 | .42 |
| Social media use × media trust × AFC-Communication Technology | — | — | — | — | — | — | — | — | 0.35 | .14 |
| COVID-19 risk × media trust × AFC-Communication Technology | — | — | — | — | — | — | — | — | –0.004 | .62 |
| Adjusted $R^2$ | 0.065 | — | 0.066 | — | 0.065 | — | 0.092 | — | 0.092 | — |

[a]OLS: ordinary least squares.

[b]AFC: Age-friendly City.

[c]Not applicable.



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**Table 5.** Summary of the 3-way interaction on anxiety level.

| AFC[a]-Information index | Media trust | Association between social media use for COVID-19 information and anxiety | Association between weekly number of COVID-19 cases and anxiety |
|---|---|---|---|
| Low | High | Insignificant | Weaker |
| Low | Low | Stronger | Stronger |
| High | High | Insignificant | Insignificant |
| High | Low | Insignificant | Insignificant |

[a]AFC: Age-friendly City.

Figure 3a illustrates the double-moderation effect of trust in traditional media and AFC-Information with social media use on GAD-2 scores. Media trust significantly moderated the effect of social media use on anxiety symptoms for older adults living in low-AFC-Information communities. For example, when AFC-Information was 1 SD below the mean (AFC-Information=3.88), more social media use significantly predicted more anxiety symptoms if media trust was lower. The Johnson-Neyman technique revealed that the slope of moderation remained significant when media trust<4.63. However, when AFC-Information was 1 SD above the mean (AFC-Information=4.30), trust in traditional media no longer significantly moderated the effect of social media use on anxiety symptoms. Figure 3b illustrates the double-moderation effect of trust in traditional media and AFC-Information with community COVID-19 risk on GAD-2 scores. Media trust moderated the effect of community COVID-19 risk on GAD-2 scores for older adults living in low-AFC-Information communities. When AFC-Information was 1 SD below the mean (AFC-Information=3.88), a higher community COVID-19 risk predicted more anxiety symptoms if media trust was lower. Results from the Johnson-Neyman technique suggest the moderation effect was significant for media trust<5.64. Similarly, when AFC-Information was higher, the moderation effect of media trust became insignificant. If AFC-Information was 1 SD above the mean (AFC-Information=4.30), trust in traditional media showed no moderation effect on the relationship between community COVID-19 risk and GAD-2 scores. In summary, higher AFC-Information alleviated the anxiety generated by social media use and higher community COVID-19 risk that was associated with low trust in traditional media.


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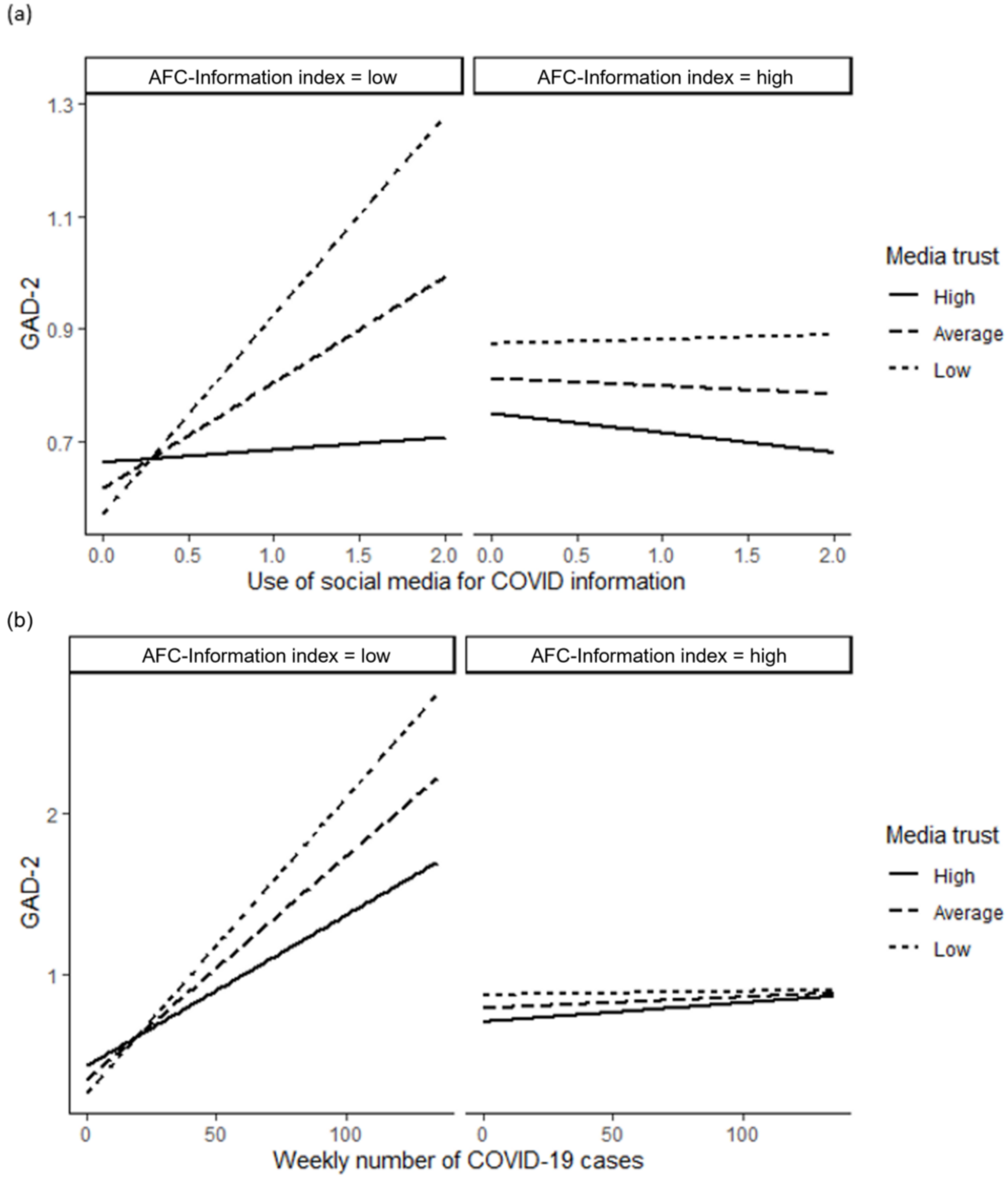
**Figure 3.** Double-moderation effect of the AFC-Information index. AFC: Age-friendly City; GAD-2: 2-item Generalized Anxiety Disorder.




## Discussion

### Principal Findings

Study findings suggest that age-friendly communication offers community-level protection on mental health in an unprecedented crisis such as the COVID-19 pandemic by moderating the anxiety associated with COVID-19 infection risk. Although a higher COVID-19 infection risk may generate perceived vulnerability [2], this study found that adequate information communicated with older adults may alleviate the anxiety associated with community COVID-19 risk. When older adults obtain a better picture of the developments of the pandemic and corresponding coping strategies, their anxiety about the potential health threats may diminish. In the meantime, results show that older adults living in districts with more age-friendly communication and digital devices experience less anxiety associated with perceived COVID-19 infection risk. Technology usage may be associated with older adults' coping strategies during times of reduced social contact. When community COVID-19 risk increases, older adults with access to information and communication technology devices could



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supplement or substitute their daily activities in the community with online alternatives [40]. They could stay connected with family members and use teleconferencing to access social and medical services [40,41]. As a result, the flexibility of these older adults allowed them to engage in daily activities in the "new normal." The anxiety associated with increased infection risk was moderated.

This study found that the anxiety associated with social media use for COVID-19 information is moderated by age-friendly communication. Although higher social media usage for COVID-19 information was positively associated with anxiety symptoms among older adults, community capacity for age-friendly communication may moderate the association. First, the perception of being better informed may lower pandemic-related anxiety [42]. Information that was adapted to reach older adults could provide an anchor point for those using social media and encountering inconsistent and incorrect information online. Community-level information valued by older adults typically originated from the public and voluntary sectors, which have strong roles in providing directed information through telephone and bulletin boards in key locations [21]. When the information sources are institutions in which older adults have developed trusting relationships over time, the communication process occurs proximally and addresses the unique context surrounding their neighborhoods. Older adults could reference information from the community to evaluate the health risks they were exposed to even under the infodemic. Moreover, communication technologies that are designed for older adults may provide a smoother user experience. Although low levels of comfort and control over technologies and cognitive challenges among older adults are considered causes of anxiety [43], age-friendly technologies in the community may help them better navigate the digital environment with reduced anxiety.

A key contribution of this study is the demonstration of the double-moderating effect of community-based information for older adults on anxiety during the infodemic. On the one hand, our results suggest that older adults who have lower trust in the media show more anxiety symptoms when they use more social media for COVID-19 information. Distrust in mainstream information may have hindered older adults' ability to judge the quality of information appropriately. Problematic information thus could impose a stronger anxiety-inducing effect [8,9]. On the other hand, our analysis found a double-moderation effect of age-friendly community information on anxiety. Existing studies have focused on the association between anxiety and information consumption behavior at the individual level, such as using social media [10,11,15]. This study expanded the examination to the information provision at the community level and the interplay between the individual and community levels. Although lower media trust may amplify the effects of social media use and community COVID-19 risk on anxiety, information available in the community for older adults determines the strength of these associations. In other words, community information mitigates the negative effects of low media trust. Even when the infodemic undermined media trust, older adults were less likely to exhibit associated anxiety symptoms.

There are several possible explanations for our findings. First, information from the community possibly overshadowed other information, diluting the effects of media trust on inducing anxiety. Studies on media use suggest that news consumption can be a ritualized and habitual behavior [44]. Therefore, when older adults are able to obtain relevant information about the pandemic and coping strategies from their routinely used information source in the community, they may pay less attention to the media for answers to resolve their concerns. It could reduce the effect of media mistrust. Second, information from the community may have served as a strong reference for older adults to determine the trustworthiness of questionable information they encountered. Since community information was mainly circulated by trusted parties outside the media [21], older adults may juxtapose it with online information to obtain a reliable judgment. Third, age-friendly communication retains the crucial element of societal engagement by providing a "gathering place" for older adults to stay connected with their community [45,46]. Anxiety induced by the infodemic on social media and distrust toward information from media sources may be mitigated by information from the community via informal interpersonal communication. Older adults value not only the clarifications obtained in conversations but also the attention from a real person [21]. Communication sustained in the community may provide the buffer for the problematic information that older adults receive online, especially when they have lower trust in the media.

This study provides evidential support for advocating age-friendly communication in local communities. On technology usage, although information delivered offline through key locations and persons is easily accessible for most older adults [22], appropriately used digital technologies may further strengthen the communication process [23]. The digital divide should be handled carefully to ensure that older adults facing the double burden of social and digital exclusion can receive support to use technology for communication and information purposes in the pandemic [47]. Providing age-friendly devices alone is not sufficient—community resources should be directed at peer learning opportunities and translating technical language to age-friendly instructions for establishing digital skills effectively [45]. More importantly, solutions should be context specific and capable of addressing challenges faced in the community [48]. In any event, media literacy education should be provided to older adults to enable community-based communication to serve as a crucial channel for promoting information consumption and critical evaluation of health information. Essential skills to debunk myths and clarification of the latest misinformation can be circulated timely at the local level. Considering the increasing use of social media for health information among older people and its relation to their heightened anxiety in a health crisis [10,11,15], the AFC framework on communication and information can be expanded to include the community's general age-friendly capacity for and utilization of social media communication, moving beyond the current scope of specifically examining the instructions provided to the population on operating digital devices. Furthermore, the interpersonal network upheld by community-level communication may help consolidate the wisdom between older adults. Resilience can be built where


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older adults may seek answers from peers and community partners when the pandemic threat is heightened or when they encounter questionable information via the infodemic.

### Limitations

The cross-sectional nature of this study means that identified associations should not be treated as causal relationships. The questionnaire was designed to be brief to facilitate expedited completion and extensive reach to older adults. Therefore, the instruments were chosen for their conciseness but provided limited detailed information. For example, social media use for COVID-19 information was constructed as a 3-point measurement. This may have lowered its sensitivity to detect actual usage frequency and hence the estimated effects of social media usage. Data quality could have been affected by the self-reported nature of the survey in terms of memory loss and social desirability bias. Since the survey respondents had established relationships with social services, which may have contributed to the high response rate, they could have utilized more community resources and had higher trust toward the information shared in the community than the general older population. Meanwhile, since the age-friendly communication variables were obtained before the COVID-19 pandemic, community capacity for age-friendly communication could have changed when older adults were later interviewed during the disruption of social life. Age-friendly social services and community resources may be inaccessible for the time being, and hence older adults would not have benefited from them. Although this study suggests the moderation effect of community capacity for age-friendly communication, the measurements did not cover the actual usage of relevant resources. Our findings may underestimate the effect for older adults who fully utilized age-friendly communication opportunities. Lastly, trust in traditional media alone was measured to gauge the influence of the infodemic. This measurement may not fully reflect the impact of the infodemic, and more dimensions of the infodemic are still worth investigating.

### Conclusion

Although perceived infection risks and social media use during the COVID-19 pandemic may induce anxiety among older adults, community capacity for age-friendly communication alleviates their effects. By lowering trust in traditional media, the infodemic may amplify the effects of perceived infection risks and social media use on anxiety. However, better information circulation in the community for older adults moderates the influence of low media trust. Context-specific age-friendly communication solutions can mitigate the anxiety intensified by the infodemic. Although it is important to curate and deliver age-specific information for older adults, efforts should be made to build older adults' capacity in evaluating and sharing useful information amid the infodemic.

## Conflicts of Interest

None declared.

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## Abbreviations

**AFC:** Age-friendly City
**GAD-2:** 2-item Generalized Anxiety Disorder
**OLS:** ordinary least squares
**WHO:** World Health Organization


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Original Paper

# Sustained Reductions in Online Search Interest for Communicable Eye and Other Conditions During the COVID-19 Pandemic: Infodemiology Study

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## Abstract

**Background:** In a prior study at the start of the pandemic, we reported reduced numbers of Google searches for the term "conjunctivitis" in the United States in March and April 2020 compared with prior years. As one explanation, we conjectured that reduced information-seeking may have resulted from social distancing reducing contagious conjunctivitis cases. Here, after 1 year of continued implementation of social distancing, we asked if there have been persistent reductions in searches for "conjunctivitis," and similarly for other communicable disease terms, compared to control terms.

**Objective:** The aim of this study was to determine if reduction in searches in the United States for terms related to conjunctivitis and other common communicable diseases occurred in the spring-winter season of the COVID-19 pandemic, and to compare this outcome to searches for terms representing noncommunicable conditions, COVID-19, and to seasonality.

**Methods:** Weekly relative search frequency volume data from Google Trends for 68 search terms in English for the United States were obtained for the weeks of March 2011 through February 2021. Terms were classified a priori as 16 terms related to COVID-19, 29 terms representing communicable conditions, and 23 terms representing control noncommunicable conditions. To reduce bias, all analyses were performed while masked to term names, classifications, and locations. To test for the significance of changes during the pandemic, we detrended and compared postpandemic values to those expected based on prepandemic trends, per season, computing one- and two-sided *P* values. We then compared these *P* values between term groups using Wilcoxon rank-sum and Fisher exact tests to assess if non-COVID-19 terms representing communicable diseases were more likely to show significant reductions in searches in 2020-2021 than terms not representing such diseases. We also assessed any relationship between a term's seasonality and a reduced search trend for the term in 2020-2021 seasons. *P* values were subjected to false discovery rate correction prior to reporting. Data were then unmasked.

**Results:** Terms representing conjunctivitis and other communicable conditions showed a sustained reduced search trend in the first 4 seasons of the 2020-2021 COVID-19 pandemic compared to prior years. In comparison, the search for noncommunicable condition terms was significantly less reduced (Wilcoxon and Fisher exact tests, $P<.001$; summer, autumn, winter). A significant correlation was also found between reduced search for a term in 2020-2021 and seasonality of that term (Theil-Sen, $P<.001$; summer, autumn, winter). Searches for COVID-19–related conditions were significantly elevated compared to those in prior years, and searches for influenza-related terms were significantly lower than those for prior years in winter 2020-2021 ($P<.001$).



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**Conclusions:** We demonstrate the low-cost and unbiased use of online search data to study how a wide range of conditions may be affected by large-scale interventions or events such as social distancing during the COVID-19 pandemic. Our findings support emerging clinical evidence implicating social distancing and the COVID-19 pandemic in the reduction of communicable disease and on ocular conditions.

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**KEYWORDS**

COVID-19; pandemic; communicable disease; social distancing; infodemiology; Google Trends; influenza; conjunctivitis; ocular symptoms; seasonality; trend; online health information; information-seeking

## *Introduction*

Infodemiology, an emerging field of study within health informatics, applies the science of distribution and determinants of information in an electronic medium such as the internet or within a population toward informing public health and policy [1-4]. The COVID-19 pandemic highlights the utility of infodemiology from the ability to predict outbreaks of coronavirus infection based on internet search engine queries, social media post–based syndrome surveillance, and search engine data mining to cluster query and click data as an estimate of the prevalence of symptoms patients sought to address outside of clinical appointments or business hours [1,2,5-7]. Although no standard methodologic approach has been established in the past decade, recently new standardized infodemiologic study methods have been proposed to strengthen the validity and utility of its application in health [8].

Google Trends has emerged as a predictive tool for disease occurrence and outbreaks. For example, one study demonstrated a strong correlation between keyword-triggered link click counts on Google and influenza cases 1 week later as the 2004-2005 Canadian influenza season unfolded (Pearson correlation coefficient $r$=0.91) [9]. Infodemiologic approaches such as use of Google Trends unlocks access to real-time predictive analysis of health-related behaviors. This was previously unfathomable, when much of public health analytics was predicated on collecting and sifting through large data sets [2,10]. For example, social media–based surveillance of foodborne diseases have been shown to be 66% effective, more rapid, and cheaper than these data-based surveillance methods [11].

Clinical studies of the COVID-19 pandemic have suggested potential links between the pandemic with changes in health conditions [12-21]. This includes studies and reports on ocular symptoms and health [22-36]. Online searches and social media reflect the clinical seasonality and epidemics of conjunctivitis [37-40]. Previously, we found evidence that during the start of the COVID-19 pandemic (through April 2020), some ocular-related terms (in multiple languages on a worldwide level) showed an increased search trend. These terms included "burning," "sore," and "red" eyes [5]. Subsequently, other studies of search data through June 2020 found a strong correlation between some ocular search terms and cases of COVID-19 on a country level in Europe [41]. In our prior study, searches for English-language conjunctivitis- and pink eye–related terms in March and April 2020 were lower compared with those in prior years. We had conjectured that one cause of these search trend results could be that implementation of school closures and social distancing starting in March 2020 had reduced the incidence of contagious conjunctivitis cases, resulting in reduced information-seeking about conjunctivitis [5]. However, our findings were limited as our study data time series ended quite early into the pandemic in April 2020.

In this study, using masked analyses of searches geolocated to the United States for 1 full year after the pandemic began, we assessed whether a reduction in searching occurred for conjunctivitis in the United States compared to the prior 9 years. We then assessed whether this was sustained for multiple seasons throughout the COVID-19 pandemic in 2020-2021. We also assessed whether the search volume decreased for other common school- and workplace-based communicable diseases, including strep throat, chicken pox, the common cold, as well as other conditions of acute exposure such as sexually transmitted diseases (STDs) and bug bites. We compared the results for that class of terms (referred to as "communicable") to searches for control "noncommunicable" conditions, including some ocular terms for which we and others had previously found had increased search activity at the start of the pandemic [5,41]. We also assessed whether terms with stronger seasonal variation were more likely to have a decreased search trend during the COVID-19 pandemic. In addition, we assessed whether there was sustained change across multiple seasons, compared to the prior 9 years, for the group of terms we had classified as COVID-19 pandemic–related (related to a search about distinguishing or identifying COVID-19 symptoms).

## *Methods*

### Google Search Data

Weekly relative search frequency volume data for search terms in English for the United States were obtained on March 9, 2021, for the weeks of March 1, 2011, through February 28, 2021, as previously described using the Google Health application programming interface (API) [40,42-44]. This provided a long baseline of prepandemic data as a basis for comparisons (described below). Queries of this API allow specification of the following: a set of search terms (eg, "*coronavirus symptoms*," "*shingles treatment*"), time range (start date and end date), interval (*day*, *week*, *month*), and geolocation (eg, "*United States*"). For any given query, for each search term, a search activity value is provided at each time interval, which represents the relative share of search for that term in proportion to all Google searches that were made within the specified time range and geolocation [45]. Search terms were chosen based on our prior studies [5], COVID-19, and on



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common terms used in the United States for communicable and noncommunicable conditions. Some terms served as a surrogate for ambiguously named conditions to improve the health-specificity of search data (eg, we used "*cold medicine*" for the common cold and "*shingles treatment*" for shingles). Classifications were assigned a priori. We classified 16 terms as COVID-19 pandemic–related conditions, including respiratory, allergic, or flu-like terms (as we assumed they may represent a symptomatic search for those affected by, or initially concerned about, COVID-19). We also included 29 terms that were classified as communicable (communicable conditions unrelated to the COVID-19 pandemic) and 23 terms that were classified as noncommunicable (control noncommunicable conditions, less likely related to the COVID-19 pandemic).

## Masking of Terms, Classifications, and Location

To reduce bias, actual search terms were masked using numeric codes before the data were analyzed. To further mask, data for the same terms for two other masked countries were also included and names of our assigned classification groups were also encoded. In this way, individuals assessing statistical outcomes were naïve to the actual terms and to their assigned classifications, as well as to the country of search term origin.

## Statistical Analysis

### *Overview*

The masked statistical analysis, described in detail below, included identifying seasonal search features for each term. It also included fitting models for spring (March to May 2020), summer (June to August 2020), autumn (September to November 2020), and winter (December to February 2020-2021). This was done to contrast search interest during each season of the first year of the pandemic with that of the same season from the prior 9 years, by identifying seasons for each term that differed (as well as those that were specifically reduced) during the pandemic compared to the prior 9 years. We then compared those results for terms representing different classes of conditions, as well as to the seasonality of terms, as described in detail below.

### *Analysis of Changes in Search Trends in 2020-2021 Seasons Compared to Prior Years*

To test for the significance of changes in the period following March 2020, the following algorithm was used. Time series were first subject to the Hampel filter for outlier removal (R package *pracma*). For more complete series (time series with fewer than 20% missing data), we detrended the time series using the residuals from Theil-Sen regression with respect to the calendar time for the pre-COVID-19 epoch (March 2011 to February 2020). The 9 years of pre-COVID-19 time-series data were intended to provide sufficiently precise estimations of prepandemic seasonal and secular trends for our planned comparison of these features during the pandemic period. Theil-Sen regression is a nonparametric fixed-effects regression model designed to minimize the influence of outliers [46,47]. Thus, when sufficient data were available, we compared postpandemic values to what would have been expected based on prepandemic trends, as has been done in other studies (eg, [48,49]). We then compared the levels of search for spring 2020 (and the other seasons) to the pre-COVID-19 trend line as follows. We applied a robust linear mixed-effects regression model to compare the residuals of observations for each season, thus comparing the levels for spring 2020, summer 2020, autumn 2020, and winter 2021 to the corresponding times of previous years. Using this model, we computed both one- and two-sided *P* values. Significant two-sided *P* values represented a *P* value for a search change (increase or decrease) in 2020-2021 compared to prior years. Significant one-sided *P* values represented a *P* value for search reduction in 2020-2021 compared to prior years. For time series containing more than 20% missing (or zero) data, we performed robust mixed-effects regression using indicators for spring, summer, autumn, and winter of 2020 as predictors (clustering on year); one- and two-sided *P* values were computed using the standard normal distribution. This analysis only compared values for each season after the pandemic began to those before. We interpreted all significant two-sided *P* values as indicating an increase if significance was not also seen using the one-sided tests specific to identifying decreases. All computations were performed using R for MacIntosh v.4.0 (R Foundation for Statistical Computing, Vienna, Austria); the R packages *pracma*, *mblm*, and *robustlmm* were used for Hampel filter, Theil-Sen, and robust linear mixed models, respectively [50-52].

### *Comparing Changes in Searches in 2020-2021 Seasons for Communicable Versus Noncommunicable and Non-COVID-19 Classification Groups*

We then performed an analysis of the previously calculated *P* values for search reduction by term groups to ask if non-COVID-19 terms representing communicable disease were more likely to show significant reductions in searches in 2020-2021 than noncommunicable terms. We compared the *P* values for search reduction between these two groups using the Wilcoxon rank-sum test. Similarly, we assessed the binary classification of significance at the .05 level using the Fisher exact test (where a significant *P* value indicates a difference in the proportion of *P* values less than .05 found between the two groups).

### *Determining Seasonal Characteristics and Their Relationships to Search Reductions in 2020-2021*

Standard circular statistical methods were used for seasonal analysis, computing the circular mean, a measure of central tendency for the occurrence time of searches within the yearly cycle [53]. We also report the amplitude-to-mean (AtM) ratio (ie, the ratio of the difference between the peak and the mean to the mean itself) as an estimate of the degree of seasonality. Large AtM values correspond to large swings or oscillations, while small values correspond to minor fluctuations on a yearly cycle. Statistical significance of seasonality per term was assessed using Morlet wavelets, reporting the largest daily *P* value for the power at the annual cycle over the course of the time series (excluding the first and last years) [44,54]. This provided a conservative requirement for consistency of the annual cycle for all years. Calculations were performed using the R package *WaveletComp* [55]. Using the *P* values reflecting seasonality for a term, for each season, we then also assessed if there was a relationship between the *P* value for search


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reduction in 2020-2021 and the seasonal *P* value for that term. This was assessed using Theil-Sen regression.

### *Unmasking, Describing, and Visualizing Results*

After all statistical analyses were completed, search terms, country, and classifications were then unencoded (unmasked). The weekly (x axis) and resulting mean search interest values (y axis) for terms were plotted. Weekly data were plotted as log-transformed Hampel-smoothed raw mean values+1 for improved scaling and visualizations. Seasons are indicated with vertical dashed line separators. The 2020 weekly mean search values are plotted as a red solid line, 2021 values are plotted as a red dashed line, 2017-2019 plots are gold, 2014-2016 data are green, and 2011-2013 data are blue. *P* values at the top of each panel for any season indicate if searches in 2020-2021 were significantly different overall (red, *P* values for search change) or specifically lower (blue, *P* values for search reduction), compared to those in the same quarters in 2011-2019 (differences significant at *P*>.05 are presented in tables). In addition, the overall seasonality is presented for each term (black text on the lower left of each panel in figures), indicating if a term is significantly seasonal. If significantly seasonal (defined as *P*<.05), the AtM (as an indicator of relative seasonal strength) and a circular mean week (as an indicator of the peak high season) are provided. All of the statistical values described above are included in figures and all *P* values are also presented in tables. We subjected *P* values to false discovery rate correction prior to reporting.

### Ethics Considerations

This study received approval from the University of California San Francisco institutional review board (14-14743) and adhered to the Declaration of Helsinki.

## Results

### Overview of Changes in Search Trends in 2020-2021 Seasons Compared to Prior Years

Overall, we found that at the start of the pandemic (spring 2020), many terms of all three classifications appeared to have search patterns that differed from those in prior years. Some changes persisted for subsequent seasons. Further details and statistical analysis results are described below first for COVID-19–related terms and then for non-COVID-19–related terms (including comparison of search term groups classified as representing communicable conditions vs noncommunicable conditions).

### COVID-19–Related Search During the Pandemic

Of the terms we had a priori classified as COVID-19 pandemic–related, resulting quarterly *P* values for the search change and for search reduction, as well as plotted data, indicated significant search increases compared to prior years. Of note, this group of terms includes those we classified as *potentially related*, due to the public's concern about conditions with symptoms similar to those of COVID-19 (such as flu and allergy). Increases were observed for spring and summer 2020-2021 and often in additional seasons. A common exception was that several potentially flu-related terms switched to a significant decrease in winter 2020 (*P*<.001) (see Figure 1 and Table 1).

**Figure 1.** Search interest for COVID-19–related terms in 2020-2021 seasons compared to the same seasons in 2011-2019. In each panel, the x axis indicates week of the year and the y axis indicates weekly mean search interest values (Hampel-filtered and log-transformed for presentation purposes) for that term. Solid red, 2020 values; dashed red, 2021 values; gold, 2017-2019; green, 2014-2016; blue, 2011-2013. The 4 seasons are separated with vertical dashed lines. *P* values at the top of each panel for each season indicate if searches in that season of 2020-2021 were significantly (P<0.05) different overall (red, 2-sided test) than the same quarters in 2011-2019. Significant reductions are indicated by blue *P* values. Nonsignificant (*P*>.05) values are not shown. Seasonal characteristics for each term are shown as black text on the lower left of each panel. For terms with seasonality (*P*<.05), amplitude to mean ratios (AtM) are provided as an indicator of relative seasonal strength, as are circular mean week (Wk.) as an indicator of peak high season (assuming annual seasons); standard deviations are in parentheses.

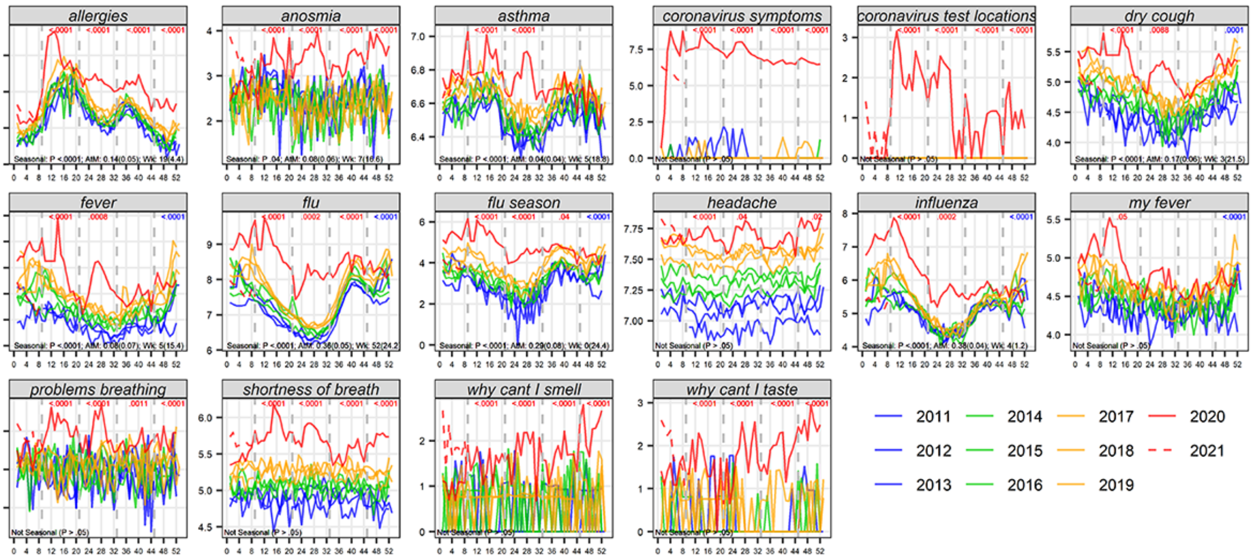




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**Table 1.** Search interest for COVID-19–related terms in 2020-2021 seasons compared to the same seasons in 2011-2019 (related to Figure 1).

| Terms | Seasonality[a] | | | *P* value[b] for test of different search from prior years for each term | | | | *P* value[c] for test of lower search from prior years for each term | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | *P* value | AtM[d], mean (SD) | Week[e], circular mean (SD) | Spring | Summer | Autumn | Winter | Spring | Summer | Autumn | Winter |
| allergies | <.001 | 0.14 (0.05) | 19 (4.4) | <.001 | <.001 | <.001 | <.001 | >.99 | >.99 | >.99 | >.99 |
| anosmia | .04 | 0.08 (0.06) | 7 (16.6) | <.001 | <.001 | <.001 | <.001 | >.99 | >.99 | >.99 | >.99 |
| asthma | <.001 | 0.04 (0.04) | 5 (18.8) | <.001 | <.001 | .13 | .25 | >.99 | >.99 | .11 | .17 |
| coronavirus symptoms | >.99 | —[f] | — | <.001 | <.001 | <.001 | <.001 | >.99 | >.99 | >.99 | >.99 |
| coronavirus test locations | >.99 | — | — | <.001 | <.001 | <.001 | <.001 | >.99 | >.99 | >.99 | >.99 |
| dry cough | <.001 | 0.17 (0.06) | 3 (21.5) | <.001 | .009 | .33 | <.001 | >.99 | >.99 | .27 | <.001 |
| fever | <.001 | 0.14 (0.05) | 19 (4.4) | <.001 | <.001 | <.001 | <.001 | >.99 | >.99 | >.99 | >.99 |
| flu | <.001 | 0.36 (0.05) | 52 (24.2) | <.001 | <.001 | <.001 | <.001 | >.99 | >.99 | >.99 | <.001 |
| flu season | <.001 | 0.29 (0.08) | 0 (24.4) | <.001 | <.001 | .04 | <.001 | >.99 | >.99 | >.99 | >.99 |
| headache | .22 | — | — | <.001 | .04 | .43 | .02 | >.99 | >.99 | >.99 | >.99 |
| influenza | <.001 | 0.38 (0.04) | 4 (1.2) | <.001 | <.001 | .10 | <.001 | >.99 | >.99 | >.99 | <.001 |
| my fever | .13 | — | — | .05 | .13 | .86 | <.001 | >.99 | >.99 | .66 | <.001 |
| problems breathing | >.99 | — | — | <.001 | <.001 | <.001 | <.001 | >.99 | >.99 | >.99 | >.99 |
| shortness of breath | .43 | — | — | <.001 | <.001 | <.001 | <.001 | >.99 | >.99 | >.99 | >.99 |
| why cant I smell | >.99 | — | — | <.001 | <.001 | <.001 | <.001 | >.99 | >.99 | >.99 | >.99 |
| why cant I taste | .61 | — | — | <.001 | <.001 | <.001 | <.001 | >.99 | >.99 | >.99 | >.99 |

[a]Indicates if the search for the years 2011-2019 shows a significant (*P*<.05) seasonal trend.

[b]Two-sided *P* values regarding any change in search from prior years for each season.

[c]One-sided *P* values regarding a decrease in search from prior years for each season.

[d]AtM: amplitude to mean ratio, indicating relative seasonal strength.

[e]Indicates peak high season.

[f]Not applicable; AtM and circular mean values are provided only for search terms where statistical evidence of that term being seasonal was found.

### Changes in Searches in 2020-2021 Seasons for Communicable Versus Noncommunicable and Non-COVID-19 Classification Groups

The two ocular terms we had classified a priori as communicable, "conjunctivitis" and "pink eye," both had significant reductions for all 4 seasons of 2020-2021 (*P*<.001) compared to prior years. Overall, in 2020-2021, these and other communicable condition search terms appeared to have more reductions in search compared with the reductions in control noncommunicable terms. To test this hypothesis further, we compared the *P* values for search changes and reductions between the communicable and noncommunicable class of terms (excluding COVID-19–related terms).

We first assessed if *P* values for the search change in the non-COVID-19 communicable term group differed significantly from *P* values for the search change in the noncommunicable group (Figure 2, red *P* values; Table 2 "different search from prior years"). In spring 2020, we found no evidence for a significant difference between these groups for the *P* values (Wilcoxon rank-sum test, *P*=.99) or in the proportion of search terms with significant *P* values (Fisher exact test, *P*=.83). In contrast, for the subsequent 3 seasons in 2020-2021, the levels of searches were significantly different in 2020-2021 (compared to past years) for the communicable versus control noncommunicable groups of terms. This was observed when comparing the *P* values per group (Wilcoxon rank-sum test: summer *P*=.05, autumn *P*=.02, winter *P*=.006). Similarly, the proportion of search terms with significant search changes in 2020-2021 was significantly higher for the communicable group compared with the noncommunicable group (Fisher exact test: summer *P*=.01, autumn *P*=.01, winter *P*=.003).

We also assessed specifically if significant reductions in search differed for the communicable and noncommunicable classifications of non-COVID-19 term groups. To do so, we compared the *P* values for search reduction (see Table 2, "lower search from prior years") between groups, by season. We found little evidence for a significant difference in overall reductions in search between these groups in spring 2020 (Wilcoxon rank-sum test: *P*=.04, Fisher exact test: *P*=.09). For each of the subsequent 3 seasons in 2020-2021, the levels of search were much more significantly reduced in 2020-2021 (compared to past years) for the communicable class of terms than for the noncommunicable term group (Wilcoxon rank-sum test: summer *P*<.001, autumn *P*<.001, winter *P*<.001; Fisher exact test: summer *P*<.001, autumn *P*<.001, winter *P*<.001).



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The Wilcoxon rank-sum test and Fisher exact test *P* values for the overall differences in search postpandemic between the two classification groups (communicable and noncommunicable conditions) per season, described above, are shown in Table 3.

**Figure 2.** Search interest for non-COVID-19, communicable, and noncommunicable terms in 2020-2021 seasons compared to the same seasons in 2011-2019. Time-series annual mean weekly search interest; *P* values indicating changes in 2020-2021 and seasonal values are all as described for Figure 1. Panel labels indicate communicable (shown first) and noncommunicable (shown second) classes that were compared group-wise using the Wilcoxon rank-sum test and Fisher exact test (described in the text and in Tables 2 and 3).


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**Table 2.** Search interest for non-COVID-19 communicable versus noncommunicable term groups in 2020-2021 seasons compared to those seasons in 2011-2019.

| Term | Seasonality[a] | | | *P* values[b] for test of different search from prior years for each term | | | | *P* values[c] for test of lower search from prior years for each term | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | *P* value | AtM[d], mean (SD) | Week[e], circular mean (SD) | Spring | Summer | Autumn | Winter | Spring | Summer | Autumn | Winter |
| **Communicable and/or acute exposure conditions (non-COVID)** | | | | | | | | | | | |
| bug bite | <.001 | 0.38 (0.05) | 29 (1.2) | .54 | .43 | .06 | <.001 | .41 | >.99 | .05 | <.001 |
| chicken pox | .06 | —[f] | — | <.001 | <.001 | <.001 | <.001 | <.001 | .009 | <.001 | <.001 |
| chlamydia | .83 | — | — | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 |
| cold medicine | <.001 | 0.25 (0.04) | 51 (21.6) | <.001 | .003 | <.001 | <.001 | <.001 | .004 | <.001 | <.001 |
| conjunctivitis | <.001 | 0.06 (0.04) | 13 (11) | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 |
| ear infection | <.001 | 0.07 (0.05) | 4 (18.6) | <.001 | .05 | .001 | <.001 | <.001 | .05 | <.001 | <.001 |
| fifth disease | <.001 | 0.14 (0.06) | 11 (2.5) | <.001 | .03 | .02 | <.001 | <.001 | .03 | .02 | <.001 |
| german measles | .38 | — | — | .71 | .91 | .81 | .21 | .97 | .90 | .63 | .14 |
| gonorrhea | .48 | — | — | <.001 | .01 | <.001 | .02 | <.001 | .01 | <.001 | .01 |
| HIV | .05 | 0.02 (0.03) | 13 (14.8) | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 |
| hpv | .62 | — | — | <.001 | .15 | .09 | <.001 | <.001 | .14 | .07 | <.001 |
| impetigo | .03 | 0.07 (0.06) | 35 (11) | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 |
| lice | <.001 | 0.06 (0.05) | 35 (9.8) | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 |
| measles | .01 | 0.23 (0.07) | 12 (3.6) | .10 | .01 | .06 | <.001 | .08 | .01 | .05 | <.001 |
| meningitis | .62 | — | — | <.001 | .008 | <.001 | <.001 | <.001 | .008 | <.001 | <.001 |
| mononucleosis | .25 | — | — | <.001 | .77 | .55 | <.001 | <.001 | .75 | .44 | <.001 |
| mumps | .62 | — | — | .01 | .004 | .002 | <.001 | .01 | .004 | .002 | <.001 |
| pertussis | .64 | — | — | <.001 | .84 | .36 | .003 | <.001 | >.99 | .28 | .002 |
| pink eye | <.001 | 0.09 (0.06) | 9 (17.4) | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 |
| ringworm | <.001 | 0.03 (0.04) | 27 (10.6) | .04 | <.001 | <.001 | <.001 | .03 | <.001 | <.001 | <.001 |
| rubella | .01 | 0.05 (0.05) | 12 (14.5) | .15 | .69 | .79 | .01 | .12 | .65 | .62 | .008 |
| salmonella | .62 | — | — | .25 | .45 | .43 | <.001 | .20 | >.99 | .35 | <.001 |
| scabies | .11 | — | — | <.001 | .02 | <.001 | <.001 | <.001 | .02 | <.001 | <.001 |
| shingles treatment | .19 | — | — | .15 | .47 | .33 | .93 | >.99 | >.99 | >.99 | .62 |
| std | .02 | 0.01 (0.03) | 20 (15.9) | <.001 | <.001 | .005 | <.001 | <.001 | <.001 | .004 | <.001 |
| stomach flu | <.001 | 0.33 (0.06) | 3 (1.2) | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 |
| strep throat | <.001 | 0.12 (0.07) | 5 (19.9) | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 |
| syphilis | .88 | — | — | .22 | .81 | .36 | .93 | .17 | .78 | .29 | .70 |
| tuberculosis | .05 | — | — | .53 | .04 | .74 | .02 | .40 | >.99 | .60 | .02 |
| **Noncommunicable, control conditions (non-COVID)** | | | | | | | | | | | |
| arthritis | .26 | — | — | <.001 | .33 | .65 | .07 | <.001 | >.99 | >.99 | .05 |
| broken bone | .23 | — | — | <.001 | .03 | .53 | .004 | <.001 | .03 | .43 | .003 |
| burning eyes | >.99 | — | — | <.001 | .002 | .04 | <.001 | >.99 | >.99 | >.99 | >.99 |
| cancer | .26 | — | — | <.001 | <.001 | .007 | <.001 | <.001 | <.001 | .006 | <.001 |
| cataracts | .97 | — | — | <.001 | .33 | .50 | .12 | <.001 | .30 | .41 | .08 |
| claritin | <.001 | 0.16 (0.06) | 18 (3.2) | .50 | .63 | .59 | .002 | .39 | >.99 | .46 | .002 |
| corneal ulcer | .26 | — | — | .10 | .04 | .74 | .86 | .08 | .03 | .60 | .56 |



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| Term | Seasonality[a] | | | P values[b] for test of different search from prior years for each term | | | | P values[c] for test of lower search from prior years for each term | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | P value | AtM[d], mean (SD) | Week[e], circular mean (SD) | Spring | Summer | Autumn | Winter | Spring | Summer | Autumn | Winter |
| diabetes | .01 | 0.02 (0.05) | 6 (18.9) | <.001 | .84 | .20 | .93 | <.001 | >.99 | .16 | .70 |
| diabetic retinopathy | .88 | — | — | .15 | .70 | .43 | .40 | .12 | >.99 | >.99 | .26 |
| dry eyes | .13 | — | — | .02 | .93 | .04 | <.001 | .02 | >.99 | >.99 | >.99 |
| eczema | <.001 | 0.04 (0.05) | 9 (17.2) | .30 | .19 | .04 | .003 | .24 | .18 | .03 | .002 |
| glaucoma | .41 | — | — | <.001 | .42 | .36 | .03 | <.001 | .38 | .29 | .02 |
| heart attack | .01 | 0.04 (0.06) | 12 (10) | .15 | .41 | .34 | .03 | .12 | .37 | .28 | .02 |
| high blood pressure | <.001 | 0.05 (0.04) | 5 (13.2) | <.001 | .91 | .66 | .29 | <001 | .89 | >.99 | .20 |
| itchy eyes | <.001 | 0.1 (0.05) | 18 (5.3) | <.001 | .003 | .10 | .22 | >.99 | >.99 | >.99 | >.99 |
| macular degeneration | .78 | — | — | <.001 | .42 | .36 | .08 | <.001 | >.99 | >.99 | .05 |
| memory loss | .92 | — | — | <.001 | .81 | .79 | .93 | <.001 | >.99 | .62 | .71 |
| pollen | <.001 | 0.29 (0.07) | 17 (1.7) | <.001 | <.001 | <.001 | .28 | >.99 | >.99 | >.99 | >.99 |
| pregnant | .05 | — | — | .38 | .43 | .79 | .80 | .30 | .38 | .62 | .53 |
| red eyes | .19 | — | — | .004 | .72 | .86 | .59 | >.99 | >.99 | .66 | .39 |
| sore eyes | .83 | — | — | .51 | .22 | .04 | .12 | .39 | >.99 | >.99 | >.99 |
| stroke symptoms | <.001 | 0.09 (0.04) | 26 (8) | .25 | .91 | .36 | .06 | >.99 | >.99 | >.99 | >.99 |
| toothache | .62 | — | — | .06 | .41 | .13 | .34 | >.99 | .37 | .11 | .23 |

[a]Indicates if the search for the years 2011-2019 shows a significant ($P$<.05) seasonal trend.

[b]Two-sided $P$ values regarding any change in search from prior years for each season.

[c]One-sided $P$ values regarding a decrease in search from prior years for each season.

[d]AtM: amplitude to mean ratio, indicating relative seasonal strength.

[e]Indicates peak high season.

[f]Not applicable; AtM and circular mean values are provided only for search terms where statistical evidence of that term being seasonal was found.

**Table 3.** Comparison of the differences and reductions in search postpandemic (*P* values in Table 2), for communicable vs noncommunicable condition search terms groups, by season.

| Season | Difference from prior years[a] | | Search lower than prior years[b] | |
|---|---|---|---|---|
| | Wilcoxon rank-sum test | Fisher exact test | Wilcoxon rank-sum test | Fisher exact test |
| Spring | .99 | .83 | .04 | .09 |
| Summer | .05 | .01 | <.001 | <.001 |
| Autumn | .02 | .01 | <.001 | <.001 |
| Winter | <.001 | .003 | <.001 | <.001 |

[a]*P* values when testing if significant changes in search after the start of the pandemic differed for the communicable and noncommunicable classifications of non-COVID-19 term groups.

[b]*P* values when testing if significant reductions in search after the start of the pandemic differed for the communicable and noncommunicable classifications of non-COVID-19 term groups.

## Seasonal Characteristics and Their Relationship to Reductions in 2020-2021

Although we found searches for a number of terms from all 3 classifications that appeared to be seasonal, it appeared that seasonal terms were more likely to have a reduced search frequency in 2020-2021 seasons (see panels in Figure 2, including the black text on the lower left of all panels and Table 2 "Seasonality" *P* values). We hypothesized that seasonal conditions might be reduced by social distancing measures during the pandemic more than for those that are less seasonal. To test this hypothesis, for each season of each non-COVID-19 term, we compared the *P* values for search reduction against the seasonality *P* values for that term using Theil-Sen regression.



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For spring, we found no significant correlation between a term having reductions in search in 2020-2021 and with the seasonality of a term ($P$=.95). However, for summer, autumn, and winter, we found a significant correlation between a term having reductions in search in 2020-2021 with the seasonality of that term (Theil-Sen: summer $P$<.001, autumn $P$<.001, winter $P$<.001).

## Discussion

### Principal Results

#### *Decreased Searches for Communicable and Seasonal Disease Search Terms During 2020-2021*

Overall, in our masked analysis, searches for many of the 29 non-COVID-19 communicable terms (including those related to conjunctivitis) were significantly decreased during the first 4 seasons of the 2020-2021 pandemic compared with the prior 9 years. For example, 18 of the terms (*"chicken pox," "chlamydia," "cold medicine," "conjunctivitis," "ear infection," "fifth disease," "gonorrhea," "HIV," "impetigo," "lice," "meningitis," "mumps," "pink eye," "ringworm," "scabies," "std," "stomach flu," "strep throat"*) showed reductions for all 4 seasons of the pandemic (see Table 2). For 3 consecutive seasons in 2020-2021 (summer, autumn, winter), the levels of search were much more significantly reduced in 2020-2021 for the non-COVID-19 communicable terms group than for the noncommunicable terms group. The conjunctivitis-related findings of sustained reduction in search continue to lend support to our hypothesis described in our prior study from the start of the pandemic, based on reduced searches for conjunctivitis terms, that social distancing from the pandemic may lead to reductions in infectious conjunctivitis [5]. Recently, Lavista Ferres et al [56] provided support of this hypothesis, demonstrating that a 37% decrease in emergency department encounters for infectious conjunctivitis was associated with implementation of social distancing, reduced smartphone mobility, and reduced online search. Our results also support a broader hypothesis that non-COVID-19 communicable disease in general may be reduced in comparison to control noncommunicable conditions due to implementation of social distancing. In a separate assessment independent of our search term classifications, we also found a significant correlation between reductions in search for a term in 2020-2021 and seasonality of search for that term. This is not surprising, as it appears that many terms of communicable conditions were seasonal and with apparent higher seasonality overall compared to noncommunicable conditions.

#### *Increase of Searches With Non-COVID-19 Ocular Terms During the Pandemic*

Of the terms we had initially classified as not clearly COVID-19 pandemic–related and as noncommunicable, the only terms that showed significant increases in 2020-2021 for one or more seasons included "*pollen*" and several ocular terms (*"burning eyes," "dry eyes," "itchy eyes," "red eyes," "sore eyes"*). Despite this, no other control ocular conditions (*"cataracts," "corneal ulcer," "diabetic retinopathy," "glaucoma," "macular degeneration"*) were significantly increased. This suggests that unlike communicable ocular conditions, which had a lower search during the pandemic (conjunctivitis), or noncommunicable chronic ocular conditions (without a sustained change in search), these other ocular conditions may have indeed increased during the pandemic. This appears most likely for "*burning eyes*" as well as "*dry eyes*" and "*itchy eyes.*" These findings lend support to some clinical studies (although not all of them draw the same conclusions) suggesting that some of these elevated ocular symptoms may be linked to COVID-19 or to other impacts of the pandemic, such as mask-wearing and increased screen time [5,28-36,41]. For example Nasiri et al [28] found common ocular manifestations in patients with COVID-19, including dry eye, redness, tearing, itching, eye pain, and discharge, and Moshirfar et al [33] reported that facemask wearing may cause ocular irritation and dryness in regular mask wearers.

#### *Sustained Decrease in Searching Non-COVID-19 Noncommunicable Terms During the Pandemic*

A few noncommunicable terms had sustained search reductions in 2020-2021. Search for "*cancer*" was reduced for all 4 seasons compared to prior years. Chen et al [18] reported declines in colorectal, prostate, and breast cancer screening rates with the start of the COVID-19 pandemic through mid-summer. It is possible that fewer positive results from screening of healthy adults could potentially have led to fewer people searching for "*cancer.*" For some terms in our communicable condition group representing conditions covered by routine annual clinical screening (such as "*std*"), the decreased search may therefore also reflect less screening services or test results rather than a reduced prevalence. Johnson et al [20] reported large declines in STD testing and in STD programmatic operations during the first 6 months of the pandemic. Our observed sustained reduction in search for bone fracture ("*broken bone*") reflects what has also been observed clinically during the pandemic. For example, one systematic review reported a 43% decline in the number of fractures presenting to hospitals during the pandemic compared to prepandemic levels that they attributed to less driving, sports, and other outdoor activities during the pandemic [19].

#### *Impact of the Pandemic on Searching for COVID-19 and Influenza Terms*

Unlike the non-COVID-19 groups, in several seasons of 2020-2021, most search terms in the group we had classified as related to COVID-19 had significant search increases. An exception was that earlier increases in search for influenza-related terms reversed in winter to become significant decreases. This could indicate that early on in the pandemic, COVID-19 symptoms may have been misconstrued as being related to flu [57] or that searches to distinguish COVID-19 from flu were common. By winter 2020, these reasons may have waned, while, in parallel, an actual drop in flu cases (and therefore less flu searches) may have occurred due to social distancing during the peak flu season. This has been suggested from clinical data as well. For example, a systematic review performed by Fricke et al [57] showed that defined influenza cases and influenza positivity rate were lower during the pandemic than in former seasons.



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### Limitations

As with many infodemiology studies, it is possible that multiple other causes can affect search trends besides the occurrence rate of a disease. We may expect this for some terms such as those related to conditions reported in the news during the pandemic. However, the fact that our general finding of more reduced search for communicable than noncommunicable terms suggests that this is not the case globally. Furthermore, a search reduction due to news stories is much less likely than an increase. Reduced search for a term related to news about that term also would not likely be sustained for several seasons. Many of our health terms exhibited a general overall search reduction in spring 2020 (other than those potentially related to COVID-19). Those in the noncommunicable group tended to return to normal levels by summer 2020. This may indicate that seeking medical care for these other conditions was reduced due to public concern of going to clinics as well as closed clinics. Some terms had no significant changes noted during the pandemic compared to prior years. This could reflect unchanged clinical conditions. Alternatively, the search volume for some terms may be too low overall, preventing determining statistical significance using our methods.

For a small number of terms, although searches in 2020-2021 visually appeared to be lower than in prior years, they were not shown to be significantly different than those in prior years. This could be due to our analysis accounting for secular trends already moving in that direction (eg, see the red line in the "*pregnant*" panel of Figure 2). Indeed, other epidemiological studies have seen a decrease during the pandemic that was also partially obscured by a prior secular trend [58,59].

### Comparison With Prior Work and Significance

This study lends support to our prior study hypotheses, and confirms theoretical public health and epidemiological assumptions about the value of social distancing to reduce the impact of conjunctivitis epidemics [5,56,60]. It also builds upon and complements a growing body of evidence from clinical and other epidemiologic studies suggesting that social distancing and public health interventions such as school closures during the pandemic can potentially reduce the prevalence of numerous other communicable diseases, including pediatric respiratory tract infection, non-COVID-19 acute pediatric infections, varicella, measles, rubella, head lice, influenza, and STDs, as well as other condition [12-17,19-21,56].

Use of online information-seeking behavior data to infer changes in disease can be simultaneously applied to entire countries, states, and smaller regions, and to numerous conditions, potentially worldwide. Being able to leverage such low-cost early monitoring can help detect or predict clinical or epidemiological status or outcomes early on during an event to potentially allow for improved modeling and planning by public health programs. Such approaches could be considered to complement findings from clinical studies and to reveal findings prior to availability of clinical data, such as what occurred during the COVID-19 pandemic. Indeed, an early study of reduced disease term search data, at a time when clinical data were unavailable, suggested that one cause was due to a potential decline in clinical cases, which, many months later, was confirmed from clinical data [5,56].

### Conclusions

Compared to studies based on more costly and less publicly available individual-level clinical data, we demonstrate the use of online search data to study the impacts of interventions such as social distancing at very low cost. Results from the study of online search data lend support to emerging clinical evidence implicating social distancing and the COVID-19 pandemic in the reduction of communicable disease and in the impact on ocular conditions.

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## Authors' Contributions

Each author of this manuscript contributed to multiple of the following roles: data ascertainment and collection, study design, analysis, visualizations, manuscript writing and revision.

## Conflicts of Interest

TML, TCP, MSD, and SDM received National Institutes of Health-National Eye Institute (NIH-NEI) grant support through the University of California San Francisco (UCSF), and JC did as well through a subcontract from UCSF. The other authors declare no conflicts of interest.

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## Abbreviations

**API:** application programming interface
**AtM:** amplitude-to-mean ratio
**NIH-NEI:** National Institutes of Health National Eye Institute
**STD:** sexually transmitted disease


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Original Paper

# Using Natural Language Processing to Explore Mental Health Insights From UK Tweets During the COVID-19 Pandemic: Infodemiology Study

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## *Abstract*

**Background:** There is need to consider the value of soft intelligence, leveraged using accessible natural language processing (NLP) tools, as a source of analyzed evidence to support public health research outputs and decision-making.

**Objective:** The aim of this study was to explore the value of soft intelligence analyzed using NLP. As a case study, we selected and used a commercially available NLP platform to identify, collect, and interrogate a large collection of UK tweets relating to mental health during the COVID-19 pandemic.

**Methods:** A search strategy comprised of a list of terms related to mental health, COVID-19, and lockdown restrictions was developed to prospectively collate relevant tweets via Twitter's advanced search application programming interface over a 24-week period. We deployed a readily and commercially available NLP platform to explore tweet frequency and sentiment across the United Kingdom and identify key topics of discussion. A series of keyword filters were used to clean the initial data retrieved and also set up to track specific mental health problems. All collated tweets were anonymized.

**Results:** We identified and analyzed 286,902 tweets posted from UK user accounts from July 23, 2020 to January 6, 2021. The average sentiment score was 50%, suggesting overall neutral sentiment across all tweets over the study period. Major fluctuations in volume (between 12,622 and 51,340) and sentiment (between 25% and 49%) appeared to coincide with key changes to any local and/or national social distancing measures. Tweets around mental health were polarizing, discussed with both positive and negative sentiment. Key topics of consistent discussion over the study period included the impact of the pandemic on people's mental health (both positively and negatively), fear and anxiety over lockdowns, and anger and mistrust toward the government.

**Conclusions:** Using an NLP platform, we were able to rapidly mine and analyze emerging health-related insights from UK tweets into how the pandemic may be impacting people's mental health and well-being. This type of real-time analyzed evidence could act as a useful intelligence source that agencies, local leaders, and health care decision makers can potentially draw from, particularly during a health crisis.

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**KEYWORDS**

Twitter; mental health; COVID-19; sentiment; lockdown; soft intelligence; artificial intelligence; machine learning; natural language processing



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## Introduction

COVID-19 was identified as a new type of coronavirus in early January 2020 [1]. Since then, the disease has rapidly spread to and affected almost all parts of the world. In the United Kingdom, the first outbreak was reported on January 31, 2020, with a national lockdown following on March 26, 2020. Shortly before this, COVID-19 was declared a global pandemic by the World Health Organization (WHO) on March 11, 2020 [2,3].

The COVID-19 pandemic continues to have a profound effect on mental health [4]. In a key position paper published in June 2020, the authors explored the current and future potential psychological, social, and neuroscientific effects of COVID-19 and set out a series of priorities and longer-term strategies for mental health research [4]. One of the immediate research priorities presented in the paper was "surveillance." In particular, the authors suggested that finding useful ways to monitor and analyze data on the mental health effects of the COVID-19 pandemic across the whole population, as well as vulnerable subgroups, was essential [4].

With over 300 million active monthly users, Twitter is one of the most popular social media platforms available. Twitter is a free microblogging service that enables its users to post, read, and respond to each other's "tweets" (ie, short messages limited to 280 characters). Social media data are being increasingly used as a data source to inform health-related research, with the potential for offering a more efficient means of data collection over traditional, time-consuming, and costly survey-based methods [5]. In particular, Twitter has been used to monitor, track trends, and disseminate health information during past viral pandemics [6-9]. Further, previous studies have successfully leveraged Twitter data for the assessment of public sentiments, attitudes, and opinions concerning health-related issues [10,11].

Channels of soft intelligence like Twitter, leveraged using novel artificial intelligence (AI) techniques (including natural language processing [NLP]), offer an opportunity for real-time analysis of public attitudes, sentiments, and key topics of discussion [12]. As aforementioned, previous case studies have shown that applying NLP can aid health researchers in gaining insights from large, unstructured data sets, such as Twitter. However, the true value of this type of work, including the data set itself, analysis methods, and how it might be integrated into more formal public health research outputs, is still uncertain. For example, a lot of previous work so far has focused on the use of internally developed, bespoke tools or packages, which tend to require a certain level of technical expertise around machine learning (ML) in order operate effectively. However, as methods continue to mature, we are seeing a growing number of "off-the-shelf" solutions become available, which appear to be more accessible and require less technical understanding of the underlying ML concepts.

The aim of this study was to further explore the value of soft intelligence as a meaningful source of evidence, which, when analyzed using an accessible NLP platform, can support public health research activity. In this article, we report the findings from a case study that examined a large collection of tweets relating to mental health posted from the United Kingdom during the COVID-19 pandemic.

## Methods

### Data Collection

An advanced AI-based, text analytics platform using NLP was used to initially analyze the tweets. The analytics platform, "Wordnerds," is described by its developers as a "text analysis and insights platform using machine learning techniques" [13]. In particular, this off-the-shelf platform supports analysis of metadata, topic, and sentiment to understand the context of a tweet and to group tweets together into topic clusters that contain tweets relating to each other or discussing similar issues. This facilitates a more accurate and sophisticated insight into the vaccine conversation on Twitter compared with methodologies that rely solely on a qualitative count of single words, phrases, or hashtags [14].

We developed a search strategy comprising a list of terms related to COVID-19, the lockdown, and mental health to search (or "scrape") for relevant tweets (see Textbox 1).

**Textbox 1.** Search strategy for relevant tweets.

Corona OR covid OR lockdown

AND

mental health OR anxiety OR depression OR anxious OR depressed OR depressing OR trauma OR traumatic OR "obsessive compulsive disorder" OR OCD OR vulnerable OR loneliness OR lonely OR isolated OR isolation OR sleep OR stress OR stressful OR self-harm OR self-harming OR suicide OR suicidal OR well-being

Search terms were identified through discussion within the research team and scanning recent literature around mental health. Once the strategy had been agreed upon, it was reviewed by a topic expert and information specialist. We then began prospectively searching for and scraping relevant tweets using Twitter's advanced search application interface [15]. A geolocation filter was applied to the search strategy to limit the collection of tweets to those posted in the United Kingdom only.

In this article, we report the findings from our analysis of relevant tweets in the United Kingdom collected over a 24-week period, from July 23, 2020 to January 6, 2021.

### Preparing and Cleaning the Data

All collated tweets were anonymized. Before analyzing the data, the retrieved results were run through a final keyword filter. This filter was comprised of a series of terms and keywords associated with mental health problems to help ensure a more relevant, cleaner, and less noisy data set for analysis. For



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example, general terms such as "isolation" and "well-being" were filtered out. Further, terms associated with eating disorders were added alongside the original terms.

The final keyword filter applied is summarized in Textbox 2.

**Textbox 2.** Keyword filter used to clean the data set.

mood OR "mental health" OR depression OR anxiety OR anxious OR depressed OR depressing OR trauma OR traumatic OR OCD OR compulsive OR vulnerable OR loneliness OR lonely OR isolated OR sleep OR stress OR stressful OR self-harm OR self-harming OR suicide OR suicidal OR anorexia OR anorexic OR bulimia OR bulimic OR eating disorder OR binge eating OR OFSED (other specified feeding or eating disorder)

## Data Analysis

We used Wordnerds to interrogate the tweets. The developers state that their platform uses a range of different technologies in order to deliver its various analyses, including contextual word embeddings and collocation methods [13]. To date, we have found no other published studies coordinated by an academic research group that have used this specific tool.

Using the platform, we were able to track and determine the weekly frequency of tweets relevant to our initial search strategy from the United Kingdom between July 23, 2020 and January 6, 2021. We also tracked the frequency of subsets of these tweets that incorporated terms for specific mental health problems, as listed in Textbox 3.

The NLP platform was then used to explore the sentiment (ie, positive, neutral, or negative) of the whole corpus of tweets. Sentiment was determined using contextual word embedding techniques, including classification of grammar to understand how words interact [16].

**Textbox 3.** Keyword filters used to identify specific mental health problems.

**Anxiety:** "anxious," "anxiety"

**Depression:** "depression," "depressed," "depressing"

**Stress:** "stress," "stressful," "stressed"

**Loneliness:** "loneliness," "lonely," "alone"

Following sentiment analysis, the platform's topic analysis feature was used to identify and cluster key emerging topics of discussion, both with positive and negative underlying sentiment. For this analysis, the platform automatically clustered key topics of positive and negative discussion using topic collocation methods. This is a probabilistic method of identifying interesting sentence fragments and words that occur frequently together within a data set. The results of the platform's topic analysis were examined, and its findings were summarized by 2 of the authors (KL and RG). These summaries were checked by 2 further authors (CM and GCW).

Due to the high volume of tweets collected, the topic analysis was split between 2 equal time periods. The first covered summer 2020 to autumn 2020, when lockdown restrictions were relaxed. The second covered the autumn to winter period in 2020, when regional and then further national lockdown restrictions were introduced.

## Ethical Considerations

Institutional review board approval was not sought as this study used only publicly available data. All posts were de-identified, and there was no direct interaction with Twitter users.

# Results

## Tweet Volume

We captured and collated 286,902 tweets posted by users in the United Kingdom from July 23, 2020 to January 6, 2021. The volume of tweets by week, together with key events taking place during this study period, is visualized in Figure 1. Further notable events or issues that occurred throughout the study period are summarized in Table 1 (weeks 1 to 12) and Table 2 (weeks 13 to 24).

As shown in Figure 1, the highest volume of tweets occurred week commencing (w/c) October 29, 2020, with 51,340 tweets. The lowest volume was observed w/c December 3, 2020, with 12,622 tweets. The data show a fairly consistent baseline trend over the study period. Spikes in the volume of tweets occurred in September, October, and December, typically during periods leading up to (or during) a major change in social distancing and lockdown measures across the United Kingdom.

The first peak was observed w/c September 17, 2020, the week after the introduction of the "rule of 6," whereby a mix of 6 people from any household could meet indoors or outdoors. A similar peak was observed w/c October 8, 2020. This was the week leading up to the government's introduction of a new tiered system, whereby regions across the United Kingdom were allocated to 1 of 3 tiers (and later a fourth tier) based on prevalence of COVID-19. Higher tiers corresponded with tighter restrictions, including closing nonessential businesses and limits placed on social gatherings.

The largest peak was observed w/c October 29, 2020, the week before the second national lockdown began. The final peak occurred w/c December 31, 2020, the week leading up to the start of a third national lockdown. For all 3 national lockdowns, all nonessential businesses were closed, and UK residents were restricted from meeting anyone outside of their "social bubble" (ie, their household or, for people living alone, themselves plus one other household).



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**Figure 1.** Volume of tweets from July 23, 2020 to January 6, 2021. Key events during the study period included the (1) rule of 6 (up to 6 people from any number of households could meet indoors or outdoors), (2) tier system (regions across England were assigned a tier from 1 to 3 based on epidemiological indicators, and these tiers dictated the restrictions in that area, such as which businesses could open and how many individuals could meet in a group during national lockdown—nonessential businesses were closed and people were prohibited from meeting outside of their support bubble).

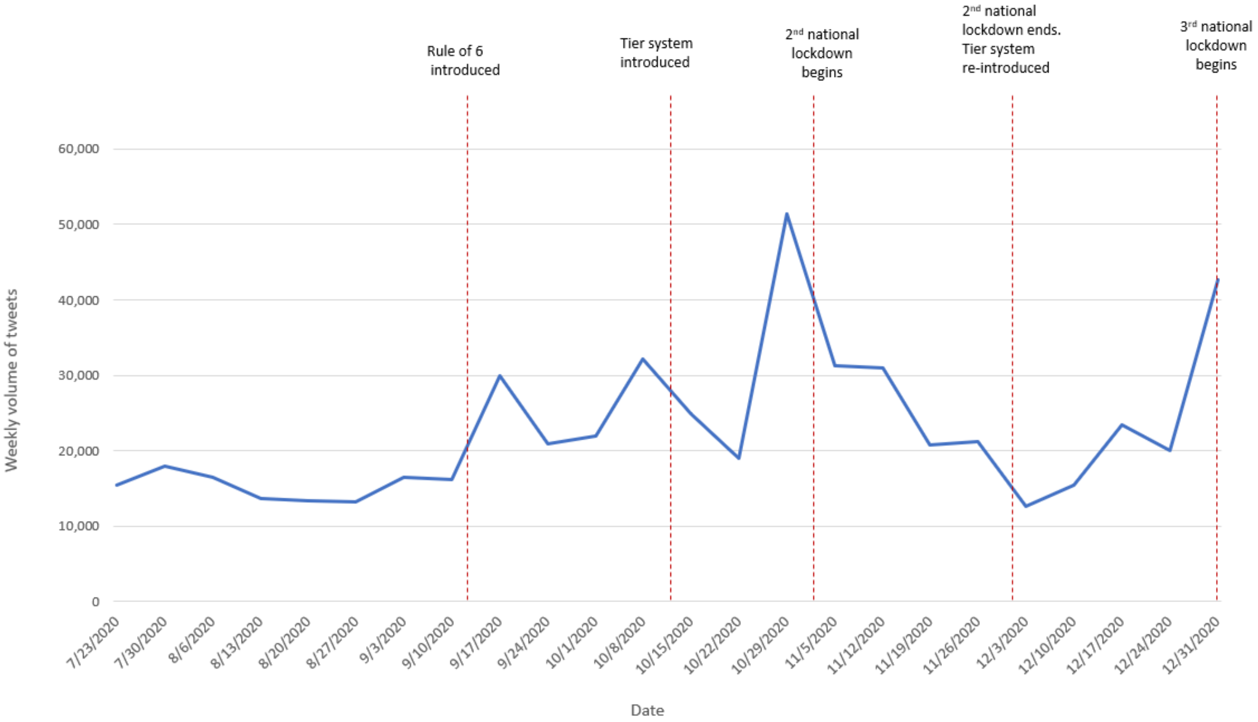


**Table 1.** Notable events that occurred from July 23, 2020 to October 14, 2020.

| Weeks | Events |
| --- | --- |
| Weeks 1-2 | • "Health Protection Regulations 2020" comes into force (ie, mandatory wearing of face masks in most indoor establishments).<br>• Gyms, swimming pools, and other indoor sports facilities reopen.<br>• England reports highest number of excess deaths in Europe for February to June.<br>• Major incident is declared in Greater Manchester after rise in cases. |
| Weeks 3-4 | • Stricter measures are reintroduced in Preston, Lancashire.<br>• England's revamped contact-tracing app begins public trials.<br>• General Certificate of Secondary Education (GCSE) results are published with grades based on teachers' assessments.<br>• The Education Secretary confirms free appeals for A-Level and GCSE. |
| Weeks 5-6 | • Ban on property evictions is extended until September 20.<br>• Greater Manchester Police report breaking up 126 illegal gatherings.<br>• Thousands of lockdown protesters gather in Trafalgar Square. |
| Weeks 7-8 | • Health experts express doubt about mass testing plan: "Operation Moonshot."<br>• World Suicide Prevention Day is on September 10.<br>• "Rule of 6" for indoor and outdoor gatherings is announced. |
| Weeks 9-10 | • Local lockdown measures are announced for Newcastle.<br>• Restrictions are relaxed for childcare purposes between households.<br>• Couples in established relationships can meet without social distancing.<br>• Second version of National Health Service (NHS) contact-tracing app becomes publicly available.<br>• £10,000 (US $13,035) fine for failing to self-isolate is announced. |
| Weeks 11-12 | • Lockdown restrictions are tightened in the Northeast.<br>• Tier system comes into force, replacing local lockdowns.<br>• World Mental Health Day occurs on October 10. |


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**Table 2.** Notable events that occurred from October 15, 2020 to January 6, 2021

| Weeks | Events |
|---|---|
| Weeks 13-14 | • Shielding ends for clinically vulnerable<br>• Additional financial support to businesses in Tier 3 is announced. |
| Weeks 15-16 | • Month-long national lockdown in England from November 5, 2020 is announced.<br>• Clinically vulnerable are asked to shield again.<br>• Furlough scheme is extended until March 2021.<br>• Pfizer/BioNTech press release announces vaccine is 90% effective.<br>• Travel window for university students to return for Christmas is announced. |
| Weeks 17-18 | • Government publishes their “staying mentally well this winter” guidance.<br>• Plans to ease restrictions for 5 days over Christmas are announced. |
| Weeks 19-20 | • Indoor care home visits can resume subject to lateral flow test.<br>• Medicines and Healthcare products Regulatory Agency (MHRA) approves Pfizer/BioNTech vaccine for rollout in the United Kingdom.<br>• Joint Committee on Vaccination and Immunisation (JCVI) publishes vaccine priority groups.<br>• National lockdown ends, and Tier system resumes. Most regions in England are placed in Tier 2 or 3.<br>• Shielding ends for clinically vulnerable.<br>• First COVID-19 vaccine is administered. |
| Weeks 21-22 | • Self-isolation period is reduced from 14 days to 10 days.<br>• New variant of the virus is identified.<br>• Further regions of the United Kingdom enter highest Tier.<br>• Furlough scheme is extended to April 2021.<br>• Large parts of Southeast England move into the new, stricter Tier 4.<br>• Christmas relaxation period is reduced from 5 days to 1 day.<br>• Travel restrictions for South Africa are enforced.<br>• Most of England will enter Tier 4 from December 26, 2020 is announced. |
| Weeks 23-24 | • MHRA approves AstraZeneca/Oxford vaccine.<br>• JCVI publishes updated guidance.<br>• UK Prime Minister announces third national lockdown from January 4, 2021, with schools remaining closed. |

## Mental Health Problems

Table 3 summarizes the volume of tweets that utilized at least one of the terms related to anxiety, depression, stress, or loneliness. In total, 113,312 (39.50%) of the 286,902 tweets scraped through the initial search strategy related to anxiety, depression, stress, or loneliness.

Figure 2 presents the volume of tweets utilizing terms related to anxiety, depression, stress, or loneliness around each keyword filter over the study period.

Across all of the mental health problems that were focused on here, the highest volume of tweets was observed w/c October 29, 2020, and the lowest volume of tweets occurred w/c December 3, 2020. The “Anxiety” filter returned the highest total number of tweets, and the “Loneliness” filter returned the lowest (see Table 3). The trend in tweet frequency for each filter mirrored the trend reported for the overall data set over the study period.

During the first half of the analysis period (w/c July 23, 2020 to w/c October 22, 2020), tweet volume between the 4 mental health problem filters varied. In particular, tweets related to the “Anxiety” filter were consistently posted most often, and tweets relating to the “Loneliness” filter were consistently posted least. There was a spike in volume across all 4 filters w/c October 29, 2020, the start of the second national lockdown. Following the spike, the volume of tweets across all of the filters was broadly similar for the remainder of the analysis period.

**Table 3.** Keyword filters and resultant volume of tweets for specific mental health problems.

| Filter | Keyword terms | Tweets (N=113,312) |
|---|---|---|
| Anxiety | “anxious,” “anxiety” | 37,213 (32.84%) |
| Depression | “depression,” “depressed,” “depressing” | 29,523 (26.05%) |
| Stress | “stress,” “stressful,” “stressed” | 26,725 (23.59%) |
| Loneliness | “loneliness,” “lonely,” “alone” | 19,851 (17.52%) |


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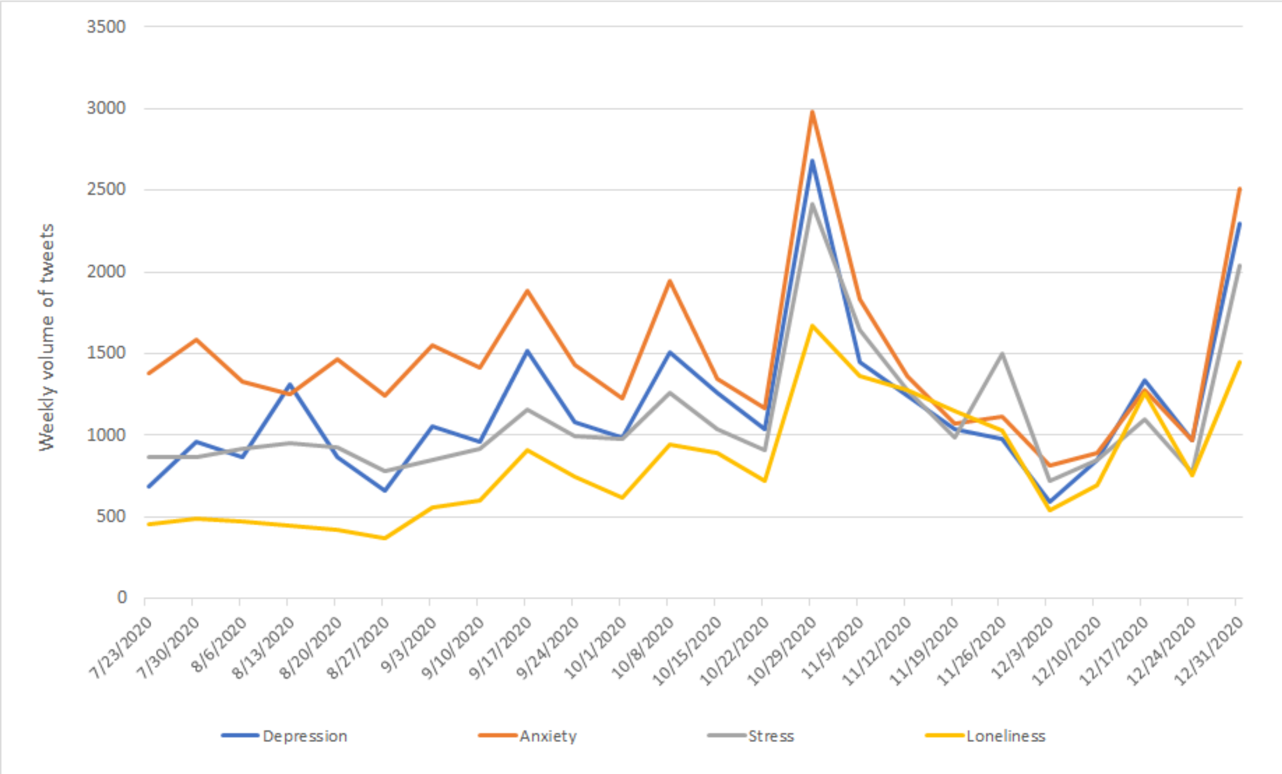
**Figure 2.** Volume of tweets from July 23, 2020 to January 6, 2021.




## Sentiment Analysis

Of the 286,902 tweets, 34,347 (11.97%) were identified as having positive sentiment, 217,728 (75.89%) as having neutral sentiment, and 34,827 (12.14%) as having negative sentiment, with an overall sentiment score of 50% assigned. A score below 50% suggests negative sentiment, and a score greater than 50% suggests positive sentiment. Textbox 4 presents a selection of example tweets that the NLP platform classified as both positive and negative.

Here, the overall score of 50% indicates neutral sentiment across all tweets over the study period. Figure 3 visualizes the weekly change in sentiment over the study period from July 23, 2020 to January 6, 2021.

**Textbox 4.** Examples of positive and negative tweets classified by the NLP platform.

**Example tweets classified with positive sentiment**

*...Since lockdown my anxiety has dramatically gotten so much better. I used to get stress spots, panic attacks before presentations, etc. Na bruh, working from home has been a life saver...*

*If anyone is struggling with lockdown (or wants to reduce stress/anxiety). I would really recommend trying gratitude journaling. I've shared some tips below – I hope they'll be helpful*

*…Never been so happy to set foot in a gym today. I feel so much happier getting back into a routine and pleased to see I haven't lost much strength through pregnancy and lockdown. It's made me realise how important it is for my own mental health...*

**Example tweets classified with negative sentiment**

*...I'm finding this lockdown harder than the last one. For me it's not just the weather, it's having no end in sight which is a struggle when you suffer with anxiety and depression...*

*…genuinely think a second lockdown would completely destroy my mental health. I'm nervous about the next few weeks/months...*

*Feeling absolute rubbish today, feel like my mental health is debilitating can't bring myself to get out of bed, my only escape is drinking with to forget these awful times*



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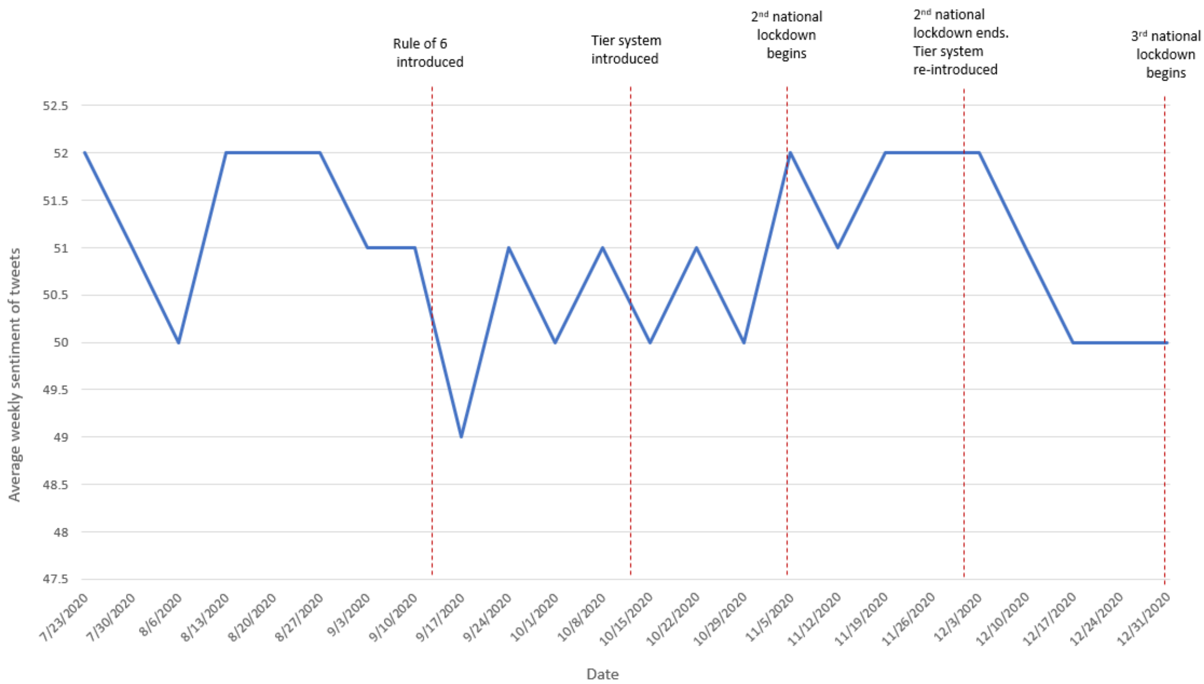
**Figure 3.** Sentiment of tweets from July 23, 2020 to January 6, 2021.




Sentiment remained neutral or positive throughout most of the study period. The highest assigned sentiment score, 52%, occurred in weeks 1, 4 to 6, 16, and 18 to 20. The lowest assigned sentiment score, 49%, occurred in week 9 (w/c September 17, 2020).

Overall, the data show a relatively consistent trend in sentiment over the study period. When sentiment fluctuation did occur, it was similar to the trend observed with tweet frequency and coincided with major changes to lockdown or social distancing rules.

## Topic Analysis

In this section, results are reported for 2 time periods, as follows: (1) July 23, 2020 to October 14, 2020 and (2) October 15, 2020 to January 6, 2021.

### *Results of the Topic Analysis for Weeks 1 to 12*

This section presents the results of a topic analysis based on 115,700 scraped tweets posted from July 23, 2020 to October 14, 2020.

### *Summary of Clustered Topics With Positive Sentiment*

"Mental health" emerged as a key topic of discussion underpinned with positive sentiment. The importance of mental health throughout the "coronavirus pandemic," as a critical health issue, was shared widely by people on Twitter. During this period, people openly discussed their mental health and how they had been coping. People also shared praise for specific local and national mental health services, as well as key public figures (eg, Marcus Rashford).

There was considerable discussion based around "World Mental Health Day" and "World Suicide Prevention Day." People were sharing helpful strategies (eg, videos, charities, help lines, exercise regimes, healthy eating advice) others could use to protect and maintain their mental health. There were also calls from people to be particularly vigilant and make sure they are checking in with any "vulnerable people" in their life.

Positive discussion was observed around "working from home." Various users were sharing helpful resources to support working from home effectively, including strategies that people had found useful during the previous national lockdown. Some people reported that mandatory working from home had helped them to achieve a better work-life balance and reduced their anxiety.

Specific examples of mental health tweets underpinned with positive sentiment from weeks 1 to 12 are presented in Textbox 5.

**Textbox 5.** Sample of clustered tweets from weeks 1 to 12 with positive sentiment.

*...Never been so happy to set foot in a gym today. I feel so much happier getting back into a routine and pleased to see I haven't lost much strength through pregnancy and lockdown. It's made me realise how important it is for my own mental health...*

*...I eventually took time out from March as it just got too much. My anxiety was through the roof and frankly I was glad of lockdown - I didn't want to leave the house anyway. I'm in a much better place now thankfully...*

*...This coming Thursday is world suicide prevention day and we need to be talking about this in the context of covid, lockdown, the economy and more. Most of all we need to talk and respond with compassion and support...*



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*...As many return to working from home, worth reminding ourselves of all those self-care tips we were bombarded with in March. @[redacted] on managing anxiety and emotional fatigue...*

*...Since lockdown my anxiety has dramatically gotten so much better. I used to get stress spots, panic attacks before presentations, etc. Na bruh, working from home has been a life saver...*

*...Lockdown was great for my mental health despite not being furloughed. While working from home I experienced being able to sleep well, eat well, exercise regularly, hear myself think, and feel alive, rather than dragging myself through each day merely surviving to begin the next...*

### Summary of Clustered Topics With Negative Sentiment

“Second lockdown” emerged as a key topic of discussion underpinned with negative sentiment. People were sharing their fears, concerns, and anxieties over the prospect of a second national lockdown and the impact this would have on theirs (and other’s) mental health. People recalled and spoke openly about how their mental health had suffered during the previous lockdown, referencing specific problems such as “anxiety,” “depression,” and posttraumatic stress disorder. Some people shared that they had been diagnosed with depression for the first time due to the previous national lockdown.

Many people were angry that not enough had been done by the government to protect “vulnerable people” during the previous national lockdown. Suicide was also discussed. People were claiming that suicide rates had increased during lockdown, particularly among younger people. There was widespread sharing of warnings from key educational figures that the pandemic would have long-lasting negative effects on “children.” Further, some argued that people were using “mental health” as an excuse to avoid further lockdown restrictions. Many people were concerned that a second lockdown would be much worse for people’s mental health than the first (the lockdown coinciding with winter and students returning to university were both seen as contributing negative factors). Those who refused to wear masks were a further source of anxiety for some people, with a high proportion of tweets calling on others to “wear a mask.” People also discussed COVID-19 tests during this period. In particular, some people shared how stressful and anxiety-inducing taking the test, and also waiting for the results, can be.

Tweets contained within some of the other topic clusters generated by the platform, such as “care homes” and “covid deaths,” did not appear to be related to mental health.

Specific examples of mental health tweets underpinned with negative sentiment from weeks 1 to 12 are presented in Textbox 6.

**Textbox 6.** Sample of clustered tweets from weeks 1 to 12 with negative sentiment" to be consistent with the other textboxes.

*...went into the year hopeful and ready to turn my life around...then covid happened and the world became a giant prison. Depression slowly came back, anxiety eating away and all emotion and feeling slowly dry up. Mind became a wasteland pretty much. Lifeless and desert...*

*...I have to get a COVID test done before going back to work at the end of the month and the anxiety I am having from the thought of them sticking that thing up my nose...*

*...I’m finding this lockdown harder than the last one. For me it's not just the weather, it’s having no end in sight which is a struggle when you suffer with anxiety and depression...*

*...genuinely think a second lockdown would completely destroy my mental health. I’m nervous about the next few weeks/months...*

*...I'm all for people following the rules - wear your masks and keep distance when required, but this is very true and will make people more depressed by lack of communication with real people. Depression will be a huge and sad factor if this new lockdown does go ahead. Stay safe...*

*...This bizarre competition between suicide and Covid deaths needs to end. I understand the mental health issues that can arise from lack of social interaction and other factors from Covid but this weird death competition between the 2 needs to stop...*

### Results of the Topic Analysis for Weeks 13 to 24

This section presents the results of a topic analysis of 171,202 scraped tweets posted from October 15, 2020 to January 6, 2021. Table 2 summarizes a selection of notable events that occurred during this time period.

Tables 4 and 5 present the top 10 most discussed topics that occurred throughout the study period.



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**Table 4.** Top 10 most discussed positive and negative topics from July 23, 2020 to October 14, 2020.

| Ranking | Clustered topic | Number of tweets |
| --- | --- | --- |
| **Topics with positive sentiment** | | |
| 1 | “mental health” | 5499 |
| 2 | “vulnerable people” | 1513 |
| 3 | “lockdown anxiety” | 491 |
| 4 | “communities... support” | 348 |
| 5 | “health... important” | 327 |
| 6 | “coronavirus pandemic” | 266 |
| 7 | “work from home” | 257 |
| 8 | “support... provide” | 246 |
| 9 | “improved... health” | 234 |
| 10 | “world day” | 233 |
| **Topics with negative sentiment** | | |
| 1 | “mental health” | 5192 |
| 2 | “people... vulnerable” | 1421 |
| 3 | “children... coronavirus” | 1037 |
| 4 | “covid... deaths” | 743 |
| 5 | “wear a mask” | 566 |
| 6 | “test for covid” | 419 |
| 7 | “lockdown... gone” | 411 |
| 8 | “care homes” | 405 |
| 9 | “second lockdown” | 377 |
| 10 | “anxiety... depression” | 365 |


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**Table 5.** Top 10 most discussed positive and negative topics from October 15, 2020 to January 6, 2020..

| Ranking | Clustered topic | Number of tweets |
|---|---|---|
| **Topics with positive sentiment** | | |
| 1 | "suicide lockdown" | 10,096 |
| 2 | "mental health" | 10,031 |
| 3 | "people…vulnerable" | 1860 |
| 4 | "friends or family" | 526 |
| 5 | "need…support" | 451 |
| 6 | "ones you love" | 409 |
| 7 | "community…helping" | 306 |
| 8 | "stress & anxiety | 295 |
| 9 | "night's sleep" | 275 |
| 10 | "difficult times" | 259 |
| **Topics with negative sentiment** | | |
| 1 | "mental health" | 10,299 |
| 2 | "vulnerable people" | 1767 |
| 3 | "going…lockdown" | 1025 |
| 4 | "deaths…covid" | 979 |
| 5 | "suicide rates" | 490 |
| 6 | "sleep at night" | 479 |
| 7 | "lockdown…depressing" | 474 |
| 8 | "committed suicide" | 460 |
| 9 | "coronavirus…children" | 441 |
| 10 | "wearing masks" | 441 |

### *Summary of Clustered Topics With Positive Sentiment*

During this period, a tweet suggesting suicide rates had risen by 200% since lockdown was shared widely. The tweet contained contact details for a registered UK charity, Samaritans, urging people to reach out for support if needed. This viral tweet resulted in our analysis platform recognizing "suicide lockdown" as a key topic of discussion. The information being reported by this tweet was not accurate [17,18].

As with the previous 12 weeks, "mental health" remained a key topic of discussion underpinned with positive sentiment during this period. People discussed how the lockdown had, in some ways, had a positive impact on their mental health. Various people and organizations continued to share practical tips on how to support one's mental health, particularly around strategies to reduce "stress and anxiety."

Many people continued to express concern for the mental health of perceived "vulnerable people" during lockdown, including children, young people, disabled people, those with learning difficulties, and those with any pre-existing mental health problems. Some people were calling on the government to provide further support for these groups as lockdown restrictions tightened. Many people were encouraging those that that were struggling to stay connected with others and reach out to "ones you love" and "friends and family."

"Sleep" emerged as a key topic of discussion with positive sentiment. Many people discussed how important getting a good "night's sleep" was for their mental health, particularly during these "difficult times." People shared relaxation techniques they had used, which had helped them to fall asleep, and which may help others too.

Specific examples of mental health tweets underpinned with positive sentiment from weeks 13 to 24 are presented in Textbox 7.

**Textbox 7.** Sample of clustered tweets from weeks 13 to 24 with positive sentiment.

*Suicide figures are up 200% since lockdown. Could two followers please copy and re-post this tweet? We're trying to demonstrate that someone is always listening. Call 116 123 (Samaritans UK). Just two. Any two. Copy, not RT. #MentalHealth #SuicidePrevention #SuicideAwareness*


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*important to remember with all the 200% increase in suicide tweets. Raising awareness is fantastic, but make sure it's factual. #SuicidePrevention.*

*My mental health is sooo much better now it's a real lockdown again. However I know this isn't a universal experience. For those who find lockdown harder for whatever reason, I'm a) sending virtual hugs if wanted but b) reminding you it's STRONG to reach out to a helpline!*

*As we start lockdown 3, a reminder that your situation does not have to be the worst for it to suck and for you to get help! Reach out to your loved ones & professional mental health support if you need it. Stay safe.*

*Such a tough time at the moment for everyone, another lockdown especially in winter can be devastating for mental health. My dm's are always open for anyone who needs a chat – be kind and check on your loved ones.*

*Thanks to local organisations, community groups and faith institutions that have provided vital services, human support and companionship, in person and online, to many vulnerable people during #Covid-19. We will keep working with you all to build stronger and united communities.*

*If anyone is struggling with lockdown (or wants to reduce stress/anxiety). I would really recommend trying gratitude journaling. I've shared some tips below – I hope they'll be helpful*

*#COVID19 wellbeing tip: make sure you get a good night's sleep! A good rest is so important for your mental and physical health, managing stress and much more. If you're struggling with sleep, try these tips and check out our Sleep self-help guide.*

### Summary of Clustered Topics With Negative Sentiment

"Mental health" continued to be widely discussed during this final 12-week period. Many people reflected on the negative impact that lockdowns had had on their mental health. There were concerns from some that any progress they had made with their mental health would be lost with another lockdown. There was continued anger toward the UK government about a perceived lack of support for those struggling with their mental health.

There was a lot of discussion around the looming national lockdown announced for January 4, 2021. Many people expressed concern about how long this lockdown would last and their hope that this would be the final lockdown. Some shared that they would be defying restrictions in order to prioritize their mental health. Others continued to argue that people were using their mental health as an excuse for not following the rules. There was continued worry about how the lockdown would affect perceived "vulnerable people."

During this period, people shared their thoughts about the vaccine rollout. In particular, people were concerned about the length of time between jabs and the number of canceled vaccination appointments being reported by the media.

"Sleep" continued to be a key topic of discussion with many people sharing how they had not been sleeping well. Some people shared how they had been increasing their alcohol intake in an effort to help them sleep.

Specific examples of mental health tweets underpinned with negative sentiment from weeks 13 to 24 are presented in Textbox 8.

**Textbox 8.** Sample of clustered tweets from weeks 13 to 24 with negative sentiment.

*Well lockdown 3.0 has barely started and I can already feel all the hard work I put balancing my mental health slip away*

*Tbh I just hope my mental health doesn't become as bad as first lockdown*

*Feeling absolute rubbish today, feel like my mental health is debilitating can't bring myself to get out of bed, my only escape is drinking with to forget these awful times*

*There needs to be more mental health support @BorisJohnson as that will be one of the highest collateral costs of this. People like me are struggling badly in isolation and with mental health issues and there isn't enough support. #Uklockdown #Covid*

*My mental health is already rock bottom due to not seeing my family/friends, being overworked and not sleeping – god help what another lockdown is gonna do to me*

*… everyone is talking about lockdown 3 but carehomes haven't left lockdown since the first lockdown started. Everyone is ignoring how vulnerable people feel, disables people or careworkers and carers.*

*...I've never had ocd but do have A LOT of anxiety, + have noticed the longer lockdown goes on the more my anxious behaviours start to look like obsessive ones eg. I check my cooker before bed/before leaving my house when I never did that pre lockdown, also started counting.!*

*It's only our second day of lockdown 3.0 going solo & I'm already finding harder than the others. It could be due to the distinct lack of sleep last night. What are your favourite self care activities to do? I need motivation to get off the sofa today #lockdown #lockdownblues*



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*...everyone is rotting in their own houses and getting depression I'm not saying they're less important but clearly this going in and out of lockdown isn't helping anyone is it*

*this lockdown is starting to get to me – went off my food, crying more and just generally depressed loool*

## Discussion

### Principal Findings

In this study, we identified and analyzed 286,902 geolocated tweets posted from users in the United Kingdom from July 23, 2020 to January 6, 2021 using a commercially available NLP platform. The findings showed that there was a fairly consistent trend in the volume of tweets over the study period, with spikes typically occurring during (or leading up to) a major change in social distancing measures in the United Kingdom. The NLP platform calculated an overall sentiment score of 50% indicating neutral sentiment across all tweets over the study period. Similar to volume, major fluctuations in sentiment appeared to coincide with major changes to lockdown rules.

Key topics of discussion that emerged consistently throughout the study period included (1) the impact that the pandemic and resulting lockdowns had been having on people's mental health, both positive and negative; (2) fear and anxiety around the prospect of prolonged and subsequent lockdowns and how this might (or continue to) affect people's mental health; and (3) anger and mistrust toward the government concerning a perceived lack of support for people struggling with their mental health.

Later in (and less consistently discussed throughout) the study period, other topics linked with mental health emerged, including sleep difficulties, increased alcohol intake, and anxieties concerning testing and the vaccine rollout.

Before the study, we anticipated that topics of discussion relating to mental health would be mostly underpinned with negative sentiment. It was therefore surprising that the findings of the topic analysis revealed higher levels of positive sentiment across posts associated with mental health. Consistently over the study period, people took to Twitter to share practical tips, strategies, and resources that could be used to support one's mental health, and the platform was effective in clustering these types of posts with positive sentiment.

The viral spread of misinformation and "fake news" has represented a critical issue generating mass confusion, fear, and insecurity surrounding COVID-19 [19]. The WHO has repeatedly used the term "infodemic" to describe the sheer overabundance of misinformation being shared throughout the pandemic [20]. Our findings provide further example and insight into the rapid spread of health-related misinformation, particularly via channels of soft intelligence like social media. Specifically, in the case of this study, a copy-and-paste tweet campaign falsely claiming that suicide rates had increased by 200% since the first lockdown was shared widely by users. This particular cluster of tweets ranked as the topmost discussion topic during weeks 13 to 24 over the study period.

Overall, the results of this study demonstrate that using NLP to mine and analyze sources of soft intelligence (like Twitter) can yield useful health-related insights, which agencies, local leaders, and health care decision makers can potentially draw from. These findings contribute to a growing body of literature examining the value of this type of analyzed evidence and how it might support, link to, and (where appropriate) replace more traditional survey-based methods and data [15,21-24].

### Limitations

Several limitations can be attributed to this study. First, there are still considerable limitations concerning the reliability, accuracy, and transparency of the technologies in play. As an example, on examining the results of the NLP platform's topic analysis, some of the tweets collated were not relevant to mental health (despite being identified as such). For example, tweets contained within clustered topics like "care homes" and "covid deaths" were expressing anger at the government, rather than negatively discussing mental health problems.

Some of the tweets included by the platform in its analysis were posted by businesses or charitable organizations, rather than members of the public. Such tweets, which often advertised local or national mental health services or shared self-improvement strategies, were typically classified by the platform as having positive sentiment. This created a large amount of background noise and skewed the overall sentiment toward positive. Further, tweets were not deduplicated by the platform, nor was there any formal analysis accounting for potential bot traffic. These factors will also have impacted the results.

In addition, despite the popularity of Twitter as a social networking tool, its users are not an accurate representation of the overall demographic of a population. Therefore, if we are to consider using Twitter (and similar resources) as a potential intelligence source, we must be mindful of bias concerning the key demographic information among its users (such as age, gender, and socioeconomic status).

There was also a number of limitations specific to the NLP platform that we selected. We had originally planned to run the topic analysis using the platform across all of the tweets as a single corpus. However, the platform was not able to process and analyze such a large volume of tweets in one go. Therefore, we had to split and run the topic analysis over 2 time periods (weeks 1 to 12 and weeks 13 to 24). Further, it was not possible to retrospectively search for and collect historic tweets, thus restricting possible options for analysis. Finally, although the broader methodologies that power the platform are touched on by its developers, the finer technical detail is not shared publicly due to commercial reasons.

### Conclusions

In this work, we analyzed a large collection of UK tweets relating to mental health during the COVID-19 pandemic to further explore the value of soft intelligence leveraged using NLP. Using a specialist, off-the-shelf, NLP platform, we collated



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a large corpus of tweets over a 24-week period and carried out various analyses to explore the volume, sentiment, and key trends and topics of discussion.

Our findings provide further evidence that this type of research is potentially a highly useful and efficient means to gain a rapid understanding of the key messages, concerns, and issues people are facing at scale. In the case of this reported study, we were able to draw insights into how the pandemic may be impacting people's mental health and well-being by examining both the topic and sentiment specific to the UK population. This type of real-time analysis and intelligence may be particularly useful in helping shape rapid and reactive public health engagement and communication strategies during a health crises like COVID-19.

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## Authors' Contributions

CM was responsible for project supervision; the conception, design, and conduct of the study; leading the development of the initial manuscript; and managing its revision. KL, RG, and GCW were responsible for data analysis, data interpretation, and critical review and revision of the manuscript. FP and DC provided critical review of the manuscript.

## Conflicts of Interest

The National Institute for Health Research (NIHR) Innovation Observatory purchased a license to use and evaluate the natural language processing (NLP) platform, Wordnerds. However, as independent users, the authors have no vested interest in the tool.

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## Abbreviations

**AI:** artificial intelligence
**ML:** machine learning
**NIHR:** National Institute for Health Research
**NLP:** natural language processing
**w/c:** week commencing
**WHO:** World Health Organization

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Original Paper

# Synthetic Cannabinoids in Prisons: Content Analysis of TikToks

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## Abstract

**Background:** Synthetic cannabinoids are a significant public health concern, especially among incarcerated populations due to increased reports of abuse. Recent news reports have highlighted the severe consequences of K2/Spice, a synthetic cannabinoid, among the prison population in the United States. Despite regulations against cell phone use, inmates use TikTok to post K2/Spice-related content.

**Objective:** This study aimed to examine TikTok posts for use and illicit distribution of psychoactive substances (eg, K2/Spice) among incarcerated populations.

**Methods:** The study collected TikTok videos associated with the #k2spice hashtag and used a data collection approach similar to snowball sampling. Inductive coding was used to conduct content analysis of video characteristics. Videos were manually annotated to generate binary classifications related to the use of K2/Spice as well as selling and buying activities associated with it. Statistical analysis was used to determine associations between a video's user engagement and an intent to buy or sell K2/Spice.

**Results:** A total of 89 TikTok videos with the hashtag #k2spice were manually coded, with 40% (n=36) identified as displaying the use, solicitation, or adverse effects of K2/Spice among the prison population. Of them, 44.44% (n=16) were in a prison-based setting documenting adverse effects including possible overdose. Videos with higher user engagement were positively correlated with comments indicating an intent to buy or sell K2/Spice.

**Conclusions:** K2/Spice is a drug subject to abuse among prison inmates in the United States, including depictions of its harmful effects being recorded and shared on TikTok. Lack of policy enforcement on TikTok and the need for better access to treatment services within the prison system may be exacerbating substance use among this highly vulnerable population. Minimizing the potential individual harm of this content on the incarcerated population should be a priority for social media platforms and the criminal justice system alike.

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**KEYWORDS**

social media; substance use disorder; synthetic drugs; prison; cannabinoid; synthetic; psychoactive; illicit; video; substance use; harmful; K2/Spice; TikTok



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## Introduction

Synthetic cannabinoids are a significant public health concern. Their use can cause several adverse effects (eg, anxiety, paranoia, tachycardia, lightheadedness) and can lead to significant health consequences [1,2]. The types and availability of synthetic cannabinoids are on the rise and are now popular internet search terms [2,3]. Between 2009 and 2018, more than 260 unique synthetic cannabinoids were identified on the market [4]. These compounds mimic the effect of naturally occurring cannabinoids and are created in a laboratory, often with higher potency and more severe adverse effects, and introduce the risk of impairment or even death [3,5]. Synthetic cannabinoids are commonly smoked or ingested and can also be stably transported on paper letters and cards [3,4].

Although comprising less than 5% of the global population, the United States accounts for more than 1 in 5 of the world's incarcerated population [5]. Recent news reports have highlighted increasing use of synthetic cannabinoids in correctional facilities in the United States and mass intoxications in prisons internationally [6]. In 2016, the Florida Department of Corrections estimated that more than 56 kg of synthetic cannabinoids were illegally transported into Florida correctional facilities [6]. Importantly, substance use and clinical dependence among incarcerated individuals remain higher than that in the general population [7].

It is unclear how incarcerated individuals obtain contraband substances, but it may be due to inadequate screening procedures [8]. Further, treatment for substance use within prison facilities remains insufficient to meet current needs; more than half of incarcerated individuals are indicated for treatment based on current guidelines, yet only 15% receive regular treatment [9]. Despite stringent security measures in state, federal, and private detention facilities, synthetic cannabinoids and related substance use remains a critical concern among this vulnerable population [8].

TikTok is a popular social media platform with an estimated 100 million active US users, which allows users to post short-form video content from mobile devices and is known for "viral" content that is shared and promoted among its hundreds of millions of users. Although it has also been increasingly used to obtain health-related information, especially during the COVID-19 pandemic, the quality of information on TikTok can vary widely, may not always be reliable, and can be harmful [10-12]. Harmful information found on TikTok includes sharing experiences and positive sentiment related to substance use [13-15].

Concerningly, a 2016 observational study found a significant relationship between social media and synthetic cannabinoid use among young adults [16]. Further, a separate 2016 study conducted content analysis of videos on YouTube, a popular social media platform also known for user-generated content, and found videos depicting the use and promotion of K2/Spice on the platform [17]. Social media use is also prominent among incarcerated individuals and can be a means to engage in illegal activities. Additionally, viewing substance use content on social media has been identified in this population as a trigger for relapse [18]. Building on these prior studies, research specifically examining the possible use of emerging platforms such as TikTok to promote or describe synthetic cannabinoid use or sourcing among the incarcerated population is needed.

Importantly, under the Cell Phones Contraband Act of 2010, cell phones are prohibited in federal correctional facilities; however, inmates continue to transport illegal contraband through visitors or employed personnel. As cell phones have become smaller and more sophisticated, they are capable of accessing social media platforms and other mobile apps. Today, prisoners actively record and post TikTok videos under the hashtag #PrisonTikTok, a popular content category on the platform with over 3 billion views, to share their lived experiences with incarceration including recording trending dances and showing how to prepare prison meals [19-22]. However, the use of TikTok to promote K2/Spice-related content is not well understood, though prior studies have identified content on other social media platforms not related to the incarcerated population [16,17].

As the emerging public health threat of synthetic cannabinoids continues to rise, coinciding with the use of social media among incarcerated individuals, research is needed to better understand how social media platforms are being used to possibly traffic and promote synthetic drug use. Hence, our objective was to conduct a retrospective observational infoveillance study for the purposes of exploratory analysis. We used an inductive content analysis approach to assess the use of TikTok for content related to the purported use and sourcing of synthetic cannabinoids among incarcerated populations.

## Methods

### Data Collection

For this exploratory content analysis, a seeded sample of TikTok videos with the hashtag #k2spice were retrospectively identified on June 29, 2021, using structured searches on the platform without any user login or personal search history enabled. The most relevant videos to the hashtag as determined by the TikTok search results algorithm were displayed first in order of decreasing relevance. The URLs for all the public videos returned in searches were saved, and raw video data files were downloaded using a custom script built in the Python programming language. Based on a seeded sample of 89 TikTok videos of 53 unique users/creators, we then snowball sampled for additional content from TikTok users who were coded as being associated with K2/Spice content among purported prison users. The 10 most recent posts from each of these associated TikTok user public profile pages were then collected for further analysis.

### Data Analysis

Manual annotation and content analysis of the TikTok videos were conducted by TJM, AC, and MCN. Coding was approached inductively due to the exploratory nature of the study, prior studies that have examined TikTok primarily using an inductive coding approach for TikTok videos and texts, and due to the lack of existing studies that have coded TikTok content related to synthetic drugs [14]. Authors generated a data



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set with binary classifications of whether the video discussed content related to adverse effects, selling, and consumption of K2/Spice. Authors also recorded user engagement (views, likes, comments, and shares), whether a post reflected sale of a K2/Spice product, if a post was associated with other user comments indicating intent to buy or sell K2/Spice, and whether the video appeared to be recorded in a prison-based setting. Three authors (TJM, AC, and MCN) coded all TikTok videos independently and achieved a high intercoder reliability (κ=0.95) for codes. For inconsistent results, authors reviewed that video's content and metadata with other authors and conferred on the correct classification. Pearson correlation coefficient was calculated to assess the association between user engagement metrics and characteristics indicating intent to buy or sell K2/Spice as well as the medium on which K2/Spice was purportedly sold.

### Ethics Approval

An ethics exemption was not sought for this study. All information collected during this study was available in the public domain, and the study did not involve any interaction with users. Any user indefinable information is removed from study results, and results are provided in the aggregate to ensure anonymity.

## Results

A total of 89 TikTok videos with the hashtag #k2spice were retrospectively collected. The earliest video with this hashtag was uploaded on September 7, 2020, and the most recent video was uploaded on June 28, 2021. In addition to our original hashtag of interest, #k2spice, hashtags that have also been confirmed as being related to synthetic cannabinoid content in prior research (eg, touchie, black mamba) were also detected within the videos depicting synthetic marijuana use [9]. After manual annotation, 41% (n=37) of TikToks/videos reviewed were determined to be nonsignal, 40% (n=36) were confirmed to include content displaying the use, solicitation, or adverse effects of K2/Spice among the prison population, and 18% (n=16) included synthetic cannabinoid–related content among nonprison populations.

Of the prison-related videos, 77.78% (n=28) were posted in 2021 and 44.44% (n=16) displayed apparent hallucinations, paranoia, aggression, heart palpitations, and nausea experienced by users portrayed in TikTok videos [1,2]. Additionally, 69.44% (n=25) of videos reviewed purported to engage in the sale of K2/Spice to other TikTok users, and 19.44% (n=7) of videos contained user comments engaged in a similar buying and selling activity (Table 1 and Figure 1 show anonymized examples). These comments were only found on prison-related videos, and 0% of comments of users purported to sell or purchase K2 were found on non–prison-related videos. Comments in response to prison-related posts revealed 2 users who disclosed the correctional facility from which they were posting, 1 medium and 1 minimum security facility, both being located in Georgia.

The contents of the 16 videos that displayed the alleged physical experiences of K2/Spice were characterized by psychomotor manifestations of inmates visibly collapsed, asleep or unconscious, staggering, and producing indecipherable noises. Videos contained a varied number of inmates, with some displaying a single person affected by K2 and others displaying upwards of 5 inmates seemingly experiencing the effects of the drug. Some videos also embedded trending audio clips typically used to generate more traffic to the content [23]. All users who posted adverse effects appeared to post secondhand experiences with synthetic cannabinoids (ie, 1 inmate recording another inmate's alleged experience).

There was a significant positive relationship between views, comments, and shares with comments indicating an intent to buy K2/Spice (respectively, $r$=0.428, $P$=.01; $r$=0.506, $P$=.002; and $r$=0.445, $P$=.007). There was also a significant positive relationship between a video's views, comments, and shares with comments indicating an intent to sell K2/Spice (respectively, $r$=0.470, $P$=.004; $r$=0.533, $P$=.001; and $r$=0.492, $P$=.003). There was a significant negative correlation between K2/Spice being sold via a paper medium (ie, K2/Spice allegedly sprayed on a card or paper for obfuscation and use) being shown within the video and digital comments indicating an intent to buy K2/Spice ($r$=–0.408, $P$=.02) and sell K2 spice ($r$=–0.371, $P$=.03).

**Table 1.** Examples of TikTok comments (N=561).

| Theme | TikTok comments (paraphrased) | Description | Comments indicating activity, n (%) |
|---|---|---|---|
| Buy | • Where can I find it? They don't have it in my area anymore.<br>• How can I get the K2 spray online? What should I type in to order it? | • An account commenting on a TikTok video, wanting to obtain K2. | 9 (1.6) |
| Sell | • Email me to place an order.<br>• Hi, I provide strong quality k2 spice papers and liquid for purchase at economical prices! Shipping is 100% concealed and delivery is secure. | • Account of a seller commenting on their TikTok on how to place an order.<br>• Account of a seller commenting on their TikTok about the quality of their products, shipping, and delivery. | 11 (2.0) |


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**Figure 1.** Accounts selling K2/Spice on TikTok. (A) An account showing a piece of paper advertising paper K2 and liquid K2. The paper also a date on it. (B) An account selling greeting cards with K2 on it. The video shows different greeting cards for different occasions. The K2 is inconspicuous.


## Discussion

### Principal Findings

This observational infoveillance study analyzed 89 TikTok videos using the hashtag #k2spice and found that 40% of the content included discussing the use, solicitation to purchase or sell, or adverse effects of K2/Spice among prison populations. We also found a significant positive relationship between interactions with TikToks that included selling and buying activity among users. These exploratory results provide additional evidence that K2/Spice is a drug subject to abuse among the incarcerated population, and discussions about its use and sourcing are actively occurring on social media. Specifically, we found that the harmful effects of synthetic cannabinoid use are being recorded and shared on TikTok, and these TikToks are surfacing on K2/Spice-specific hashtag/keyword searches, potentially exposing other users to this content [24].

Our study specifically identified videos and comments that provided seller contact information and purported proof of product, indicating that content detailing where and how K2/Spice can be obtained in prison systems including through discrete packaging is being posted. We note that this appears to be a direct violation of TikTok drug content policies [25]. Several user-posted videos also demonstrated ways to evade drug screening procedures in prisons, such as placing K2/Spice on envelopes and greeting cards or putting it in a nasal spray, making it more difficult to detect the drug. This is consistent with previous findings noting the risks of its evasiveness and increasing use among this population due to being colorless, odorless, and highly potent [26]. Importantly, this open promotion of the sourcing of K2/Spice in state and federal correctional facilities may mean that screening procedures in prison facilities are being actively circumvented, introducing unique public health and substance abuse safety risks that require further study and response.

Our general findings align with several local news reports describing adverse psychological effects from K2/Spice use in state prisons, though the adverse effects of these synthetic drugs occur in all populations including those specifically involved in polysubstance abuse [27,28]. However, these consequences may be exacerbated in a population known to face social stigma, limited access to health care, unique psychological and mental health pressures, and risk of physical harm due to incarceration [5,26]. Additionally, continuing use of contraband substances while incarcerated may delay parole and the timely reintegration of individuals incarcerated for minor drug offenses because federal correctional facilities require the successful completion of rehabilitation programs [5].

Our results also suggest that higher user engagement on videos displaying K2-related adverse effects is associated with more comments intending to buy or sell K2/Spice. This may indicate that content specific to sourcing behavior may lead to higher interaction among TikTok users viewing behavioral-related content, warranting more targeted content moderation. This was observed despite TikTok guidelines stating that any content



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depicting or promoting drug consumption or solicitation will be removed, and violating accounts, when warranted, will be reported to legal authorities [25]. As TikTok is one of the newest and fastest growing social media platforms, it can be difficult to proactively identify content that violates user guidelines. However, regulation and the need to develop novel surveillance technologies is important as multiple studies have already identified unflagged calls for violence, harmful "internet challenges" (eg, Tide pod challenge), and antisemitism on the platform [12,29,30].

Synthetic cannabinoids are unregulated and often used in combination with other substances, which may increase the risk of adverse health effects [31]. In the presumed absence of rigorous prison screening standards for synthetic cannabinoids, specific harm may be brought on incarcerated populations who have recognized disparities in access to substance use treatment and psychosocial support [32]. Synthetic cannabinoids are increasingly easier to obtain and are deceptively described as cannabis cessation tools, emphasizing the importance of screening and peer-to-peer education [9]. The means by which synthetic cannabinoids such as K2/Spice are transported into prisons are also an issue of concern. Cards and letters are soaked with synthetic cannabinoids and serve as a substrate for substances such as K2/Spice, with varying concentrations creating "hot spots" that are unlikely to be known by incarcerated individuals [33].

There has been an increased pressure on social media companies to regulate the sale of illegal drugs occurring on their platforms as overdoses from opioid use, intentional and accidental self-injuries, and fentanyl poisonings continue to rise in the United States. Social media surveillance may represent a viable means to identify new trends and behaviors associated with this ongoing public health threat, particularly among traditionally hard to reach populations. The increasing popularity of synthetic cannabinoids has not been widely described in the literature, which has made it difficult to develop evidence-based interventions and policies to mitigate its harm. Results from this study can inform future research seeking to further characterize the use of social media platforms to promote both the use and trafficking of synthetic cannabinoids as well as lay the foundation for more targeted interventions in these uniquely vulnerable populations. Future studies should further validate exploratory results generated from this study, using additional hashtags and keywords, as well as data from other social media platforms, and augment these findings with other qualitative and quantitative research.

### Limitations

This study has certain limitations. Results are exploratory in nature, limited to a convenience sample of public content on TikTok, and may not be indicative of broader substance use patterns or themes in the general population. This study was also limited in its data collection and sample of data by the TikTok search algorithm, which displays videos based on their relevance to the keyword(s) searched at a particular point in time. Keywords associated with substance use are often monitored and removed by social media platforms, leading users to use pseudonyms or code words to evade content moderation. In fact, as of this writing, the term "k2spice" is now blocked as a search term on the TikTok platform, though using it in the context of a hashtag (#k2spice) during searches is not. Hence, the results of this study are not generalizable to all synthetic cannabinoid discussions or content occurring on the platform.

Although this study identified additional hashtags associated with synthetic cannabinoid use, it did not purposefully examine these hashtags for additional incarceration-related content and did not examine prison-specific hashtags (eg, #PrisonTikTok). Future studies should incorporate new, emerging, and trending substance-related and incarceration-related keywords, code words, and hashtags to better understand the changing social network dynamics of synthetic cannabinoid promotion and behavior. Moreover, as findings are based on a convenience sample generated by the platform's own search algorithms, the scope of K2/Spice access and abuse among specific marginalized populations warrants additional investigation and inclusion of additional data sources that may be used by incarcerated populations. We were also unable to confirm if the contents described in this study were actually generated in correctional facilities due to the limited metadata available from TikTok accounts and posts.

### Conclusions

TikTok is a popular social media platform with millions of daily active users. Our study highlights the growing risk for the public and specific marginalized populations who may interact with and post psychoactive substance–related content on TikTok. Minimizing the potential individual and population-specific harm of this content on vulnerable prison populations should be a priority for platforms and the criminal justice system alike, as well as making attempts to strengthen substance abuse screening policies and evidence-based treatment to better ensure timely rehabilitation and reentry into society.

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## Data Availability

The raw data supporting the conclusions of this article will be made available by the authors in a deidentified and aggregated format.



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## Authors' Contributions

TJM collected the data. TJM, AC, and MN conducted data analyses. All authors contributed to the design, formulation, drafting, completion, and approval of the final manuscript.

## Conflicts of Interest

TJM, MN, and TKM are employees of the startup company S-3 Research LLC. S-3 Research is a startup funded and currently supported by the National Institutes of Health, National Institute on Drug Abuse through a Small Business Innovation Research contract for opioid-related social media research and technology commercialization. Authors report no other conflicts of interest associated with this manuscript.

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Original Paper

# Skin Cancer Narratives on Instagram: Content Analysis

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## Abstract

**Background:** Skin cancer is among the deadliest forms of cancer in the United States. The American Cancer Society reported that 3 million skin cancer cases could be avoided every year if individuals are more aware of the risk factors related to sun exposure and prevention. Social media platforms may serve as potential intervention modalities that can be used to raise public awareness of several diseases and health conditions, including skin cancer. Social media platforms are efficient, cost-effective tools for health-related content that can reach a broad number of individuals who are already using these spaces in their day-to-day personal lives. Instagram was launched in 2010, and it is now used by 1 billion users, of which 90% are under the age of 35 years. Despite previous research highlighting the potential of image-based platforms in skin cancer prevention and leveraging Instagram's popularity among the priority population to raise awareness, there is still a lack of studies describing skin cancer–related content on Instagram.

**Objective:** This study aims to describe skin cancer–related content on Instagram, including the type of account; the characteristics of the content, such as the kind of media used; and the type of skin cancer discussed. This study also seeks to reveal content themes in terms of skin cancer risks, treatment, and prevention.

**Methods:** Through CrowdTangle, a Facebook-owned tool, we retrieved content from publicly available accounts on Instagram for the 30 days preceding May 14, 2021. Out of 2932 posts, we randomly selected 1000 posts for review. Of the 1000 posts, 592 (59.2%) met the following inclusion criteria: (1) content was focused on *human* skin cancer, (2) written in English language only, and (3) originated from the United States. Guided by previous research and through an iterative process, 2 undergraduate students independently coded the remaining posts. The 2 coders and a moderator met several times to refine the codebook.

**Results:** Of the 592 posts, profiles representing organizations (n=321, 54.2%) were slightly more common than individual accounts (n=256, 43.2%). The type of media included in the posts varied, with posts containing photos occurring more frequently (n=315, 53.2%) than posts containing infographics (n=233, 39.4%) or videos (n=85, 14.4%). Melanoma was the most mentioned type of skin cancer (n=252, 42.6%). Prevention methods (n=404, 68.2%) were discussed in Instagram posts more often than risk factors (n=271, 45.8%). Only 81 out of 592 (13.7%) posts provided a citation.

**Conclusions:** This study's findings highlight the potential role of Instagram as a platform for improving awareness of skin cancer risks and the benefits of prevention practices. We believe that social media is the most promising venue for researchers and dermatologists to dedicate their efforts and presence that can widely reach the public to educate about skin cancer and empower prevention.

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**KEYWORDS**

digital health; social media; skin cancer; Instagram; melanoma; oncology; cancer; skin; content analysis; narrative; information sharing; online platform



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## Introduction

### Background

Skin cancer, in general, and melanoma, specifically, are among the deadliest forms of cancer in the United States [1,2]. The number of individuals in the United States diagnosed with skin cancer has increased over the last 30 years [1]. Individuals aged 15-39 years have seen more deaths from melanoma in this time frame because of the growing trends in the use of tanning services and increased popularity of tanned skin [2]. The American Cancer Society reported that 3 million skin cancer cases could be avoided every year if individuals are more aware of the risk factors related to sun exposure and other forms of prevention [3].

Social media platforms may serve as potential intervention modalities that can be used to raise public awareness of several diseases and health conditions, including skin cancer. Social media platforms are efficient, cost-effective tools for health-related content that can reach a broad number of individuals who are already using these spaces in their day-to-day personal lives [4]. Additionally, social media provides a feedback loop, enabling researchers to access users' online conversations regarding their specific needs, ultimately allowing messages developed in public health campaigns to align with those needs [5].

Instagram was launched in 2010, and it is now used by 1 billion users, of which 90% are under the age of 35 years [6]. These users generate 95 million posts each month in addition to 3.5 billion "Likes" each day [6]. In a recent study investigating the potential of various social media platforms to advance skin cancer awareness, Instagram had the greatest number of skin cancer–related posts [7]. Additionally, the hashtag #SunDamage was in the top 20 hashtags associated with dermatology-related content on Instagram [8]. Moreover, trends discussing skin cancer prevention dominate among others on Instagram, signifying its potential to specifically raise awareness about prevention among young people who may be susceptible to content promoting risky skin health behaviors such as tanning [9]. However, existing research results have limited generalizability due to the restricted study period, keywords, and sample size (eg, 150 posts) [6].

Social media is becoming a potential intervention modality to raise skin cancer awareness, especially via image-based platforms [10,11], such as Instagram. However, there is still a need to conduct additional research addressing the potential as well as the drawbacks of social media for raising public awareness regarding skin cancer [11]. This study fills this gap by describing skin cancer–related content on Instagram, including the origin (ie, source characteristics) and attributes (ie, content characteristics) of these social media posts. The study also seeks to reveal content themes in terms of skin cancer risks, treatment, and prevention.

### Research Questions

Accordingly, the following research questions (RQs) were proposed:

- RQ1: What are the source and content characteristics of Instagram posts related to skin cancer?
- RQ2: To what extent are different types of skin cancer covered on Instagram?
- RQ3: How do messages frame causes and solutions regarding skin cancer causes, treatments, and prevention?
- RQ4: To what extent do Instagram posts on skin cancer address the susceptibility and severity of skin cancer; benefits and barriers associated with diagnosis, prevention, and treatment; call to action; and readers' self-efficacy?

## Methods

### Data Collection

We used CrowdTangle [12], a tool owned and operated by Facebook, which tracks the engagement of the publicly available content on Facebook pages, subreddits, and Instagram accounts. Through CrowdTangle, we retrieved content from publicly available accounts on Instagram for the 30 days preceding May 14, 2021. Only posts written in the English language from users based in the United States were included. Guided by previous research [9], we selected the following keywords to locate relevant posts on Instagram: "skin cancer" OR "melanoma" OR "basal cell carcinoma" OR "squamous cell carcinoma" OR "skin cancer awareness" OR #skincancer OR #melanoma OR #basalcellcarcinoma OR #squamouscellcarcinoma OR #skincancerawareness.

The initial search for our main sample yielded 2982 posts. We reordered the full set of posts descending from the highest number of "total interactions," defined by CrowdTangle as an indicator of engagement—total reactions, comments, and shares combined. We selected the top 1000 posts in terms of total interactions, and then used Research Randomizer [13] to produce a file with numbers 1 through 1000 in a random order. By merging this file with the sample of 1000 posts, each post was assigned a study number. By randomly ordering the sample of 1000 posts, this ensured that each coder would be assigned a set of posts with a variety of total interactions.

The following inclusion criteria for post content were assessed by the coders: (1) directly related to human skin cancer, (2) in the English language only, and (3) originating from the United States. Content mentioning skin cancer in animals was excluded. Of the sample of 1000 posts, 408 (40.8%) did not meet the inclusion criteria, resulting in an analytic sample of 592 (59.2%) Instagram posts.

### Codebook Development

Although there has been increased interest in applying machine learning methods to the analysis of social media data, it has also been suggested that these techniques may present challenges when applied to qualitative coding in social science research [14]. For this study, we developed a codebook through an iterative process, guided by previous social media content analytic research. The codebook included variables related to source and post characteristics, as well as the type of media used. Coded source characteristics included whether the Instagram account or profile represented an individual or organization. Individual profiles were coded according to



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self-identification (eg, influencer, parent, business owner, dermatologist, and esthetician). For organizational accounts, organization type was coded using information displayed in the user's profile or links embedded in the user profile or bio to the organization's website (eg, business, media outlet, health care organization, and nonprofit). [9,14]. Subsequently, the content was coded into 3 categories depending on whether it addressed (1) risk factors, (2) prevention, or (3) treatment [9,15]. For the citation source, we followed the classifications used by Walsh-Buhi et al [16] from a prior content analytic study that analyzed Instagram posts. Citation sources were classified as a cancer organization, health website, celebrity, the Centers for Disease Control and Prevention, or World Health Organization. A copy of the full codebook can be found in Multimedia Appendix 1.

### Pilot

Coding was conducted independently by 2 trained undergraduate students, in multiple stages, to assess the reliability of the codebook constructs. As a precursor to coding the final sample, the coders underwent a pilot stage, in which posts from the time period of February 24 to March 25, 2021, were downloaded. A total of 1173 posts were downloaded and sorted in descending order by "total interactions." The first 60 posts were used for coder training purposes and to provide additional insight on the reasons for exclusion/inclusion. Once this initial training took place, 35 posts were reviewed and coded by the 2 raters, of which 16 posts met our inclusion criteria. The 2 raters and a moderator met and held a discussion for 1-2 hours every 2 weeks to identify problematic variables and reach perfect agreement [17]. The codebook was revised following this pilot phase to incorporate feedback from the raters and make the definitions more accurate.

### Coding of the Main Sample

The sample for the main study was downloaded from CrowdTangle, including posts from the 30 days preceding May 14, 2021, as described above. The 2 undergraduate raters independently coded 250 posts each. Each rater double-coded 10% (n=25) of posts from the other rater's sample of 250 posts. Of the 50 posts double-coded by the raters, 45 met the inclusion criteria. Interrater reliability was assessed using Cohen κ statistics to determine the level of consistency in codes between each rater. Of the 66 codebook variables for which a Cohen κ could be calculated, 82% (n=54) of the variables resulted in a moderate or higher agreement. The median Cohen κ was 0.78, reflecting substantial agreement between the raters on identifying codebook constructs [17]. Another meeting was held to discuss and resolve the discrepancies and address problematic variables, resulting in a final codebook. The remaining study sample posts (n=500) were then coded.

### Ethical Considerations

Institution Review Board approval was not required as CrowdTangle only imports data from public accounts on Instagram.

## Results

### RQ1: What Are the Source and Content Characteristics of Posts Related to Skin Cancer?

Of the 592 posts that met the inclusion criteria, the sources of content originated from 2 different types of profiles. Profiles representing organizations (n=321, 54.2%) were slightly more common than individual accounts (n=256, 43.2%). For posts that could not be clearly classified as being derived from either an individual or organization, an "other" category (n=15, 2.5%) was selected.

As displayed in Table 1, influencers such as public figures or celebrities were more commonly represented in this sample of posts as a source of skin cancer information than physicians, dermatologists, and other sources. Although in the case of organizational profiles, those in the "Business" category (222/321, 69.2%) led over those with medical criteria such as health organizations and health information provider. The type of media included in the posts varied. Posts containing photos (315/592, 53.2%) were more common than posts containing infographics (233/592, 39.4%) or videos (85/592, 14.4%).

For posts that could not be clearly classified as being derived from either an individual or organization, an "other" category (15/592, 2.5%) was selected, and these posts were not included in Table 1.


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**Table 1.** Source characteristics of skin cancer–related posts on Instagram (N=577).

| Source characteristic[a] | Post, n (%) |
|---|---|
| **Content in the bio/profile or post of an individual (n=256)** | |
| Influencer or public figure | 152 (59.4) |
| Physician | 107 (41.8) |
| Dermatologist | 83 (32.4) |
| Parent | 51 (19.9) |
| Business owner | 37 (14.4) |
| Journalist | 14 (5.5) |
| Esthetician | 11 (4.3) |
| Nurse or other health worker | 4 (1.6) |
| Health educator | 2 (0.8) |
| **Content in the bio/profile or post of an organization (n=321)** | |
| Business | 222 (69.2) |
| Health information provider | 53 (16.5) |
| Nonprofit | 39 (12.1) |
| Health care organization | 34 (10.6) |
| News organization | 8 (2.5) |
| Government entity | 5 (1.6) |
| School | 1 (0.3) |

[a]Source characteristics for each broader type of profile (individual or organization) exceed 100% when added together because multiple categories may have been selected for a particular post (eg, a business and a health care organization).

### RQ2: To What Extent Are Different Types of Skin Cancer Covered on Instagram?

More than half (318/592, 53.7%) of the posts analyzed mentioned skin cancer generally but did not specify the type (Table 2). Melanoma (252/592, 42.6%) was the most mentioned type of skin cancer.

**Table 2.** Posts mentioning types of skin cancer on Instagram (N=592).

| Type of skin cancer | Post, n (%) |
|---|---|
| Skin cancer mentioned generally, but type was not specified | 318 (53.7) |
| Melanoma | 252 (42.6) |
| Basal cell carcinoma | 29 (4.9) |
| Squamous cell carcinoma | 29 (4.9) |

### RQ3: How Do Messages Frame Causes and Solutions Regarding Skin Cancer Causes, Treatments, and Prevention?

Just under half of all posts (271/592, 45.8%) included information regarding some kind of skin cancer risk factor. The “sun” was coded as the top named risk factor for skin cancer (227/271, 83.8%), followed by artificial tanning (eg, indoor tanning; 48/271, 17.7%) and genetics (15/271, 5.5%).

Information regarding prevention methods (404/592, 68.2%) was included in Instagram posts more often than risk factors (271/592, 45.8%). Within prevention methods, wearing sunscreen (280/404, 69.3%) was the most commonly mentioned method, followed by getting checked by a physician (131/404, 32.4%) and wearing protective gear/clothes (101/404, 25%; Table 3).


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**Table 3.** Posts discussing prevention methods of skin cancer (N=404).

| Prevention method | Post, n (%) |
|---|---|
| Wearing sunscreen | 280 (69.3) |
| Getting checked by a physician | 131 (32.4) |
| Wearing protective gear/clothes | 101 (25) |
| Self-examination | 50 (12.4) |
| Staying away from the sun | 41 (10.1) |
| Mentioning warning signs | 37 (9.2) |
| Not using tanning beds | 21 (5.2) |
| Using self-tanning products | 19 (4.7) |

### RQ4: To What Extent Do Instagram Posts on Skin Cancer Address the Susceptibility and Severity of Skin Cancer; Benefits and Barriers Associated With Diagnosis, Prevention, and Treatment; Call to Action; and Readers' Self-efficacy?

Table 4 displays the different type of posts revealed in the analyses. Posts addressing the benefits of skin cancer prevention (120/402, 29.9%) and encouraging readers to adopt a certain behavior (209/592, 35.3%) were heavily mentioned compared to posts discussing the prevalence (96/592, 16.2%) and the seriousness (75/592, 12.7%) of skin cancer. Only 4.9% (29/592) of the posts highlighted a specific diagnostic method. Of these 29 posts, 4 (14%) explained the specific benefit of the diagnostic method. The results showing the top mentioned hashtags are displayed in Table 5. Only 13.7% (81/592) of the posts provided some type of citation. Cancer organizations, health websites, and physicians were the top sources of citations, as displayed in Table 6.

**Table 4.** Types of content portrayed in Instagram posts.

| Content type[a] | Post, n (%) |
|---|---|
| Information urging readers to adopt a certain behavior (N=592) | 209 (35.3) |
| Benefits of skin cancer prevention (n=402) | 120 (29.9) |
| Prevalence of skin cancer (N=592) | 96 (16.2) |
| Seriousness of skin cancer (N=592) | 75 (12.7) |
| Diagnostic method (N=592) | 29 (4.9) |
| Benefit of diagnostic method (n=29) | 4 (13.8) |

[a]Due to skip logic in the extraction survey, some posts were not rated for certain content types.

**Table 5.** Top 10 hashtags appearing in the study sample posts (N=592).

| Hashtag | Number of mentions, n (%) |
|---|---|
| #skincancerawareness | 165 (27.9) |
| #skincancer | 134 (22.6) |
| #skincare | 98 (16.6) |
| #melanoma | 89 (15) |
| #sunscreen | 88 (14.9) |
| #skincancerawarenessmonth | 87 (14.7) |
| #melanomaawareness | 78 (13.2) |
| #melanomamonday | 76 (12.8) |
| #spf | 67 (11.3) |
| #dermatology | 65 (11) |



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**Table 6.** Types of sources cited in posts (N=81).

| Citation source | Post, n (%) |
|---|---|
| Cancer organization | 34 (42) |
| Health or web source (eg, WebMD) | 21 (26) |
| Physician | 14 (17) |
| Research community | 11 (14) |
| Centers for Disease Control and Prevention or federal organizations | 5 (6) |
| Celebrity | 3 (4) |
| World Health Organization | 2 (2) |

## Discussion

### Principal Findings

This study aimed to describe the content landscape of skin cancer on Instagram, specifically focusing on the content source and type of information posted by users. The study also reveals the themes of the posts in terms of skin cancer causes, diagnosis, and prevention methods. To the best of our knowledge, this is the first study to identify the sources of skin cancer content on Instagram.

Overall, slightly more content originating from organizational accounts was posted than content from accounts owned by individuals. Business-owned accounts (eg, Skin Store, Baby Bum) tended to post about skin cancer more than those of a medical background, such as health organizations or health information providers. Among individual account owners, influencers (not from a medical background) posted skin cancer–related content more than individuals who possessed medical expertise (eg, dermatologists, other physicians). The term *influencer* is considerably newer and can be defined as individuals who purposely use social media for advertising specific products and services. Influencers establish trust with their followers over time and successfully market to their customer base, leading to the presence of a new marketing method known as Influencer Marketing [18]. It is noteworthy to acknowledge the partnership between the beauty industry and social media in general [19], as celebrities and influencers play an important role in advertising for the beauty industry.

Although sunscreen promotion was the most commonly identified prevention method represented in Instagram posts (that discussed skin cancer prevention methods), such posts also contained other prevention methods included in prevention guidelines [20]. For example, getting a checkup from a physician, wearing protective clothes, and self-examinations were included in 33%, 25.4%, and 12.6% of the posts, respectively. Interestingly, other important prevention methods were infrequently mentioned in the reviewed posts, representing missed opportunities. For instance, one of the more critical prevention methods—avoiding ultraviolet (UV) radiation—was mentioned as staying away from the sun and not using tanning bed in only 10.3% and 4.8% of the posts, respectively. As exposure to UV radiation—from outdoor (ie, sun) and indoor (ie, tanning beds, lamps, or booths) light—is the most important risk factor for skin cancer [21,22], including a prevention focus in these areas might be beneficial in future skin cancer campaigns or interventions on social media. Moreover, as indoor tanning is prevalent among younger adults and women [23], it is critical that social media campaigns or interventions also focus their prevention messaging on tanning bed use.

Given that the majority of the posts originated from nonmedical accounts, it is concerning that only 13% of the posts in this sample cited their information from a credible source, such as a cancer organization. A behavioral intent study found that, of its participants, 91% said that online communities (such as Instagram) play a role in their health decisions [24]. Considering the percentage of people who report using these online platforms for health decisions, the scarcity of credible information seen in this sample is concerning. Misinformation on social media continues to be a public health challenge that needs to be addressed and combated [25] in future research.

### Comparison to Prior Work

In contrast to skin cancer content on Pinterest [14] and in Facebook groups [26], a higher percentage of posts in our sample included content about prevention and encouraging others to wear sunscreen than those discussing the risk factors. This aligns with previous research on Instagram and YouTube [9,27]. For example, Basch and Hillyer [9] similarly found a higher proportion of messages focused on prevention than risk, and they speculated that Instagram could serve as a health promotion tool, particularly among adolescents and young adults. This highlights the importance of studying individuals' behaviors on Instagram, and it is worth extending similar inquiries to other social media platforms as well.

### Limitations

As with other research, this study is not devoid of limitations. First, we were only able to collect information from publicly available Instagram accounts. Second, our inclusion criteria may have limited the generalizability of our results. For example, we only included content in English. We also excluded profiles that mentioned they were originating from a non–US-based location. A final potential drawback of this work may be limiting the study to only a single time period within the year. For example, the sample of Instagram posts was extracted during the month of May, which was Skin Cancer Awareness Month. Posts in Winter months may look different than those in spring and summer months, and we suggest that future research consider such possible issues of seasonality.


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### Strengths and Future Research Recommendations

Despite these limitations, this study has several strengths and implications. The study findings illuminated a paucity of medically credible sources related to skin cancer on Instagram, at least in our sample. For example, a relatively high percentage of the sources of skin cancer content in our sample were of a nonmedical nature. In addition, almost 90% of the skin cancer information in this sample was not backed by any credible citations, which is concerning. As linking health behavior to misinformation is difficult to observe, further research is needed to confirm that the spread of misinformation among users could lead to poor decision-making as it relates to skin cancer prevention, as well as public confusion [25,28].

Although Instagram is the most viewed social media platform regarding skin cancer [7], there are only a handful of studies addressing the potential of Instagram as a venue to reach out, educate, and increase public awareness regarding skin cancer. In this study, the results exposed the dominance of nonmedical skin cancer–related content on Instagram, raising concerns about the presence of misleading information. Future studies should deeply analyze content accuracy, what type of misinformation is currently spreading, and whether it is confined to causes or treatment or prevention methods. Furthermore, the findings from this study call on the medical community and public health officials to collaborate and provide leadership on these platforms. In addition, we ask them to work on more innovative and interactive techniques to engage with users and address their specific needs regarding skin cancer information, especially on key issues such as tanning bed use and avoiding other UV radiation.

### Thoughts on Possible Interventions

As a possible intervention strategy, given that influencers were prevalent in our sample, medical experts could partner with celebrities and influencers to lead awareness campaigns on skin cancer. In considering the overall presence of physicians on social media, dermatologists are among the top [29]. In fact, there are a few examples of medical influencers who have had a positive impact on skin cancer awareness. For example, Dr Sandra Lee, also known as Dr Pimple Popper [29], has had a strong reach with millions of followers and subscribers on Instagram and YouTube.

An example of a nonmedical celebrity who has raised awareness about skin cancer is Australian actor Hugh Jackman, who was diagnosed 6 times with basal cell carcinoma on his nose, which required a surgical treatment. Jackman took advantage of his popularity and used his social media platforms to advise followers regarding the risks of exposure to the sun by openly sharing his experience and medical process. This led to increased public awareness, verified by a spike in online searches for "Basal Cell Carcinoma" at the time of his skin cancer–related post [30].

### Conclusions

In summary, this study's findings highlight the potential role of Instagram as a platform for improving awareness of skin cancer risks and the benefits of prevention practices. As skin cancer remains one of the most common cancers in the United States [1,2], public health organizations must adopt innovative ways to educate and engage with priority populations via social media platforms. Given the popularity of social media and its potential as a cost-effective method for the dissemination of health information [31], it is crucial to study the users' engagement patterns and conversational themes around skin cancer across additional social media platforms to better understand the landscape of skin cancer narratives and how it can be used to guide the creation of customized messages and interventions that target user needs. We believe that social media is one of the most promising venues for researchers and dermatologists to dedicate their efforts and presence that can widely reach the public to educate about skin cancer and empower skin cancer prevention.


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## Conflicts of Interest

None declared.


Multimedia Appendix 1
Codebook.
[DOCX File , 54 KB - infodemiology_v2i1e34940_app1.docx ]

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## Abbreviations

**RQ:** research question
**UV:** ultraviolet


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Original Paper

# Spread of COVID-19 Vaccine Misinformation in the Ninth Inning: Retrospective Observational Infodemic Study

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## Abstract

**Background:** Shortly after Pfizer and Moderna received emergency use authorizations from the Food and Drug Administration, there were increased reports of COVID-19 vaccine-related deaths in the Vaccine Adverse Event Reporting System (VAERS). In January 2021, Major League Baseball legend and Hall of Famer, Hank Aaron, passed away at the age of 86 years from natural causes, just 2 weeks after he received the COVID-19 vaccine. Antivaccination groups attempted to link his death to the Moderna vaccine, similar to other attempts misrepresenting data from the VAERS to spread COVID-19 misinformation.

**Objective:** This study assessed the spread of misinformation linked to erroneous claims about Hank Aaron’s death on Twitter and then characterized different vaccine misinformation and hesitancy themes generated from users who interacted with this misinformation discourse.

**Methods:** An initial sample of tweets from January 31, 2021, to February 6, 2021, was queried from the Twitter Search Application Programming Interface using the keywords “Hank Aaron” and “vaccine.” The sample was manually annotated for misinformation, reporting or news media, and public reaction. Nonmedia user accounts were also classified if they were verified by Twitter. A second sample of tweets, representing direct comments or retweets to misinformation-labeled content, was also collected. User sentiment toward misinformation, positive (agree) or negative (disagree), was recorded. The Strategic Advisory Group of Experts Vaccine Hesitancy Matrix from the World Health Organization was used to code the second sample of tweets for factors influencing vaccine confidence.

**Results:** A total of 436 tweets were initially sampled from the Twitter Search Application Programming Interface. Misinformation was the most prominent content type (n=244, 56%) detected, followed by public reaction (n=122, 28%) and media reporting (n=69, 16%). No misinformation-related content reviewed was labeled as misleading by Twitter at the time of the study. An additional 1243 comments on misinformation-labeled tweets from 973 unique users were also collected, with 779 comments deemed relevant to study aims. Most of these comments expressed positive sentiment (n=612, 78.6%) to misinformation and did not refute it. Based on the World Health Organization Strategic Advisory Group of Experts framework, the most common vaccine hesitancy theme was individual or group influences (n=508, 65%), followed by vaccine or vaccination-specific influences (n=110, 14%) and contextual influences (n=93, 12%). Common misinformation themes observed included linking the death of Hank Aaron to “suspicious” elderly deaths following vaccination, claims about vaccines being used for depopulation, death panels, federal officials targeting Black Americans, and misinterpretation of VAERS reports. Four users engaging with or posting misinformation were verified on Twitter at the time of data collection.



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**Conclusions:** Our study found that the death of a high-profile ethnic minority celebrity led to the spread of misinformation on Twitter. This misinformation directly challenged the safety and effectiveness of COVID-19 vaccines at a time when ensuring vaccine coverage among minority populations was paramount. Misinformation targeted at minority groups and echoed by other verified Twitter users has the potential to generate unwarranted vaccine hesitancy at the expense of people such as Hank Aaron who sought to promote public health and community immunity.

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**KEYWORDS**

infoveillance; infodemiology; COVID-19; vaccine; Twitter; social listening; social media; misinformation; spread; observational; hesitancy; communication; discourse

## Introduction

On January 5, 2021, Major League Baseball (MLB) legend and Hall of Famer, Hank Aaron, publicly received his first dose of the Moderna vaccine series at Morehouse School of Medicine in Atlanta, Georgia, USA. Two weeks later, he passed away at the age of 86 years due to natural causes. Following his death, a prominent antivaccine activist and founder of a known antivaccine group posted information on the popular microblogging site Twitter, which claimed an unfounded link between Aaron's death and the COVID-19 vaccine [1]. This claim was erroneously based on reports of elderly deaths following COVID-19 vaccination reported into the Vaccine Adverse Event Reporting System (VAERS). VAERS, established in 1990, is a public US database and passive reporting system comanaged by the US Centers for Disease Control and Prevention and the Food and Drug Administration, where individuals can submit vaccine adverse event reports without clinical verification. Data provided by VAERS has been increasingly used by antivaccine advocates to spread misinformation [2]. This database has also seen increased reports since COVID-19 vaccines received emergency use authorization from the Food and Drug Administration [2].

In this retrospective observational event-driven infoveillance study, we sought to characterize public user reaction to the death of Hank Aaron on Twitter for purposes of expanding the literature on minority-specific COVID-19 misinformation topics as detected on social media platforms. Twitter was chosen for this study because previous research has shown that misinformation, and specifically vaccine-related misinformation and disinformation (including general antivaccination topics, misinformation about non–COVID-19 vaccines, and misinformation specific to COVID-19 vaccines), is prominent on the platform [3-8]. Additionally, information and news reports about both Aaron's initial vaccination and his death were shared on Twitter making it an ideal platform to further explore user interaction, sentiment, and dissemination of this content.

For example, a study conducted in 2021, which followed approximately 138 million tweets from a set of specific antivaccine-related keywords and accounts known to post antivaccine narratives detected large thematic clusters containing debunked claims and conspiracies along with misinformation originating from noncredible sources [7]. Another study, which examined 1.8 million vaccine-related tweets collected from 2014 to 2017, used topic modeling to identify 22% of their data set as containing antivaccine sentiment [5]. In response to growing concerns and studies identifying misinformation content, Twitter changed its content moderation policies during the COVID-19 pandemic, including, but not limited to, applying labels to tweets that contain vaccine misinformation, removing misleading content deemed to be harmful to the public, and suspending user accounts for posting COVID-19 and vaccine-related misinformation on a 5-strike system [8-10].

Hence, the primary objective of this study was to identify and characterize the impact of a specific event and assess whether it generated different types of vaccine-related misinformation. We also sought to understand the types of users who disseminated and amplified this misinformation, the overall sentiment of users toward vaccines, and if this social media-based dissemination influenced other online users' attitudes and beliefs about COVID-19 vaccine hesitancy and confidence. A subanalysis of this study also focused on whether specific online minority user populations and verified Twitter accounts were also active and engaged in this misinformation discourse.

## Methods

### Data Collection

The Twitter Search Application Programming Interface (API) allows for the retrospective collection and return of a collection of relevant tweets meeting a specific search criterion (such as certain keywords, hashtags, or account handles) within a specific period. We used the v1.1 Twitter Search API, which allowed for simple queries against the indices of recent and popular tweets up to a maximum of 7 days and behaved similarly to, but not exactly like the Search User Interface feature available in Twitter mobile and web clients [11]. Tweets and user comments associated with the keywords "Hank Aaron" and "vaccine" were queried with the Twitter Search API from January 31, 2021, to February 6, 2021 (the week immediately following the death of Hank Aaron), hereinafter referred to as the "Initial Sample." This time frame was chosen based on previous literature that has shown that Twitter users generally have a circaseptan (7 day) pattern for negative and positive sentiment in response to information on Twitter, with other similar COVID-19 misinformation research on the platform using similar data collection time frames [12,13]. From tweets collected in the Initial Sample, the authors manually coded for tweets relevant to vaccine misinformation (as detailed in the "Theoretical Framework" and "Content Coding" sections below) and then identified an additional set of Twitter direct user



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comments that interacted with these tweets for further analysis, hereinafter referred to as “Seeded Sample.” Data collection was not limited to tweets in the English language. Tweets were also detected in Spanish, Turkish, Japanese, Portuguese, German, Slovenian, and Dutch. However, non-English tweets comprised less than 1% of the total corpus of the initial tweets reviewed. Google Translate was used to translate and interpret non-English tweets.

## Theoretical Framework

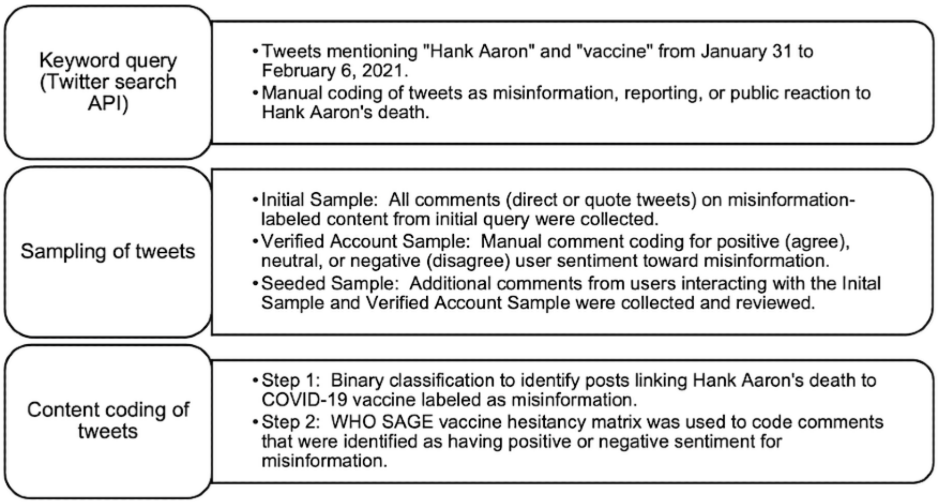
The World Health Organization’s (WHO) Strategic Advisory Group of Experts (SAGE) Working Group Vaccine Hesitancy Matrix was the underlying theoretical framework for data coding and classification [14]. This framework includes groupings for contextual influences, individual and group influences, and vaccine or vaccination-specific issues, including those specific to misinformation and disinformation. In this study, we were interested in user-propagated misinformation that fell under contextual influences and a SAGE subcategory entitled “Influential leaders, immunization program gatekeepers, and anti- or pro-vaccination lobbies.” Other data labels included news media and public reactions, which fell under contextual influences that were split from the subcategory entitled “Communication and media environment.”

## Content Coding

The Initial Sample of tweets were manually coded by authors AC, MH, and a team member no longer with the research team as (1) reporting or news media, (2) public reaction, or (3) misinformation, if they attempted to link the death of Hank Aaron with administration of the Moderna COVID-19 vaccine. All Twitter comments (direct or quote tweets) originating from misinformation-labeled content were then further classified and coded for purposes of content analysis using an inductive coding scheme based on the WHO SAGE Vaccine Hesitancy Matrix [14]. To minimize any potential repetition between the parent tweet and associated comment tweets, we conducted additional data filtering to identify direct replies and quote tweets that were exact matches, which comprised of only 2 instances in the entire corpus. To minimize loss of context between the parent and comment tweets, we nested all comments under its respective parent tweet for the purposes of content coding and contextual relevance. All tweets included in the subset of misinformation-labeled and SAGE-coded tweets were assessed for user sentiment (eg, negative [disagree], neutral, or positive [agree] sentiment) via manual annotation. From the Initial Sample, we also identified nonmedia accounts in the corpus, which were “Verified” by Twitter (“Verified Account Sample”), and reviewed historical posts from their Twitter timelines occurring after March 2020 (when COVID-19 was declared a national emergency in the United States) to assess for the presence of additional COVID-19 vaccine misinformation content or SAGE-relevant themes, a methodology similar to what was used in a prior COVID-19 vaccine misinformation study [7].

Finally, after manually confirming misinformation or SAGE-related content in the Initial Sample and Verified Account Sample, an additional set of comments from Twitter users interacting with this misinformation content was collected and reviewed for additional misinformation and hesitancy themes (ie, “Seeded Sample”), similar to a snowball sampling approach. Content coding for the Seeded Sample was conducted in August 2021 by author MH and a team member no longer with the research team. Both coders had previous experience and prior publications involving annotation of COVID-19 misinformation-related data and achieved a high intercoder reliability (kappa=0.83) for misinformation codes with discrepancies reviewed and reconciled by rereviewing SAGE categories with all authors [8,15]. A summary of the Twitter sampling and coding methodology is available in Figure 1. A list of the sample positive, neutral, and negative lexicons and terms used specifically for the purposes of manual annotation for sentiment analysis is available in Textbox 1.

**Figure 1.** Twitter sampling and coding methodology. API: Application Programming Interface; SAGE: Strategic Advisory Group of Experts; WHO: World Health Organization.





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**Textbox 1.** List of representative positive, neutral, and negative lexicons and terms.

**Positive lexicon and terms (agree)**

- “Not a coincidence” or “Not isolated”
- “Wake up”
- “No vaccine” (Action) or “I will not [get vaccinated]”
- “Exploited”

**Neutral lexicon and terms**

- “So sorry”
- “RIP”
- “[@ mention] Did you see this [The Event]?”
- “<3”

**Negative lexicon and terms (disagree)**

- “Correlation is not causation”
- “Don’t rush”
- “Shame on you”
- “Natural causes”

### Ethical Considerations

In an increasingly digital and globalized world, it is important to consider the challenges that arise when considering user consent, privacy, and social media data use [16]. There does not appear to be clear consensus regarding the proper use of these data, particularly important when assessing the impact of content that may target certain minority populations at higher risk for poorer health outcomes or who may already be underresourced in relation to digital literacy and access to high quality information sources or may lack access to equitable health care services or vaccine coverage [17,18]. It also applies to the analysis of verified accounts with user celebrities and public figures that may actively disseminate questionable information to large numbers of followers. These verified users may have a disproportionate impact on communication dynamics but are not specifically named in this study due to anonymization of results. The utility of infodemiology-informed approaches to rapidly assess emerging public health concerns, such as the infodemic and its associated misinformation-related events, should not minimize these ethical considerations [19]. Hence, one objective of this study was to identify content-specific misinformation themes that may be relevant to a specific population of users but not to overgeneralize findings beyond the exploratory nature of this study and the specific event characterized. We believe results from studies that examine sensitive topics impacting minority health on social media platforms need careful contextualization, otherwise they may risk further eroding public trust among groups already hesitant to engage with biomedical, informatics, and social science researchers.

All information collected from this study was secondary data in the public domain, and the study did not involve any interaction with users. Any user-identifiable information was removed from the study results.

### Funding

Author TKM was supported by funding from the US Food and Drug Administration Office of Minority Health and Equity contract number 75F401120C00181.

## Results

A total of 436 tweets were returned from the Twitter Search API based on our keyword query that made up our Initial Sample of tweets collected for this study. After a first round of manual coding for misinformation content per the SAGE categories, vaccine misinformation was found to be the most prominent content type detected (n=244, 56%), followed by public reaction about Hank Aaron’s death from users that did not include misinformation content (n=122, 28%), and media reporting of the event itself (n=69, 16%). Twitter user accounts disseminating or interacting with misinformation-labeled content included verified users with large numbers of followers relative to the entire group of users in the sample (25,000-200,000). Using publicly available profile metadata (ie, user account descriptions and biographies), several verified Black celebrities with large follower counts, including a singer and songwriter, a former National Basketball Association player, a current MLB player, and a former Congressional candidate, were identified as disseminating or interacting with misinformation-labeled content or had a history of posting COVID-19 vaccine-related misinformation and SAGE-identified hesitancy themes during the COVID-19 pandemic (Table 1; deidentified tweet examples and interactions are shown in Figure 2). The majority of users in our Initial Sample were nonverified and had much lower follower counts (mean=2539, max=87,505, min=0) compared with the Verified Account Sample. Notably, none of the misinformation-labeled content reviewed at the time of our content analysis in the Initial Sample or Verified Account Sample was labeled as misleading by Twitter as defined by the



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platform's COVID-19 misleading information policy. However, some content has been removed or deleted since initial data collection.

An additional 1243 comments, mostly consisted of quote tweets (n=852, 68.5%) from 973 unique users interacting with misinformation-labeled content, were then collected in the Seeded Sample, with 779 total comments included for analysis after determining that they had some degree of positive or negative sentiment toward misinformation. The majority of these comments expressed positive sentiment or agreement (n=612, 78.6%) with misinformation-labeled content and did not refute it. Common misinformation themes observed included linking the death of Hank Aaron to "suspicious" elderly deaths following vaccination, misinterpretations of VAERS data, claims that federal officials were targeting Black Americans, and other widely espoused and debunked COVID-19–related conspiracies such as depopulation, death panels, and mainstream media collusion with pharmaceutical companies and billionaires such as Bill Gates having sinister motives.

**Table 1.** Examples of deidentified misinformation content and Strategic Advisory Group of Experts vaccine hesitancy themes from verified Twitter users.

| Occupation | Follower count, n | Vaccine misinformation tweets detected during COVID-19 (n) | Vaccine misinformation content | WHO[a] SAGE[b] vaccine hesitancy themes |
|---|---|---|---|---|
| Singer-songwriter | 25,000-200,000 | Yes (<5) | Doctor's suspicious death after vaccine, concern about vaccine ingredients | Perception of the pharmaceutical industry |
| Current MLB[c] player | 25,000-200,000 | Yes (<5) | Bio-encoded vaccination history placed in the body, Hank Aaron was targeted, vaccines are forced upon less educated communities, agreeing with comments from Del Bigtree, a known anti-vaxxer. | Vaccine development, historical influences, risk outweighs benefit |
| Former NBA[d] player | 25,000-200,000 | Yes (>5) | DNA replacement, engineered SARS-CoV-2 mutants, sterilization, Satanism, depopulation, tracking chips, Bill Gates, Anthony Fauci, Hank Aaron | Vaccine safety, media environment, historical influences, politics |
| Former Congressional candidate | 25,000-200,000 | Yes (>5) | Rushed development, celebrities receive "safe" vaccines, misrepresented survival rate, supporting misinformation from Rep. Marjorie Taylor Green, questioning death of Earl Simmons (aka DMX) | Vaccine development, historical influences, risk outweighs benefit, media environment |

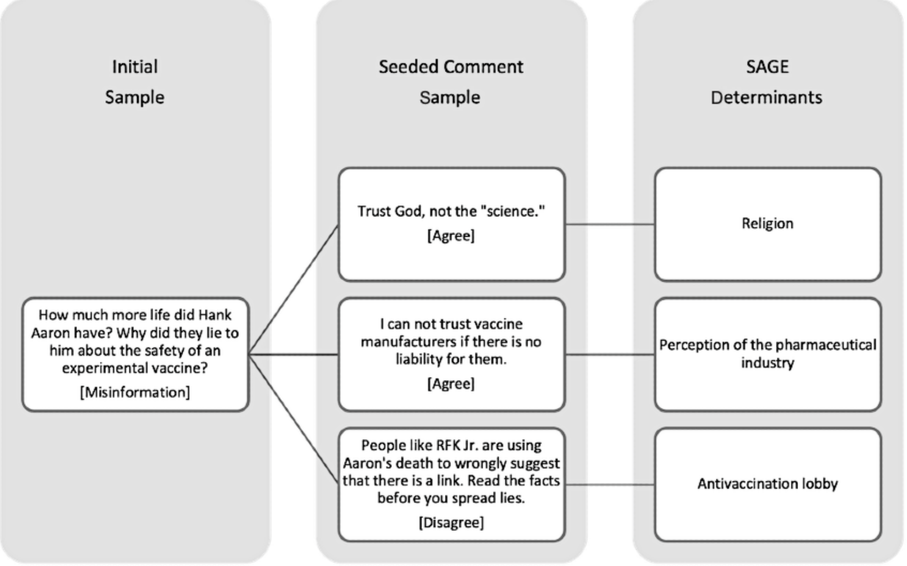
[a]WHO: World Health Organization.

[b]SAGE: Strategic Advisory Group of Experts.

[c]MLB: Major League Baseball.

[d]NBA: National Basketball Association.

**Figure 2.** Deidentified example of misinformation spread and impact on vaccine confidence using Strategic Advisory Group of Experts (SAGE) determinants.




Based on the SAGE categories for vaccine hesitancy in these user reactions to our Initial Sample of misinformation posts, 12% (n=93) of comments mentioned contextual influences (eg, sociocultural, historic, and media environment), 65% (n=508)



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mentioned individual and group influences (eg, personal or peer perceptions of vaccine), and 14% (n=110) mentioned vaccine-specific issues (eg, concerns about mode of administration). Only 9% (n=70) of comments were not classified within the SAGE misinformation or hesitancy categories. Deidentified examples of identified SAGE categories for each of the above categories are provided in Table 2. Additionally, Figure 2, illustrates the interaction components between misinformation occurring in the Initial Sample, user agreement or disagreement in the Seeded Sample, and the corresponding SAGE vaccine misinformation or hesitancy category.

**Table 2.** Deidentified and paraphrased examples of tweets with detected Strategic Advisory Group of Experts themes.

| Category and determinants | Example tweets (paraphrased) |
|---|---|
| **Contextual** | |
| Communication and media environment | You already do not see real information in the media. How can we address this? I am tired of not seeing the real information. |
| Historical influences | It‘s okay to be hesitant. Tuskegee, thalidomide, and the 1976 swine flu vaccine. Old vaccine manufacturers were sued, but COVID-19 vaccine manufacturers have no liability. |
| Politics | Vaccinated and dead two weeks later, but Biden supporters will tell you he was just old. |
| **Individual or group** | |
| Risk or benefit | Hank Aaron got the [COVID-19] vaccine. It is too risky to receive it right now. |
| Providers’ trust | Doctors who say no one dies from taking the [COVID-19] vaccine are lying. They never tell the truth. |
| Immunization is not needed | Give an alternative to the vaccine like vitamins and zinc. |
| **Vaccine or vaccination-specific** | |
| Attitude of health care professionals | They are getting everyone to get Black people to vote, even Black doctors to help convince Black people to get vaccinated. Insulting. Culture, not racism, is the issue for Black people. |
| Introduction of a new vaccine | Vaccines help prevent disease, but can still be dangerous, especially if they are new. |
| Design of vaccination program | This vaccine was rushed and was not texted for years. They should not do vaccine mandates, otherwise this will be a problem. |

# Discussion

## Principal Findings

Understanding the drivers of vaccine hesitancy in certain demographic and minority groups will be crucial in stopping the spread of the COVID-19 pandemic, especially as the world experiences vaccine inequity and variant-specific surges that disproportionately impact certain populations. Vaccine hesitancy is complex, influenced by contextual, individual and group-level, and vaccine or vaccination-specific factors that may be specific to minority groups or communities [20]. In this study, we observed a high proportion of interaction with COVID-19 misinformation specific to Black Americans that could unduly influence vaccine confidence and increase hesitancy in this heterogenous community. The untimely death of Hank Aaron, a celebrated Black athlete who expressed his public support for vaccination, was instead appropriated by antivaccination groups to spread misinformation. We observed that antivaccination actors quickly seized on the news of Hank Aaron’s death to advance dubious claims questioning the safety of COVID-19 vaccines. We also observed several celebrities from the Black community participating in misinformation dissemination before and during the events described in this study.

The WHO has named vaccine hesitancy and the COVID-19 infodemic as a critical global health issue, as it threatens to undermine one of the most important public health tools that can curb rising cases amid the spread of concerning variants, including among disproportionately impacted minority populations [21]. The US Surgeon General has also called attention to rampant COVID-19 misinformation on social media platforms, which may further contribute to vaccine hesitancy and lack of uptake (including for boosters), especially in communities with a high Centers for Disease Control and Prevention social vulnerability index, where individuals may be at higher risk of COVID-19 incidence, hospitalization, morbidity, and mortality [22,23]. It is important to recognize that misinformation from antivaccination groups has the potential to compound medical mistrust and vaccine hesitancy by advancing false narratives based on erroneous and misleading information [24,25].

Our study detected high activity of dissemination of misinformation associated with Hank Aaron’s death primarily originating from well-known antivaccination individuals, which were not labeled by Twitter as “misleading” at the time of review. By not labeling this content, this may have allowed for rumors around the death of Hank Aaron to be shared and modified by users concerned about the reasons for his death and may have also seeded further misinformation and conspiracies concerning deaths of other prominent Black Americans or public figures. This study ultimately found that misinformation compounded individual and community-level concerns about COVID-19 vaccines at a time during their crucial early adoption. These concerns were more prominent within the social media discourse surrounding Hank Aaron’s death compared to the contextual-level (eg, media environment) or vaccination-specific concerns (eg, adverse effects). This suggests that social media and other online forums may not be the



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opportune venue to promote vaccine confidence and debunk misinformation unless health promotion is targeted and contextualized to the attitudes, beliefs, and unique contextual factors of different user groups [26].

In fact, Twitter accounts from prominent well-known antivaxxer personalities, where some of the misinformation-labeled content originated in this study, remain active at the time of writing, though some US policy makers have called for accounts from the so-called "Disinformation Dozen" to be suspended from major social media platforms [27,28]. Our results also align with prior studies that have examined COVID-19 vaccine-related misinformation and found that user engagement with this content can have a direct impact on vaccine confidence, highlighting the need for stronger misinformation-specific content moderation policies coupled with more robust and consistent enforcement of new and existing policies [29,30].

## Limitations

There are several limitations to consider in this study. First, in the data collection phase, we requested a maximum of 1000 tweets from January 31, 2021 (start: 9 days after Hank Aaron's death) to February 6, 2021 (end: 16 days after Hank Aaron's death), using the Twitter Search API. This query with a narrow, but specific set of keywords returned a relevant sample of 436 tweets, but the use of additional keywords (eg, MLB, baseball player) or a longer data collection period may have yielded additional tweets that may have been different for the purposes of content analysis. Hence, the results of our study are likely not generalizable to this specific infodemic event. Instead, the objective of this study was to generate an initial sample of tweets directly relevant to Hank Aaron's untimely passing and then obtain a larger sample of user comments, interactions, and dissemination behavior by digitally "snowballing" this initial sample into additional Twitter user-generated discussions. This approach may be useful for in-depth characterization of narrow event-driven infodemic detection but has limited generalizability compared to larger scale studies that employ approaches using topic modeling, natural language processing, and supervised machine learning. Additionally, our use of follower counts in the Verified Account Sample has limitations associated with its ability to characterize misinformation dissemination as it may not reflect users' actual activities. A full social network analysis of our data set may have better elucidated communication structures (eg, information flow) and active user groups but was beyond the scope of this study [31,32]. Specifically, this analysis might have identified influential users in the Hank Aaron misinformation discourse, though for this study, we chose to focus on user sentiment to provide a more in-depth characterization of misinformation themes given the generally small size of the overall study data set (ie, both the Initial Sample and Seeded Sample). Future event-driven studies should explore the use of social network analysis and active audience analysis to measure user influence and message diffusion more robustly on social media platforms, particularly with viral misinformation content [33].

## Conclusion

Close to half a year after his passing, we continued to observe misinformation surrounding Hank Aaron's death propagating on social media networks. Other deaths of prominent African American people (eg, rapper Earl Simmons, "DMX") have also been erroneously connected with the COVID-19 vaccine by similar antivaccination groups. Hence, the real-world impact of misinformation on vaccine confidence and hesitancy in minority communities, both online and offline, needs to be addressed urgently, as the legacy of changemakers such as Hank Aaron should be about his accomplishments on and off the field, not a field of misinformation.

## Acknowledgments

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## Data Availability

Deidentified data with applicable Twitter identifications are available from authors upon request.

## Disclaimer

The opinions expressed are those of the authors alone.

## Conflicts of Interest

TKM is an employee of the start-up company S-3 Research LLC. S-3 Research is a start-up funded and currently supported by the National Institutes of Health, National Institute of Drug Abuse through a Small Business Innovation and Research contract for opioid-related social media research and technology commercialization. The authors report no other conflict of interest associated with this manuscript.

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## Abbreviations

**API:** Application Programming Interface
**MLB:** Major League Baseball
**SAGE:** Strategic Advisory Group of Experts
**VAERS:** Vaccine Adverse Event Reporting System
**WHO:** World Health Organization

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Original Paper

# Partisan Differences in Legislators' Discussion of Vaccination on Twitter During the COVID-19 Era: Natural Language Processing Analysis

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## Abstract

**Background:** The COVID-19 era has been characterized by the politicization of health-related topics. This is especially concerning given evidence that politicized discussion of vaccination may contribute to vaccine hesitancy. No research, however, has examined the content and politicization of legislator communication with the public about vaccination during the COVID-19 era.

**Objective:** The aim of this study was to examine vaccine-related tweets produced by state and federal legislators during the COVID-19 era to (1) describe the content of vaccine-related tweets; (2) examine the differences in vaccine-related tweet content between Democrats and Republicans; and (3) quantify (and describe trends over time in) partisan differences in vaccine-related communication.

**Methods:** We abstracted all vaccine-related tweets produced by state and federal legislators between February 01, 2020, and December 11, 2020. We used latent Dirichlet allocation to define the tweet topics and used descriptive statistics to describe differences by party in the use of topics and changes in political polarization over time.

**Results:** We included 14,519 tweets generated by 1463 state legislators and 521 federal legislators. Republicans were more likely to use words (eg, "record time," "launched," and "innovation") and topics (eg, Operation Warp Speed success) that were focused on the successful development of a SARS-CoV-2 vaccine. Democrats used a broader range of words (eg, "anti-vaxxers," "flu," and "free") and topics (eg, vaccine prioritization, influenza, and antivaxxers) that were more aligned with public health messaging related to the vaccine. Polarization increased over most of the study period.

**Conclusions:** Republican and Democratic legislators used different language in their Twitter conversations about vaccination during the COVID-19 era, leading to increased political polarization of vaccine-related tweets. These communication patterns have the potential to contribute to vaccine hesitancy.

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**KEYWORDS**

social media; Twitter; vaccination; partisanship; COVID-19; vaccine; natural language processing; NLP; hesitancy; politicization; communication; linguistic; pattern

## Introduction

As of December 2021, the COVID-19 pandemic has resulted in over 45 million infections and 780,000 deaths in the United States [1]. Despite the high death toll attributed to the pandemic and the emergence of safe and effective vaccines, vaccine hesitancy, particularly in Republican-leaning states, remains a significant obstacle to achieving the estimated 70% population immunity required to reach herd immunity [1-3].

It has been hypothesized that this geographic variation in vaccination may be the result of the politicization of public health topics during the COVID-19 pandemic [4]. Survey evidence from early in the pandemic suggests that such politicization may have resulted in members of the public interpreting COVID-19–related risk and adopting preventive health measures in partisan ways [5]. Consistent with these findings, geolocation data have revealed lower rates of social distancing in counties that supported Donald Trump in the 2016 election compared with counties that did not [6]. There is also evidence that these partisan differences extend to opinions about the SARS-CoV-2 vaccine. Prior research has established lower rates of vaccination among Republicans compared with those of Democrats and has found that this partisan gap in vaccination increased throughout the COVID-19 pandemic [7,8]. This gap is not explained by demographic differences, differences in institutional trust, or differences in the level of concern about the pandemic, suggesting that partisan identity, in and of itself, may be informing individuals' health care decisions and driving differences in vaccine sentiment [7].

The politicization that has characterized the COVID-19 era is especially concerning because there is evidence that politicized vaccine-related communication may contribute to vaccine hesitancy [9-12]. For example, a study of human papillomavirus (HPV) vaccination found that exposure to real-world politicized discussion about the vaccine was associated with decreased support for immunization programs and reduced trust in doctors and government [9]. A similar experimental study found that respondents exposed to a news brief that included political conflict about the HPV vaccine were less likely to support a vaccine mandate compared with those exposed to a news brief without controversy [10]. Other studies have found similar associations between politicized discussion of vaccination and decreased support of vaccine mandates and intention to vaccinate [11,12]. These findings suggest that the language politicians use to communicate with their constituents about vaccination during the COVID-19 pandemic may play an important role in determining vaccine uptake.

The existing research has established partisan differences in the way that political figures communicated with the public about SARS-CoV-2 [13-15]. Much less research projects, however, have examined communication from political leaders about vaccination (and partisan differences in that communication) during the COVID-19 pandemic. This is an important gap in the literature for several reasons. First, experimental evidence suggests that politicians' Twitter activity and communication with the public not only reflect the opinions of constituents but also have the ability to shape the vaccine perspectives of their followers [16,17]. For example, a study using tweets from former President Trump found that exposure to antivaccine tweets generated by Trump led to an increase in vaccine concern among his followers [17]. Communication about vaccination from state and federal legislators is also of particular importance given that, in addition to communicating with their constituents, these legislators enact policies that impact vaccine development and distribution. Despite the importance of legislators' communication about vaccination to the public, existing research on vaccine-related Twitter activity has primarily focused on partisan trends among the general public. No prior research has characterized the vaccine-related Twitter activity of state and federal legislators or partisan differences in such communications during the COVID-19 vaccine development process.

We previously found that the arrival of the COVID-19 pandemic was associated with a dramatic increase in the volume of legislator's vaccine-related tweets [18]. Here, we build on that previous work by characterizing the content, not just the volume, of Twitter discourse about vaccination from legislators during the COVID-19 vaccine development process. The objective of this study was to examine vaccine-related tweets produced by state and federal legislators during the COVID-19 era to (1) describe the content of vaccine-related tweets; (2) examine differences in vaccine-related tweet content between Democrats and Republicans; and (3) quantify (and describe trends over time in) partisan differences in vaccine-related communication.

## Methods

### Data

We used Quorum, a public affairs software platform that stores policy-related documents, to gather all vaccine-related tweets produced by state or federal legislators between February 1, 2020, and December 11, 2020. We defined February 1, 2020, as the arrival date of COVID-19 in the United States based on the United States' declaration of a public health emergency (January 31, 2020) and restriction of global air travel (February 2, 2020) [19]. We selected December 11, 2020, as the endpoint of our data collection because it was the date of the first Food and Drug Administration emergency use authorization for a COVID-19 vaccine [19]. While some legislators maintain both personal and professional Twitter accounts, only the tweets generated from professional Twitter accounts were used in this study.

We defined tweets as vaccine-related if they contained any of the following terms in the body of the tweet or retweet: "vaccine," "vaccination," "immunization," "vax(x)," "antivax(x)," "anti-vax(x)," "antivax(x)er," "anti-vax(x)er," "vax(x)ine," "in(n)oculate," "in(n)oculation." This term list was



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generated based on a review of search terms in the existing literature about vaccine sentiment on Twitter [20-22]. One author manually reviewed all tweets generated by this search, and any tweets that were unrelated to human vaccination were removed. This study was exempt from Institutional Review Board approval due to the public availability of the data.

### Measures

Legislators' political party was abstracted from Quorum. Tweets were defined as related to COVID-19 if they contained a word or phrase related to the disease (eg, "coronavirus" or "SARS-CoV-2"). Tweets were defined as discussing a non–COVID-19 disease if they mentioned any infectious disease other than COVID-19 (eg, "MMR" or "influenza"). A complete list of infectious disease-related terms used in the data set was compiled during a manual review of the data and was used to build these variables (Multimedia Appendix 1). We used tweet topics to quantify the political polarization of vaccine-related communication by calculating the sum of the absolute difference in topic prevalence for all tweet topics per month, as previously described [23].

### Descriptive and Bivariate Analysis

We used summary statistics to describe tweet frequency and characteristics of included tweets (ie, mentions of COVID-19 versus non–COVID-19 infectious diseases, the percent of tweets generated by each political party, and the frequency of tweets versus retweets). In order to further characterize differences in vaccine-related Twitter activity between Republicans and Democrats, we used chi-square tests to describe the relationship between political party and tweet characteristics. The tweet characteristics examined in this study were (1) mentions of COVID-19 versus non–COVID-19 infectious disease and (2) whether each tweet was an original tweet or a retweet. Descriptive analyses were conducted using Stata statistical software, version 16.1 (Stata Corp).

### Natural Language Processing Analysis

We identified all words and 2-word phrases appearing with a frequency of at least 0.1% across tweets by Democrats or Republicans. We used chi-square testing ($P$ value cut-off of Bonferroni corrected $P<.001$) to identify words used with significantly different frequency between the 2 parties. We plotted words by frequency of use in Democrat versus Republican tweets (Figure 1). To account for language changes that occurred within the COVID-19 era, we repeated this process for all 3 waves of the COVID-19 pandemic (Multimedia Appendix 2). We defined the start and end dates of each wave based on the nadir of the 7-day moving average of new cases in the United States [24].

In order to describe trends in tweet content over time, we used latent Dirichlet allocation (LDA) to define the topic or topics of each tweet [25]. LDA is a topic modeling approach that defines topics based on cooccurring words across tweets, excluding common words. The number of topics defined by LDA (in this case, 25) was selected iteratively through a combination of algorithmic coherence scores and manual review of topic interpretability, conducted by 2 authors. Each tweet could then be described by a unique probability distribution of the 25 topics.

Three authors evaluated each topic by manually reviewing the 10 words and 10 tweets most closely associated with that topic. The topics that all 3 authors agreed had a coherent meaning were included in the final analysis (20 topics total). To confirm topic interpretability, 3 authors manually checked each of these 20 topics against an additional 20 randomly selected tweets associated with each topic [23]. We used summary statistics to describe mean topic representation, defined as the mean topic probability across all tweets from a given party and time period and multiplied by 100%. We used Wilcox signed-rank tests ($P$ value cut-off of Bonferroni corrected $P<.001$) to compare mean topic representation by political party. We conducted natural language processing analyses and generated figures using R version 4.0.3 (R Foundation for Statistical Computing).


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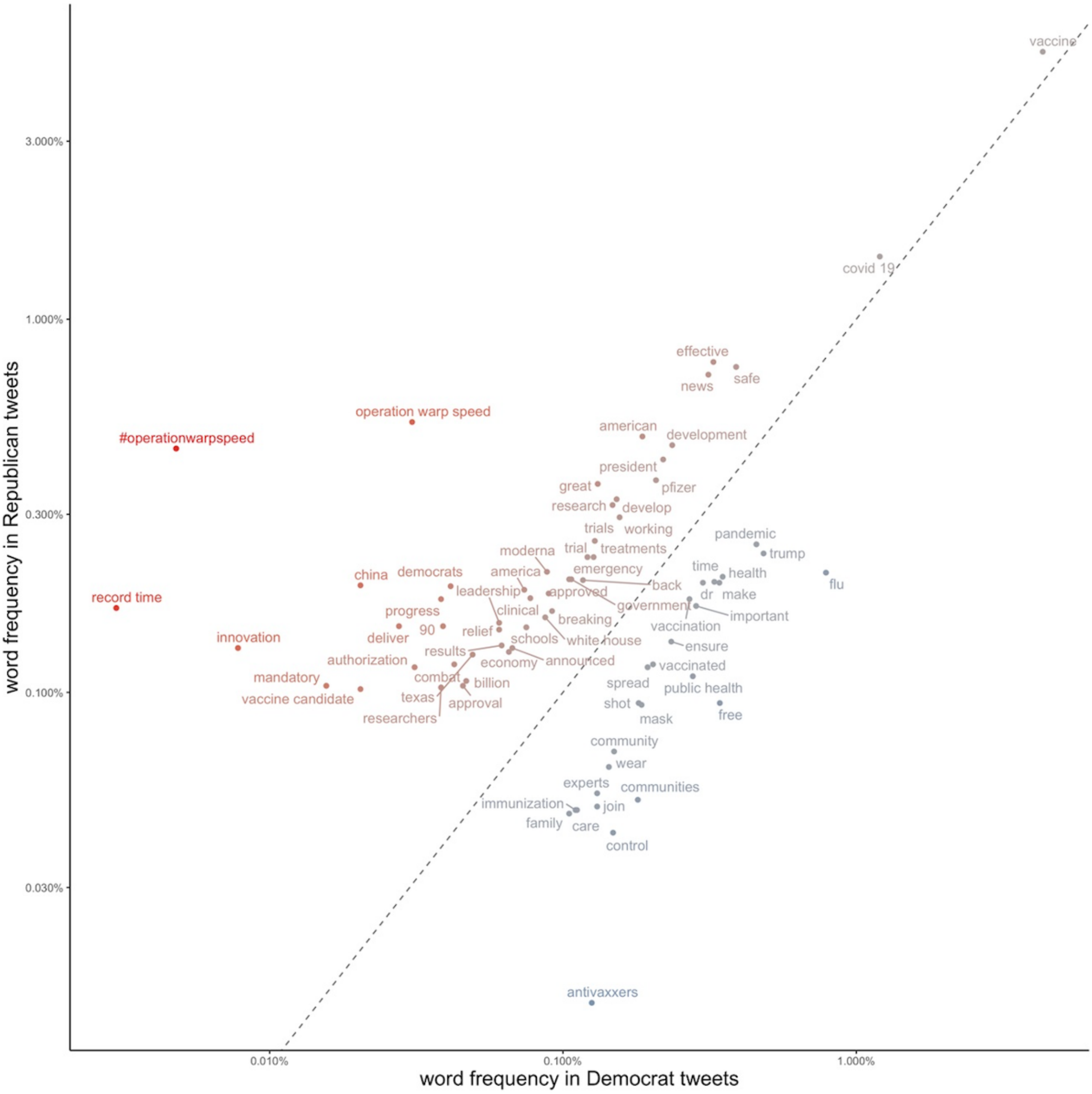
**Figure 1.** Word and term frequency in vaccine tweets for Democrats vs Republicans.




## Results

We included a total of 14,519 vaccine-related tweets. Of these tweets, 61.8% (n=8968) were generated by Democrats, 37.2% (n=5401) were generated by Republicans, and 1.0% (n=150) were generated by third-party or nondesignated legislators. The sample included 5653 (38.9%) retweets. The majority of tweets (55.1% [n=7996]) contained a COVID-19–related term, and 11.8% of tweets (n=1706) referenced a non–COVID-19 infectious disease (eg, measles and influenza). The included tweets were generated by 1984 unique legislators. The majority of the included legislators were state representatives (73.7% [n=1463]) as opposed to federal representatives (26.3% [n=521]). In terms of political party, 63.7% (n=1264) of the included legislators were Democrats, 35.1% (n=696) were Republicans, and 1.2% (n=24) were independent or undesignated.

Vaccine-related tweets generated by Republicans were less likely than vaccine-related tweets generated by Democrats to be retweets (36.7% [n=1992] for Republicans versus 40.3% [n=3614] for Democrats; *P*<.001). Republican vaccine tweets were also less likely than Democratic vaccine tweets to reference a non–COVID-19 disease (7.5% [n=404] for Republicans versus 14.4% [n=1289] for Democrats; *P*<.001), and more likely to reference COVID-19 (58.3% [n=3146] for Republicans versus 53.2% [n=4770] for Democrats; *P*<.001).

Words and phrases more commonly used among Republicans (vs Democrats) in vaccine-related tweets included “operation warp speed,” “record time,” “innovation”, and “China.” Words and phrases more frequently used among Democrats (vs Republicans) included “anti-vaxxers,” “flu,” “communities,” “public health,” and “free” (Figure 2). To account for language changes over the study period, we repeated this analysis separately during each phase of the pandemic (Multimedia



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Appendix 2). During the first wave of the pandemic, words that were strongly associated with Republicans included “clean-funding,” “cares act,” and “innovation.” During the second and third wave, keywords associated with Republicans included words related to Operation Warp Speed (eg, “record time,” “launched,” “ingenuity,” “#OperationWarpSpeed,” and “innovation”) as well as the word “mandate.” During the first and second wave of the pandemic, terms strongly associated with Democrats included language supporting vaccines and opposing the antivaccine movement (eg, “#VaccinesWork,” “#DoctorsSpeakUp,” and “#IVaxToProtect”). In wave 3 of the pandemic, the term most strongly associated with Democrats was “Meadows” (referring to former White House chief of staff Mark Meadows). Across all 3 waves, there were more terms strongly associated with Republicans than Democrats (Figure 1 and Multimedia Appendix 2).

We included 20 topics in our final analysis (Tables 1-3). The topics with the highest percent topic representation were (1) Operation Warp Speed success; (2) vaccine effectiveness; (3) COVID-19 vaccine updates; (4) COVID-19 relief package content; and (5) nonpharmaceutical interventions as a bridge to vaccine. The topics that were more prevalent among Republicans included (1) Operation Warp Speed success; (2) COVID-19 vaccine updates; (3) international efforts to hack vaccine-related research; and (4) vaccine effectiveness. The topics that were more prevalent among Democrats included (1) vaccine prioritization; (2) children and parents; (3) reliance on vaccine as pandemic solution; (4) local, free, non–COVID-19 vaccine clinics; (5) nonpharmaceutical interventions as a bridge to vaccine; (6) influenza; (7) state and local vaccine distribution plans; and (8) discussion of antivaxxers. The remaining topics were equally prevalent between Democrats and Republicans (Tables 1-3; significance was defined as Bonferroni corrected *P*<.001, and topics in each section are listed in order of decreasing magnitude of partisan difference).

**Figure 2.** Trends in partisanship over time (defined as the sum of absolute difference in mean topic representation across parties by month).

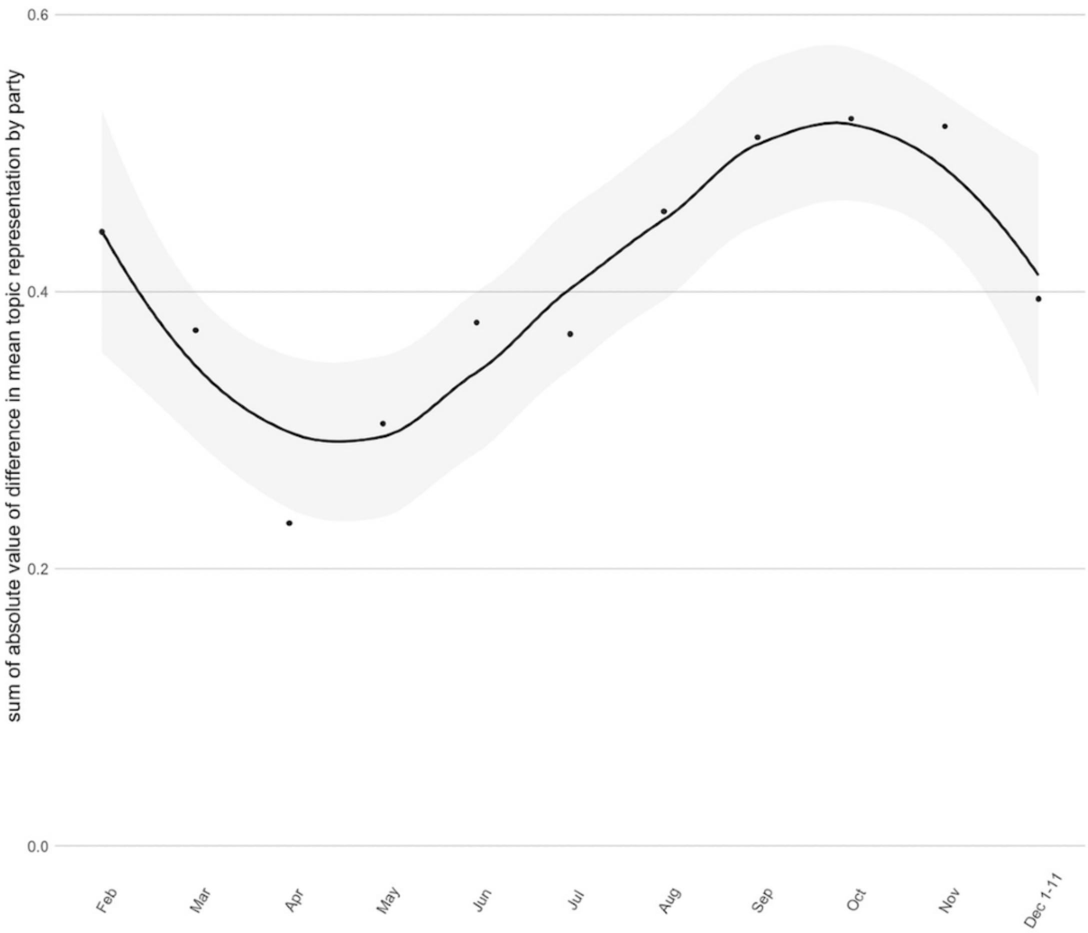



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**Table 1.** Topics with significantly higher mean representation among Republicans.

| Topic name | Keywords | Representative tweets (links and retweet handles removed for clarity) | Percent Democratic topic representation | Percent Republican topic representation |
|---|---|---|---|---|
| Operation Warp Speed success | operationwarpspeed, safe, effective, american, covid, president, develop, working, deliver, progress | "Under @realDonaldTrump leadership, Operation Warp Speed will deliver a safe and effective vaccine in record time!" | 2.4 | 12.3 |
| COVID-19 vaccine effectiveness | news, covid, pfizer, effective, great, breaking, moderna, coronavirus, pfizers, emergency | "Massively good news here. The Associated Press (@AP): BREAKING: Pfizer says early data signals its vaccine is effective against COVID-19; on track to seek U.S. review later this month." | 3.4 | 6.8 |
| COVID-19 vaccine updates | covid, trials, trial, clinical, phase, coronavirus, results, news, good, data | "Promising news from Oxford on a vaccine!" | 3.8 | 6.4 |
| International efforts to hack vaccine-related research | coronavirus, research, covid, china, global, world, develop, working, find, work | "U.S. to Warn That China Is Attempting to Steal Coronavirus Vaccine Research" | 3.1 | 4.5 |


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**Table 2.** Topics with significantly higher mean representation among Democrats.

| Topic name | Keywords | Representative tweets (links and retweet handles removed for clarity) | Percent Democratic topic representation | Percent Republican topic representation |
|---|---|---|---|---|
| Influenza | flu, protect, shot, important, vaccinated, year, people, learn, fluseason, covid | "The best way to protect against the flu this season is to get vaccinated." | 5.9 | 2.6 |
| Discussion of "anti-vaxxers" | antivaxxers, publichealth, science, protect, antivaccine, antivax, ivax, misinformation, stopantivaxviolence, vaccineswork | "Anti-vaxxers. Anti-maskers. Pro-disease." | 4.6 | 2.0 |
| Local, free, non–COVID-19 vaccine clinics | free, flu, health, immunization, school, vaccinations, county, clinic, call, today | "Need your flu shot and other vaccinations? Register by October 15 for a drive-thru flu shot clinic I am co-hosting with @RepDanMiller" | 4.7 | 2.1 |
| NPI[a] as a bridge to vaccine | mask, covid, masks, wear, continue, cases, spread, stay, wearing, hands | "We must continue to practice caution and #MaskUpPA. There is still no vaccine, so we must be careful." | 5.5 | 3.3 |
| State and local vaccine distribution plan | covid, distribution, plan, communities, ensure, states, texas, distribute, black, state, vaccination | "I wrote a letter to the Task Force on Infectious Disease Preparedness and Response to ensure minorities & communities disproportionately impacted by #COVID19 are not left behind in a #vaccine allocation & distribution plan. #txlege #ElPaso" | 5.2 | 3.4 |
| Reliance on vaccine as pandemic solution | pandemic, control, biden, virus, trump, testing, joe, lives, coronavirus, president | Mark Meadows: "We're not going to control the pandemic, we are going to control the fact that we get vaccines, therapeutics and other mitigations." Jake Tapper: "Why aren't we going to get control of the pandemic?" Meadows: "Because it is a contagious virus" #CNNSOTU | 4.1 | 2.9 |
| Children and parents | children, kids, vaccination, parents, vaccinate, diseases, time, vaccinations, medical, protect | "Parents! Make sure that your child's immunizations are up-to-date as part of your back-to-school preparations. Vaccines are a necessary precaution needed to protect infants, children and teens from serious childhood diseases. Learn more" | 4.2 | 3.1 |
| Vaccine prioritization | state, people, covid, line, teachers, healthcareworkers, session, business, essential, pandemic | "A vaccine needs to go to our health care workers, first responders, and those most vulnerable 1st, the Legislature can wait." | 3.5 | 2.5 |

[a]NPI: nonpharmaceutical interventions.



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**Table 3.** Topics with no significant difference in mean representation by party.

| Topic name | Keywords | Representative tweets (links and retweet handles removed for clarity) | Percent Democratic topic representation | Percent Republican topic representation |
|---|---|---|---|---|
| COVID relief package debate | testing, relief, schools, families, covid, democrats, senate, americans, smallbusinesses, funding | "Resources to get kids back to school or child care Dems blocked it Resources to protect workers' paychecks Dems blocked it Resources for vaccines & testing Dems blocked it Resources for another round of job-saving Paycheck Protection Program loans Dems blocked it" | 2.8 | 4.8 |
| Impact of political pressure on vaccine safety | fda, covid, safety, science, emergency, dr, confidence, process, americans, political | "Even if political pressure didn't rush a COVID19 vaccine, the mere perception among a majority of Americans that it did undermines public trust. We must prevent the vaccine from being unsafely rushed & Americans from having reason to distrust its safety." | 4.6 | 3.9 |
| Production, distribution, and rollout | covid, doses, receive, end, pfizer, million, ready, week, residents, coronavirus | "COVID-19 vaccine could be in Missouri as early as Dec. 15, 2020." | 3.7 | 4.3 |
| COVID-19 updates, press conferences, and town halls | covid, dr, today, join, discuss, watch, pm, latest, update, questions | "US_FDA Commissioner, @SteveFDA, M.D., will join us for today's Instagram live. We will discuss the progress of a #COVID19 vaccine. Be sure to watch at 2 p.m. on my Instagram page, @SenatorTimScott.#LiveWithTim" | 4.6 | 4.1 |
| President Trump | trump, president, people, fauci, dr, donald, realdonaldtrump, election, time, coronavirus | "He has completely divorced himself from reality and that's why the death of almost 195,000 Americans doesn't phase him. TRUMP: It is going away STEPHANOPOULOS: Without a vaccine? TRUMP: Sure. Over a period of time S: And many deaths TRUMP: It's gonna be herd developed" | 4.2 | 3.7 |
| COVID-19 relief package content | coronavirus, development, billion, funding, treatments, passed, local, bill, response, research | "Yesterday, I voted to support an emergency funding package to tackle #Coronavirus at home & abroad, including resources for state & local health departments and expedited vaccine development." | 5.3 | 4.8 |
| Vaccine profiteering | covid, make, government, people, coronavirus, dr, trump, stock, americans, working | "Trump's New COVID-19 Czar Holds $10 Million In Vaccine Company Stock Options" | 3.5 | 3.2 |
| Things government can (and cannot) do to increase vaccine uptake | covid, free, bill, healthcare, act, care, health, access, support, treatment | "It is one thing to have a vaccine - it is another to be able to effectively distribute it to people across the country. We must put #FamiliesFirst and pass a bipartisan relief bill that ensures additional funding for vaccine distribution." | 3.4 | 3.2 |

Polarized partisan communication decreased between February and April 2020 but increased for most of the study period (May through November) before trending down slightly during the first 11 days of December 2020. The increase in polarized communication was driven by several topics that demonstrated a widening gap in mean topic representation by political party over the study period. The topics that demonstrated a widening partisan gap with higher representation among Democrats included (1) President Trump; (2) influenza; (3) local, free non–COVID-19 vaccine clinics; and (4) state and local vaccine distribution plans. The topics that demonstrated a widening partisan gap with higher representation among Republicans included (1) Operation Warp Speed success and (2) COVID-19 relief package debate (Multimedia Appendix 3).

Several topics demonstrated decreasing partisan gaps over the study period, including the impact of political pressure on vaccine safety. While Democrats were more likely to discuss this topic early on, Republican engagement with this topic increased to match that of Democrats toward the end of the study period (Figure 3). Topics that remained relatively nonpartisan over time (ie, had similar mean topic representation at each time point) included (1) vaccine prioritization; (2) production, distribution, and rollout; and (3) COVID-19 relief package content (Multimedia Appendix 3).


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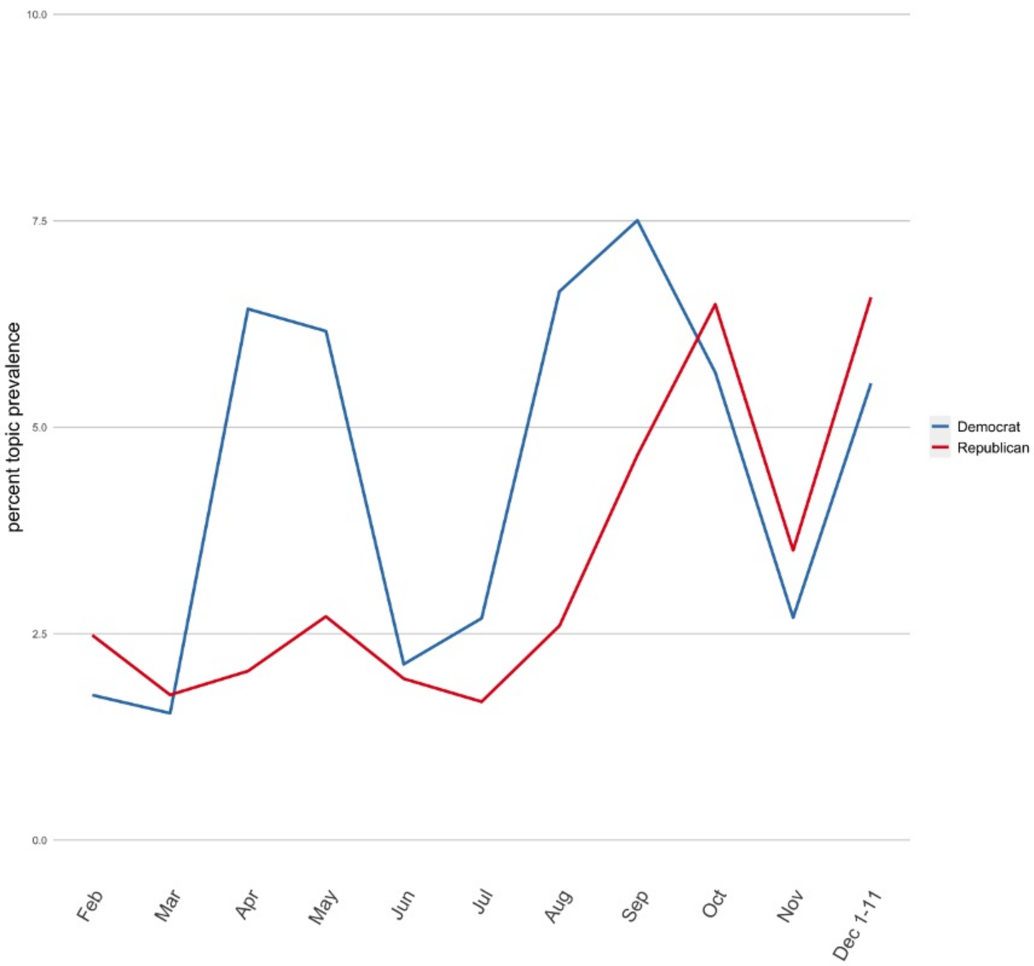
**Figure 3.** Partisan trends in Topic 5 (impact of political pressure on vaccine safety) over time.




## Discussion

### Principal Findings

We examined vaccine-related Twitter communication from state and federal legislators during the COVID-19 pandemic. We found that Republicans and Democrats used different words, phrases, and topics to discuss vaccination during the COVID-19 era. Republicans discussed vaccination using a narrow set of topics focused on progress toward the development of the SARS-CoV-2 vaccine. Democrats, on the other hand, were engaged in a more wide-ranging conversation covering a broad set of vaccine-related topics that were aligned with public health messaging related to the vaccine. We also identified patterns in legislator discussion of vaccination (eg, increased partisanship and discussion of the impact of political pressure on vaccine safety) that have the potential to contribute to SARS-CoV-2 vaccine hesitancy.

The language used by Republican legislators about vaccination during the COVID-19 era was narrowly focused on the successful development of a SARS-CoV-2 vaccine. This was illustrated in both the keywords (eg, "record time," "launched," and "innovation") and topics (eg, Operation Warp Speed success and vaccine effectiveness) that were associated with Republicans. Overall, fewer topics were associated with Republicans, and the keywords used by Republicans were more highly partisan than those used by Democrats. Both findings are consistent with the use of more focused, consistent messaging in the Republican party. In addition, Republicans were more likely than Democrats to explicitly reference COVID-19 in their tweets and were almost half as likely as Democrats to discuss vaccination for non–COVID-19 infectious diseases. This is consistent with our previous paper in which we demonstrated that, prior to COVID-19, Republican legislators were only minimally engaged in Twitter discussion about vaccination, but their engagement increased markedly with the arrival of the pandemic [18]. We hypothesized that Republican vaccine engagement may have increased because the development of a SARS-CoV-2 vaccine during a Republican presidency would represent a political victory for the party [24]. The narrow focus on Operation Warp Speed (as opposed to vaccine hesitancy, flu vaccination, or other important vaccine-related topics) described in this paper is consistent with that hypothesis. The political stakes of successful vaccine development may have been further increased by a Republican desire for an "October surprise" given that the topic Operation Warp Speed success rose in mean representation in the months leading up to the presidential election [26]. This raises the concerning implication that, with the resolution of COVID-19,



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Republicans may return to relative disengagement with the topic of vaccination.

Democrats used a broader set of topics to discuss vaccination during the COVID-19 era. Democrats were more likely to tweet about non–COVID-19 infectious diseases and tweeted about a larger number of topics than Republicans. They used a wide range of keywords (eg, “anti-vaxxers,” “flu,” “communities,” and “free”) and topics (eg, distribution of a successful vaccine, the antivaccine movement, vaccination for non–COVID-19 infectious diseases, the importance of utilizing other public health measures until a successful vaccine, and more) to discuss vaccination. These topics were also more consistent with COVID-19–related public health messaging in the lay and academic press, much of which discussed vaccine affordability, the ongoing importance of non–COVID-19 vaccines, vaccine distribution and access, and concerns about vaccine hesitancy [27-30]. The similarity between Democratic legislators’ messaging and public health messaging about the COVID-19 vaccine is consistent with the existing research. A recent study using vaccine-related Twitter data from the general public demonstrated an increase in social connection and signal boosting between Democrats and public health organizations following the arrival of the pandemic [31]. These results are also consistent with a broader literature that suggests that Democrats may be more likely than Republicans to defer to scientific authority [32,33]. Our findings may also help to explain partisan differences in intention to vaccinate. Democratic legislators’ vaccine-related tweets were more consistent with public health messaging than those of Republicans. As a result, followers of Democratic politicians may have been exposed to higher quality information related to COVID-19 vaccination, which may contribute to the partisan gap in willingness to accept the COVID-19 vaccine.

In this study, we also described patterns of vaccine-related communication from legislators that have the potential to contribute to vaccine hesitancy. The COVID-19 pandemic created an opportunity for either (1) mobilization of political leaders around a shared understanding of the importance of the vaccine or (2) an increase in polarization of the already politically polarized topic of vaccination. While there was a nadir in polarization of vaccine-related communication early in the pandemic (April 2020), the bulk of the study period was notable for increased polarization among federal and state legislators. This finding is concerning given literature suggesting that polarization in vaccination discussion may contribute to vaccine hesitancy [9,10]. Previous research by Fowler and Gollust [9] on the politicization of the HPV vaccine found that once a public health issue was politicized, it tended to remain so and failed to return to its previous baseline of politicization. In the case of this study, this finding implies that even if polarization decreases in the coming months, vaccines may remain more politicized than they were before the pandemic. Concern has also been raised in the literature that hesitancy about a specific vaccine may lead to decreased uptake of unrelated vaccines [34]. This phenomenon could further compound any harm inflicted by the politicization of the COVID-19 vaccine.

In addition to the rise in politically polarized communication during the study period, we also noted the emergence of topics that have been associated with mistrust of vaccines. For example, the topic “Impact of political pressure on vaccine safety” was initially primarily discussed by Democrats. However, by the second half of the pandemic, Republicans had joined the conversation, and the topic was again increasing in mean representation. This finding is concerning given experimental evidence that suggests that exposure to this topic may be associated with decreased belief in the importance of the COVID-19 vaccine [35]. Survey data have also demonstrated that most Americans are very or somewhat worried that the Food and Drug Administration would rush a COVID-19 vaccine in response to political pressure. Similarly, the topic of “Vaccine profiteering” has been found to be associated with increased mistrust of the COVID-19 vaccines [36]. The emergence of these themes in legislators’ Twitter activity has the potential to further legitimize and contribute to this public concern and mistrust, resulting in vaccine hesitancy.

The use of natural language processing methods for monitoring politicians’ communication may have implications for improving the quality of public health-related messages on Twitter. This is especially relevant given the increasing pressure on social media platforms to monitor public officials’ discourse following President Trump’s use of misinformation during the COVID-19 pandemic and eventual deplatforming [37]. The close monitoring of how politicians discuss public health issues is especially important in light of recent findings that politicians are more likely than scientists to appear in COVID-19–related newspaper coverage [38].

While Twitter has been used to study legislator communication about COVID-19, to our knowledge, this is the first study to examine how legislators used Twitter to communicate with the public about vaccination in the COVID-19 era [39]. Other strengths of this study include the longitudinal nature of our data and the uniquely important subpopulation of Twitter users examined in this analysis. We also note some limitations to this study. While Twitter is an important way that legislators engage with the public, many choose to engage with constituents using other platforms. As a result, this study does not capture the full scope of legislator communication with the public. There are also limitations to the natural language processing methods. While we were able to capture differences by party in the use of topics, we were unable to capture partisan differences in tone during the discussion of a given topic. For example, tweets endorsing or criticizing former President Trump’s pandemic response would both fall into the “President Trump” topic. As a result, our polarization metric may underestimate the actual differences in vaccine discussion by party.

## Conclusion

Republican and Democratic legislators engaged in substantively different conversations about vaccination on Twitter during the COVID-19 era, which led to an increase in political polarization of vaccine-related tweets throughout much of the pandemic. Republicans were engaged in a focused conversation about the successful development of a vaccine, and Democrats used a broader range of topics, which was more consistent with public


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health messaging about vaccination. These patterns have the potential to contribute to vaccine hesitancy, and future research is needed to determine the real-world impact of political communication on COVID-19 vaccine uptake.


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## Conflicts of Interest

None declared.


Multimedia Appendix 1
List of COVID-19 disease terms and non–COVID-19 disease terms.
[PDF File (Adobe PDF File), 30 KB - infodemiology_v2i1e32372_app1.pdf ]

Multimedia Appendix 2
Word and term frequency in vaccine tweets for Democrats vs Republicans by pandemic period (limited to the 30 most significantly different terms by party for ease of viewing).
[PDF File (Adobe PDF File), 308 KB - infodemiology_v2i1e32372_app2.pdf ]

Multimedia Appendix 3
Mean percent topic representation over time among Democratic and Republican posts for all included topics (5 topics did not reflect a coherent theme and were thus excluded).
[PDF File (Adobe PDF File), 373 KB - infodemiology_v2i1e32372_app3.pdf ]

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## Abbreviations

**HPV:** human papillomavirus
**LDA:** latent Dirichlet allocation


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Original Paper

# Examining Public Sentiments and Attitudes Toward COVID-19 Vaccination: Infoveillance Study Using Twitter Posts

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## Abstract

**Background:** A global rollout of vaccinations is currently underway to mitigate and protect people from the COVID-19 pandemic. Several individuals have been using social media platforms such as Twitter as an outlet to express their feelings, concerns, and opinions about COVID-19 vaccines and vaccination programs. This study examined COVID-19 vaccine–related tweets from January 1, 2020, to April 30, 2021, to uncover the topics, themes, and variations in sentiments of public Twitter users.

**Objective:** The aim of this study was to examine key themes and topics from COVID-19 vaccine–related English tweets posted by individuals, and to explore the trends and variations in public opinions and sentiments.

**Methods:** We gathered and assessed a corpus of 2.94 million COVID-19 vaccine–related tweets made by 1.2 million individuals. We used CoreX topic modeling to explore the themes and topics underlying the tweets, and used VADER sentiment analysis to compute sentiment scores and examine weekly trends. We also performed qualitative content analysis of the top three topics pertaining to COVID-19 vaccination.

**Results:** Topic modeling yielded 16 topics that were grouped into 6 broader themes underlying the COVID-19 vaccination tweets. The most tweeted topic about COVID-19 vaccination was related to vaccination policy, specifically whether vaccines needed to be mandated or optional (13.94%), followed by vaccine hesitancy (12.63%) and postvaccination symptoms and effects (10.44%) Average compound sentiment scores were negative throughout the 16 weeks for the topics *postvaccination symptoms and side effects* and *hoax/conspiracy*. However, consistent positive sentiment scores were observed for the topics *vaccination disclosure*, *vaccine efficacy*, *clinical trials and approvals*, *affordability*, *regulation*, *distribution and shortage*, *travel*, *appointment and scheduling*, *vaccination sites*, *advocacy*, *opinion leaders and endorsement*, and *gratitude toward health care workers*. Reversal in sentiment scores in a few weeks was observed for the topics *vaccination eligibility* and *hesitancy*.

**Conclusions:** Identification of dominant themes, topics, sentiments, and changing trends about COVID-19 vaccination can aid governments and health care agencies to frame appropriate vaccination programs, policies, and rollouts.

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**KEYWORDS**

coronavirus; infoveillance; COVID-19; vaccination; social media; Twitter study; text mining; sentiment analysis; topic modeling; tweets; content analysis



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## Introduction

Since the outbreak of COVID-19, caused by the SARS-CoV-2 virus, in November 2019, the pandemic continues to pose a serious threat to the lives of millions of individuals around the globe. By June 2021, the virus had infected over 176 million individuals, resulting in over 3.8 million deaths worldwide [1]. The impacts of the pandemic on the world economy, well-being, and social norms of daily living have been profound. In light of the threats posed by this virus, scientists have been racing to understand the nature of the virus and discover potential treatment regimens and therapeutic mechanisms to deal with it. Although lockdowns, social distancing, and wearing masks have been the primary measures to control the spread of the virus, effective vaccination is likely to constitute a definitive long-term strategy that can contain the pandemic and help humankind return to normal life [2]. The foreseeable long-term solution to the COVID-19 pandemic is a globally rolled out, safe vaccination program covering substantial portions of the world population. Vaccines can provide both direct protection by minimizing susceptibility to the virus among the uninfected and indirect protection by reducing spread of the virus among those infected [3]. Therefore, development and deployment of vaccines have become a central component in the global strategy to control and mitigate the spread of COVID-19 with several billions of dollars spent in research and development of the vaccines [4]. In December 2020, US regulatory authorities granted emergency and full authorization for vaccines developed by BioNTech and Pfizer, and Moderna and National Institutes of Health. In August 2021, the US Food and Drug Administration (FDA) provided approval for the Pfizer/BioNTech vaccine. Other vaccines that have been granted approvals include those developed by University of Oxford and AstraZeneca, Johnson & Johnson, Sinopharm, Sputnik-V, and Covaxin, among others. Close to 300 vaccines are currently in different phases of development to tackle the virus and its variants [5,6]. Governments across the world are devising strategies to quickly produce, procure, and distribute vaccines to their citizens [7-9].

Social media platforms have become an important conduit and rich source of data for assessing public attitudes and behaviors during health emergencies. In light of the lockdowns and restrictions imposed due to the COVID-19 pandemic, social media platforms have emerged as key forums for the public to express their opinions and experiences pertaining to the pandemic and vaccinations. Examination of social media data could reveal significant trends, patterns, and changes, and can thus serve as a tool for health surveillance and monitoring the trends. This study builds upon the extant infoveillance research on the COVID-19 pandemic by focusing on the discourse pertaining to COVID-19 vaccinations in Twitter. We analyzed over 2.94 million tweets from January 1, 2021, to April 30, 2021, to explore the trends, sentiments, and key themes pertaining to COVID-19 vaccinations.

There is growing interest in understanding public attitudes and opinions about COVID-19 vaccinations. Studies have found vaccine hesitancy to be prevalent globally across multiple countries, although there is some preliminary evidence about lower levels of hesitancy in lower- and middle-income countries as compared to developed nations such as the United States [10-12]. A number of studies have employed surveys to examine public willingness, acceptance, and hesitancy toward COVID-19 vaccines [13-19]. These studies have used responses from 100 to a few thousand respondents, often from a specific country or region. An alternate *infoveillance* approach using social media data has become a complementary, powerful mechanism to understand and explore public attitudes toward COVID-19 vaccination. A summary of studies using social media data to explore COVID-19 vaccines is provided in Table 1.

The extant studies have collectively helped us to uncover some key public concerns and trends regarding vaccinations, vaccine advocacy, and hesitancy. However, most of the existing studies have used data from early periods of the COVID-19 pandemic or initial phases of vaccination. Some of these studies have also not differentiated if the source of a tweet is an individual or an organization. Several thousands of tweets are typically made by news outlets, health agencies, or other organizations. From an infoveillance perspective, it is critical to examine the social media discourses pertaining to COVID-19 vaccines by the common public rather than by news agencies or other organizations. Building upon the emerging body of research, our study differs from this prior research in the following ways. First, we focused on tweets made between January and April 2021, capturing public attitudes during active periods of vaccinations in many countries. Second, we examined English-language tweets from all over the world, without restriction to a region or a country. Third, we focused on tweets made by individuals only, thus capturing public sentiments and concerns. Our study is uniquely positioned and differs from many other similar studies listed in Table 1, as we capture and use the tweets made by the general public, excluding those made by news outlets and other organizations. Fourth, we used advanced text-mining and topic-modeling techniques to unearth themes and topics underlying the Twitter discourse on COVID-19 vaccinations.


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**Table 1.** Summary of key studies on COVID-19 vaccines using social media data.

| Source | Data set | Time period | Key findings | Limitations/remarks |
|---|---|---|---|---|
| Yin et al [20] | 1.75 million Weibo messages from China | January to October 2020 | Identified public opinions pertaining to pricing, side effects, and inactivated vaccines | Restricted to Chinese-speaking Weibo users, including residents of China and those living abroad. The study used posts from verified users. |
| Hussain et al [21] | 23,571 Facebook posts from the United Kingdom and 144,864 from the United States; 40,268 tweets from the United Kingdom and 98,385 from the United States | March 1 to November 22, 2020 | Overall averaged positive, negative, and neutral sentiments were at 58%, 22%, and 17% in the United Kingdom, in contrast to 56%, 24%, and 18% in the United States, respectively. Public optimism regarding vaccine development, effectiveness, clinical trials, concerns over their safety, economic viability, and corporation control were identified. | Geographical scope included the United Kingdom and the United States. The study does not mention excluding tweets made by organizations and news outlets. |
| Guntuku et al [22] | 4 million tweets originating from 2957 US counties | December 1, 2020, to February 28, 2021 | Topics identified include side effects, conspiracy theories, trust issues in the US health care system in December 2020; mask wearing, herd immunity, natural infection, and concerns about nursing home residents and workers in January 2021; and access to black communities, vaccine appointments, family safety, and online misinformation campaigns in February 2021. Geographic variations on the topics across different counties were also identified. | Geographical scope was restricted to the United States. The study does not mention excluding tweets made by organizations and news outlets. |
| Bonnevie et al [23] | 1,438,251 tweets; 6498 per day | Antivaccine tweets from February 15, 2020, to June 14, 2020, as compared to those in the pre-COVID-19 period of October 15, 2019, to February 14, 2020 | Mentions of vaccine opposition increased by 79.9%. The themes identified were negative health impacts, pharmaceutical industry, policies and politics, vaccine ingredients, federal health authorities, research and clinical trials, religion, vaccine safety, disease prevalence, school, and family | No mention of exclusion of tweets made by organizations and news outlets |
| Griffith et al [24] | 3915 tweets about vaccine hesitancy from Canada | December 10, 2020, to December 23, 2020 | Vaccine hesitancy was attributed to the following themes: concerns over safety, suspicion about political or economic forces driving the COVID-19 pandemic or vaccine development, a lack of knowledge about the vaccine, antivaccine or confusing messages from authority figures, and a lack of legal liability from vaccine companies | Geographical scope restricted to Canada, with limited sample size; manual coding of tweets |
| Hou et al [25] | 7032 tweets and Weibo posts from five locations: New York, London, Mumbai, Sao Paulo, and Beijing | June and July 2020 | Beijing users (76.8%) had a higher vaccine acceptance rate as compared to those in New York (36.4%). Concerns expressed included: vaccine safety, distrust in governments and experts, widespread misinformation, vaccine production and supply, vaccine distribution, and inequity | Manual coding of tweets and Weibo posts from five locations, with limited sample size. However, this study excluded posts from news outlets and organizational accounts |
| Yousefinaghani et al [26] | 4,552,652 tweets about COVID-19 vaccines | January 2020 to January 2021 | Sentiment analysis revealed positive being the dominant polarity and having higher engagement. Themes among the positive-sentiment tweets were happiness and hope, support, and religion. Themes among the negative-sentiment tweets were fear and frustration, disappointment, anger, and politics. More discussion on vaccine rejection and hesitancy as compared to provaccine themes | Examined tweets from six countries: the United States, the United Kingdom India, Australia, Canada, and Ireland. No mention of excluding organizational tweets. |



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| Source | Data set | Time period | Key findings | Limitations/remarks |
|---|---|---|---|---|
| Hu et al [27] | 308,755 geo-coded tweets from the United States | March 1, 2020, to February 28, 2021 | Identified three phases along the pandemic timeline and documented changes in public sentiments and emotions. An increase in positive sentiment coupled with a decrease in negative sentiment concerning vaccines were noted in most states. Major international or social events and announcements by influential leaders or authorities associated with changes in public opinions toward vaccines. | Geographical scope restricted to the United States. No mention of excluding organizational tweets |
| Lyu et al [28] | 1,499,421 tweets | March 11, 2020, to January 31, 2021 | 16 topics under five broad themes were identified: opinions and emotions around vaccines and vaccination, knowledge around vaccines and vaccination, vaccines as a global issue, vaccine administration, and progress on vaccine development and authorization | Did not exclude organizational tweets, but eliminated tweets by bots and fake accounts |
| Eibensteiner et al [29] | Poll of 3439 Twitter users | February 12, 2021, and February 19, 2021 | 45.9% of Twitter users felt the safety of the COVID-19 vaccines to be adequate; over 82.8% responded affirmatively about taking the vaccination | Used an anonymized polling/survey method with a limited sample of Twitter users |

In this research, we sought to uncover important themes underlying the social media discourse pertaining to COVID-19 vaccinations. This will help us to better understand how individuals feel about COVID-19 vaccinations, their inclinations for uptake, as well as reasons behind their hesitancy. Given the prevalence of vaccine hesitancy worldwide [30], it is important to understand public attitudes toward vaccines, underlying reasons for hesitancy, and individual experiences with vaccinations. Moreover, it is also important to uncover how the public feels about various governmental- and policy-related measures that various governments across the world have taken regarding COVID-19 vaccines [31,32]. Using topic modeling and text mining, we seek to uncover the trends and themes underlying social media discourse about COVID-19 vaccinations. A deeper understanding of specific themes and topics can help to frame better responses toward COVID-19 vaccination campaigns and can help policymakers and health professionals in their efforts to improve vaccine uptake.

Our specific research goals were to (1) explore the themes and topics underlying social media discourse pertaining to COVID-19 vaccines and (2) uncover trends and temporal variations in sentiments underlying COVID-19 vaccine discourse in Twitter.

## *Methods*

### Data Set and Ethical Considerations

This study used publicly available and accessible tweets made by individuals on the Twitter platform, which formed the data set used for our analysis. We present our analysis in aggregate form without identifying specific individuals who made the Twitter posts. Therefore, the activities described do not meet the requirements of human subjects research and did not require review by an institutional review board.

### Data Gathering

We used the Python scraper *snscrape* to collect historical tweets regarding COVID-19 vaccines and vaccination [33]. Our search terms included a combination of "vaccine" and COVID-19–related terms ("covid," "coronavirus," "covid19," "covid-19," "ncov2019," and "SARS-CoV-2") to retrieve tweets published between January 1, 2021, and April 30, 2021. Snscrape and Getoldtweets are popular Python libraries that have been used in several infoveillance studies to capture Twitter data [26,34,35]. We ensured removal of retweets and duplicates so that the data set contained only the original tweets made by the users.

### Data Preprocessing

We used a machine learning approach to separate tweets made by individuals and organizations. Following the approach outlined by Chandrasekaran et al [35], we developed a naive-Bayes classifier to distinguish the Twitter user as being an individual or an organization. The accuracy was 91.81%, providing confidence about the classifier that we used to segregate tweets made by individuals.

Our next step involved preprocessing and cleaning of tweets using a set of libraries in Python. Using the *re*, *nltk*, and *sklearn* libraries, we removed punctuations, stop words, and emojis, and also lemmatized the text of tweets to prepare them for further processing.

### Topic Modeling and Sentiment Analysis

Topic modeling is an unsupervised machine learning method for identifying latent patterns of words in a large collection of documents. The most representative method for topic modeling is latent Dirichlet allocation (LDA), which is a generative probabilistic method [36]. LDA does not assume any prior knowledge of topics, and through appropriate tuning of parameters, one can explore different topic formations and clusters [37]. Often, LDA can simply generate topics that can neither be meaningful nor effective. To overcome the restrictions


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and limitations of LDA, newer algorithms such as Correlation Explanation (CorEx) have been developed [38]. The CorEx model, similar to LDA, does not make any assumptions about topics in the underlying data. Further, CorEx identifies latent topics that are maximally informative about a collection of documents by examining how words are used in tweets and picks up on patterns to assess what the tweets convey. CorEx allows a researcher to iterate with different numbers of topics, review them, and identify the optimal number of topics for further assessment. CorEx has been effectively used in a number of health infoveillance studies to uncover topics in Twitter data [39,40].

We used CorEx and iterated with a varying number of topics (eg, 5, 10,15, 20, 30). The keywords for different topics were assessed by the authors to ascertain their coherence and meaningfulness pertaining to a topic. The total correlation scores were compared across iterations to decide on the optimal number of topics produced. Next, we reviewed the results to infer appropriate topics on the basis of keywords. We also examined a set of randomly chosen tweets for each topic to assess if those tweets were consistent with the topic. Through discussions, the authors then grouped the topics into broader themes. Our procedures are consistent with similar studies that have examined social media data using text mining and topic modeling [35,39]. Further, we also computed the sentiment score for each tweet using the VADER (valence aware dictionary and sentiment reasoner) tool in Python. VADER is a lexicon and rule-based sentiment analysis tool that is appropriate for social media texts such as tweets [41]. VADER's polarity score quantifies the sentiment of a tweet in the range from –1 (extreme negative) to 1 (extreme positive). VADER's scoring method takes into account both the polarity and the intensity of emotion expressed in a tweet. The VADER output labels each tweet into one of the following five sentiments: overly positive (polarity score≥0.70), positive (polarity score between 0.01 and 0.70), neutral (polarity score between –0.01 and 0.01), negative (polarity score between –0.01 and –0.70), and overly negative (polarity score≤–0.70). We used the polarity score to classify the sentiment in the tweets.

In addition to topic modeling and sentiment analysis, we also performed qualitative analysis of tweets in each theme/topic to obtain further insights and temporal trends in the vaccine-related tweets.

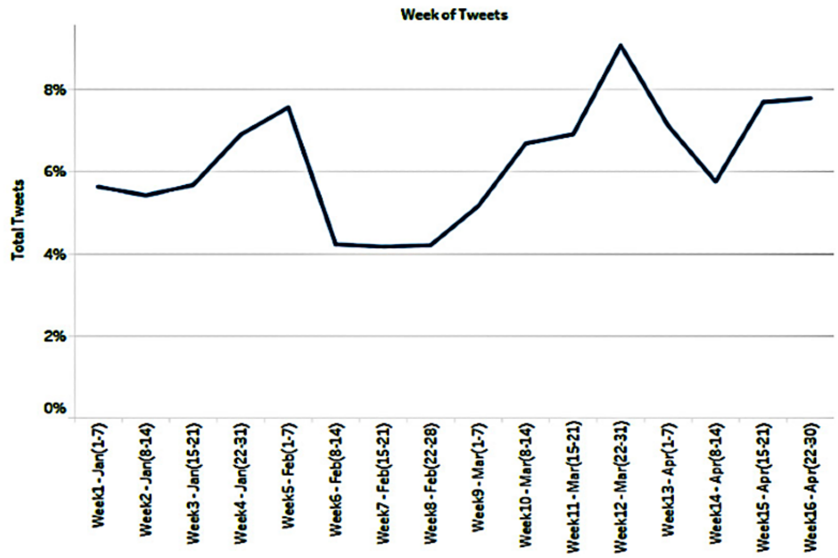
## Results

### Tweets Retrieved

Our data gathering resulted in an initial set of 3,707,187 tweets. We removed 762,657 tweets made by organizations. Consistent with our research goal of assessing public sentiments and attitudes, 2,944,530 tweets made by 1,210,225 Twitter users were included in our analysis.

The trends in the number of tweets about COVID-19 vaccines from January to April 2021 are presented in Figure 1. All of the weeks had over 100,000 tweets; however, a spike in the number of tweets was observed in the week of March 22-31, 2021. This was the week when the eligibility for receiving COVID-19 vaccines was changed to cover several individuals and groups with several US states opening up vaccination to larger sets of individuals.

**Figure 1.** Proportion of COVID-19 vaccine–related tweets from January to April 2021.




### Themes and Topics

Our CoreX topic modeling resulted in 16 topics (Table 2), which were further categorized into six broad themes: *vaccination experiences* (17.27%), *pharma industry (vaccine development, production, and distribution)* (15.71%), *vaccination policies* (21.42%), *vaccination rollout* (5.99%), *attitudes toward vaccination* (37.12%), and *gratitude toward health care workers* (2.49%). The topics and representative keywords are shown in Multimedia Appendix 1. The top three topics that were tweeted in the January to April 2021 timeframe were: *regulatory issues (mandatory vs optional)* (13.94%), *vaccine hesitancy* (12.63%), and *postvaccination symptoms and side effects* (10.44%).


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**Table 2.** Topics and broad themes underlying COVID-19 vaccine–related tweets (N=2,944,530).

| Themes and topics | Tweets, n (%) |
|---|---|
| **Vaccination experiences** | 508,658 (17.27) |
| Vaccination disclosure | 201,102 (6.83) |
| Postvaccination symptoms and effects | 307,556 (10.44) |
| **Pharma industry: vaccine development, production, and distribution** | 462,529 (15.71) |
| Vaccine efficacy | 139,280 (4.73) |
| Clinical trials, approvals, and suspensions | 182,673 (6.20) |
| Vaccine distribution and shortage | 140,576 (4.77) |
| **Vaccination policies** | 630,606 (21.42) |
| Vaccine affordability | 116,205 (3.95) |
| Regulation: mandatory versus optional | 410,466 (13.94) |
| Travel | 103,935 (3.53) |
| **Vaccination rollout** | 176,329 (5.99) |
| Vaccination appointment and scheduling | 105,586 (3.59) |
| Vaccination sites | 70,743 (2.40) |
| **Attitudes toward vaccination** | 1,093,050 (37.12) |
| Vaccination eligibility and policies | 76,605 (2.60) |
| Vaccination promotion and advocacy | 264,368 (8.98) |
| Vaccination hesitancy | 371,843 (12.63) |
| Opinion leaders and endorsement | 172,002 (5.84) |
| Hoax/conspiracy | 208,232 (7.07) |
| Gratitude toward health care workers | 73,358 (2.49) |

## Temporal Trends in Sentiments

We computed the sentiment scores of COVID-19 vaccination tweets and tracked their changes over the time period of our study. The results are presented in Figure 2. The proportion of positive or overly positive tweets was always greater than that of negative or overly negative tweets in all of the weeks examined. Overall, 41.62% of the tweets had a positive sentiment, 31.16% had a negative sentiment, and 27.22% had neutral sentiment scores.

We further examined the trends in sentiments of the 16 topics over time. These results are presented in Multimedia Appendix 2. A large proportion of tweets about *postvaccination symptoms and side effects* (40%-45%) and those about *conspiracy/hoax* (35%-45%) had negative or overly negative sentiments in all weeks of our examination. In contrast, greater proportions of tweets about *vaccination disclosure* (35%-40%), *vaccine efficacy* (45%-55%), *clinical trials and approvals* (30%-40%), *vaccine affordability* (35%-35%), *vaccine regulation* (30%-35%), *travel* (35-45%), *opinion leaders and endorsement* (30%-50%), and *gratitude to health care workers* (30%-45%) carried positive or overly positive sentiments throughout the time period of our research.

We also examined the trends in the average sentiment score for each of the 16 topics over the time period of examination and plotted the average compound scores by topic and week. The results are presented in Multimedia Appendix 3. Average compound sentiment scores were found to be negative throughout the time period of our examination for the following themes: *postvaccination symptoms and side effects*, *hoax/conspiracy*, and *vaccine hesitancy*. We found reversal of average sentiment scores from positive to negative during a few weeks for the topic of *vaccination policies*. For the rest of the topics, the average compound sentiment scores were consistently positive for all weeks.


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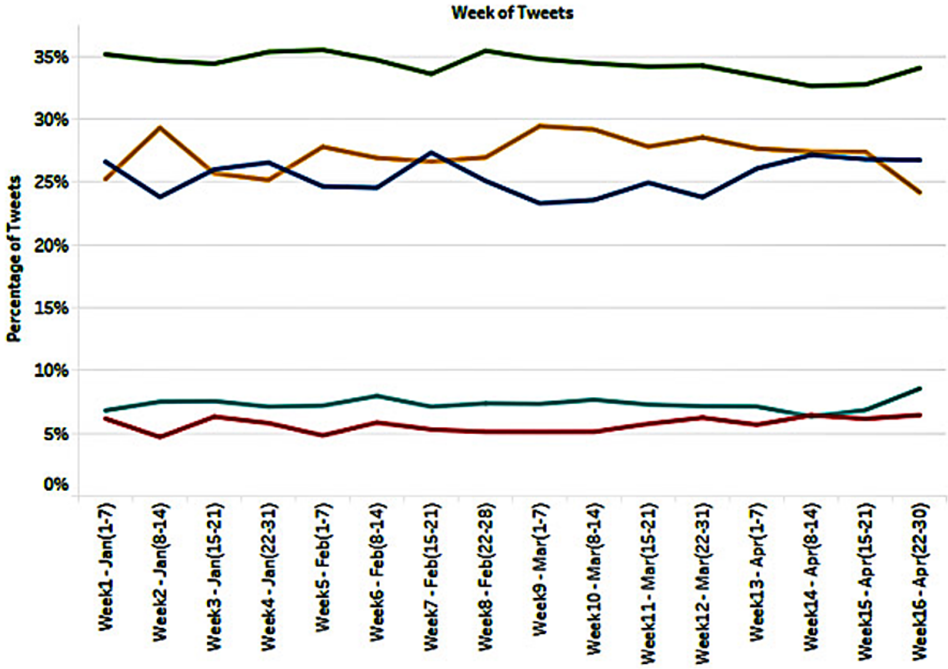
**Figure 2.** Proportions of positive, negative, and neutral tweets about COVID-19 vaccination.




## Qualitative Content Assessment

### Overview

To further examine the public sentiments and attitudes toward COVID-19 vaccines and vaccination rollouts, we qualitatively examined the tweets for the top three themes that emerged from our topic modeling assessment.

### Public Attitudes Toward COVID-19 Vaccine Regulation

Approximately 14% of the tweets about COVID-19 vaccination in the study period focused on the issue of whether vaccines need to be made mandatory. Many tweeters argued for mandatory vaccination, especially in places of work, schools, education institutions, and for travel:

> *Just like having a vaccination card to go to school, I feel businesses and all schools should make it mandatory to have Covid vaccine*
>
> *Would you refuse to take the Covid vaccine; if it became compulsory to work?*
>
> *If, eventually, we need to show proof of vaccination to go to theatres, restaurants, sporting events etc then no, it's not truly optional - by any reasonable measure that's coerced vaccination.*

Tweeters also argued for making COVID-19 vaccines mandatory to health care workers. Several countries such as France have introduced mandatory vaccination requirements for health care workers. Saudi Arabia announced that all of the employees in the public, private, and nonprofit sectors must be vaccinated before they can return to work. Italy introduced a vaccination requirement for all of their health care workers and pharmacists [42]. There were many tweets that supported this type of mandatory vaccination

> *I support #MandatoryVaccination for nurses*
>
> *Let's keep pushing for #MandatoryVaccination of those who care for our most vulnerable Ridiculous that we're making vaccination optional for healthcare workers...vaccinate or GTFO.*

Tweeters opposed to mandatory vaccination opined about how such mandates can be extended to other areas and expressed displeasure:

> *Its all part of the #mandatoryvaccination by coercion agenda. They are going to achieve it by: Divide and Rule -> getting the #vaccinated to blame the #unvaccinated. Threatening people with no sport events pubs etc. These narratives will grow and grow over the coming months. What happens to #MyBodyMyChoice if we're forced into #mandatoryvaccination ? Next it will be #forced #abortion and #sterilization?*

### Vaccine Hesitancy

Approximately 12.63% of the tweets in our data set were about vaccine hesitancy that highlighted the reluctance of a set of Twitter users to receive COVID-19 vaccines. When we qualitatively examined these tweets, we found tweeters simply spelling out their stance to reject the vaccines, with many users highlighting reasons for not accepting vaccines. Promoting COVID-19 vaccines will need a clear understanding (particularly for those against COVID-19 vaccines) of whether people are willing to be vaccinated and the reasons why they are willing or unwilling to do so. We observed some common reasons cited by Twitter users for their vaccine hesitancy. Some users expressed concerns on how quickly the vaccines were developed and wondered about safety. For instance, one user tweeted "I don't trust a vaccine that was developed in such a short period of time, when we can't even find one for so many other illnesses," and another user tweeted "I don't trust that jab...it's usually years before a vaccine is ready....too rushed.. I don't trust it." There were others who expressed concerns about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effectiveness of vaccines and if the vaccines can protect against newer strains of the virus. As one tweeter stated, “I’m not getting the vaccine. No one knows what’s in it or the long term effects of it, or if it can stop new variants.” From some other tweets, we observed public mistrust of the pharmaceutical industry, medical community, and governments:

> *I don't trust pharma and I won't be having any covid vaccine till it's been around for a while longer and the guinea-pigs have put it to good testing*
>
> *I don’t trust this vaccine, I don’t trust the CDC, I don’t trust free donuts from Krispy Kreme (LMFAO), i don’t trust our government*
>
> *Nope! Not getting the “vaccine”. I don’t trust the government nor companies who work with the government*

### Postvaccination Symptoms and Effects

Over 10% of tweets in our data set were about users sharing their experiences on symptoms and side effects of COVID-19 vaccines. Moreover, the average compound sentiment for this topic remained negative throughout the 4-month period. Twitter users shared information about the dose and their experiences subsequent to vaccination. While some users reported little or no side effects (“24 hours after my first jab of the Covid-19 vaccine, I have not observed any untoward effect from the vaccine”), others provided more detailed information on side effects and how they progressed over a period of time following the vaccination:

> *Had the jab at 11am yesterday and the chills & aches started at about 7pm last evening. Lots of Tylenol & fluids.*
>
> *I received my 2nd covid shot yesterday morning. The biggest side effects were weakness and terrible dizziness.*
>
> *Day 2 post-vaccine was no cake walk. Fever, major aches, brain fog, sore everywhere. But man am I glad I got it*

Mentions of side effects were often accompanied by messages expressing elevated feelings about protection against the virus:

> *I had side effects from the vaccine, but that 24 hours of chills and fever was worth it to keep myself, friends, family, and my community safe.*
>
> *I would much rather take 48 hours of aches and chills from the second dose of the vaccine than risk gasping for my last breath in an ICU away from family.*

## Discussion

### Principal Findings

A growing number of studies have used data from social media to explore and understand public concerns and attitudes about the COVID-19 pandemic. As governments around the world are trying to tackle the pandemic through mass vaccination, it is important to uncover public opinions and attitudes toward COVID-19 vaccines. We used a repository of approximately 3 million tweets from January 2021 until the last week of April 2021 to uncover the trends in sentiments of various themes and topics pertaining to COVID-19 vaccines. We focused on tweets made by individual users and excluded those made by news outlets and other organizations. Through topic modeling, we found 16 topics pertaining to COVID-19 vaccines that were grouped into six broad themes. Further, we examined sentiments associated with these topics and the changes in sentiments over the 4-month period.

A key finding from our study is that the regulation pertaining to COVID-19 vaccines was the most discussed issue by Twitter users. The number and proportion of tweets on this theme were greater than those for all the other topics. The proportion of tweets with positive sentiments about regulation of the vaccination outweighed the proportion of negative and neutral tweets pertaining to this topic. We found vaccine hesitancy to be the second most discussed topic. We also observed negative sentiment scores for many weeks for this topic. Our qualitative analysis provided some preliminary insights into reasons behind vaccine hesitancy: shorter duration of the vaccine development cycle, concerns about effectiveness of the vaccine in controlling the virus and its variants, and general mistrust about the pharmaceutical and medical industries and governments. Another topic that was widely discussed was postvaccination side effects and symptoms. The average sentiment scores for this topic were negative throughout the time period examined.

To control the COVID-19 pandemic, it is important that a substantial portion of the worldwide population acquire immunity through vaccination. Policymakers and public health officials are increasingly focusing on ways to boost and accelerate vaccine uptake. Vaccination campaigns are being designed to address misinformation and public concerns regarding the vaccines. In addition, several efforts are being made to increase vaccine supply, introduce incentive mechanisms for encouraging vaccine uptake, and enhance public education and outreach programs. However, our findings indicate that vaccine mandates and vaccine hesitancy continue to dominate the minds of the general public, as can be seen from their posts on social media. It is important to take their attitudes into account while framing and designing vaccination campaigns and programs.

It should also be noted that most COVID-19 vaccines have been approved for emergency use and authorization, rather than through a regular licensing route. As more vaccines that are currently authorized for emergency use obtain regular approval and licenses by authorities such as the FDA, the issue of vaccine mandates is likely to gain more prominence. More employers and authorities could enforce vaccine mandates. Schools and educational institutions in many parts of the world have started mandating COVID-19 vaccines. Further, vaccination is also a requirement for most international travel. It is more likely to become a requirement for even domestic travel in several countries. A complementary approach to mandating COVID-19 vaccines is creation of trust and favorable attitudes toward vaccines in the minds of the public. Mass outreach and education programs along with incentives for vaccination can go a long way in accelerating vaccination uptake. Further, endorsement by leaders and celebrities and experience-sharing by peer


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individuals could also help alleviate concerns regarding vaccines.

This study points to the key issues surrounding COVID-19 vaccinations in the minds of the general public, as expressed through social media. Findings from our study bear important implications for the design of vaccination campaigns and programs. Identification of reasons for vaccine hesitancy throws light on questions that need to be answered by health policymakers and health care practitioners in order to allay the apprehensions pertaining to vaccines and their side effects. Moreover, experience sharing from the public on vaccination, side effects, and their mindsets could also serve as a morale booster for others. Some social media posts also serve as testimonials for the efficacy of vaccinations and their effectiveness. Future vaccination drives and campaigns can take into account the experiences of a fairly large body of individuals to design appropriate responses to increase vaccination uptake.

### Limitations and Future Work

This study used tweets posted from January 1 to April 31, 2021. Vaccination efforts accelerated in several parts of the world shortly after (June-July of 2021), which have not been captured by our study. It should also be noted that we used a machine learning classifier to separate tweets made by individuals and exclude those made by organizations and news outlets. This helped us to remove numerous tweets made by media outlets and organizations so that we could capture the attitudes of the general public. The classifier exhibited an accuracy of 91.81%, which is comparable or better than those reported in many other studies [35,43,44]. Given the large number of tweets as well as Twitter users in our data set, we did not specifically examine if any set of users acted as influencers or "supertweeters." Examining the tweets of celebrities or other influencers could help to uncover the impacts of these influencers on vaccination campaigns as a potentially fruitful area of future work.

Another limitation is that we covered only tweets posted in the English language. Due to the nature of the data we gathered, we did not explore any geographical disparities in the tweets, which could also be a fruitful extension to our work. Another extension of our work would be to examine emotions expressed in tweets pertaining to COVID-19 vaccinations. Another important limitation of our study is that we have captured only the attitudes and opinions of Twitter users, who have a presence in social media. Twitter users tend to be technology-savvy, adept in using social media, and own smartphones, and therefore may not represent the entire population set. A larger set of the population who do not have a presence on Twitter has not been covered by our study.

### Conclusion

With variants of the virus causing COVID-19 creating multiple waves of the pandemic in several countries, it is important to accelerate the rate of vaccinations and improve uptake. As COVD-19 vaccination efforts move forward, it will be important to continue to monitor public opinions regarding vaccine mandates, vaccine hesitancy, and vaccination uptake. Some individuals and groups are likely to continue to oppose vaccines, whereas there may be many others who could be convinced by appropriate education and outreach programs. While mandates by governments or employers could be contested on legal grounds, appropriate exemptions will need to be made for people with certain health conditions or special situations. Infoveillance based on social media data can provide rich insights for policymakers and health officials to frame appropriate policies and programs for COVID-19 vaccination.

## Conflicts of Interest

None declared.

Multimedia Appendix 1
Themes, topics, and keywords.
[DOCX File , 16 KB - infodemiology_v2i1e33909_app1.docx ]

Multimedia Appendix 2
Trends in sentiments of tweets.
[DOCX File , 1754 KB - infodemiology_v2i1e33909_app2.docx ]

Multimedia Appendix 3
Average sentiment scores and trends.
[DOCX File , 357 KB - infodemiology_v2i1e33909_app3.docx ]

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## Abbreviations

**CorEx:** Correlation Explanation
**FDA:** Food and Drug Administration
**LDA:** latent Dirichlet allocation
**VADER:** valence aware dictionary and sentiment reasoner



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Original Paper

# Public Opinion and Sentiment Before and at the Beginning of COVID-19 Vaccinations in Japan: Twitter Analysis

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## Abstract

**Background:** COVID-19 vaccines are considered one of the most effective ways for containing the COVID-19 pandemic, but Japan lagged behind other countries in vaccination in the early stages. A deeper understanding of the slow progress of vaccination in Japan can be instructive for COVID-19 booster vaccination and vaccinations during future pandemics.

**Objective:** This retrospective study aims to analyze the slow progress of early-stage vaccination in Japan by exploring opinions and sentiment toward the COVID-19 vaccine in Japanese tweets before and at the beginning of vaccination.

**Methods:** We collected 144,101 Japanese tweets containing COVID-19 vaccine-related keywords between August 1, 2020, and June 30, 2021. We visualized the trend of the tweets and sentiments and identified the critical events that may have triggered the surges. Correlations between sentiments and the daily infection, death, and vaccination cases were calculated. The latent dirichlet allocation model was applied to identify topics of negative tweets from the beginning of vaccination. We also conducted an analysis of vaccine brands (Pfizer, Moderna, AstraZeneca) approved in Japan.

**Results:** The daily number of tweets continued with accelerating growth after the start of large-scale vaccinations in Japan. The sentiments of around 85% of the tweets were neutral, and negative sentiment overwhelmed the positive sentiment in the other tweets. We identified 6 public-concerned topics related to the negative sentiment at the beginning of the vaccination process. Among the vaccines from the 3 manufacturers, the attitude toward Moderna was the most positive, and the attitude toward AstraZeneca was the most negative.

**Conclusions:** Negative sentiment toward vaccines dominated positive sentiment in Japan, and the concerns about side effects might have outweighed fears of infection at the beginning of the vaccination process. Topic modeling on negative tweets indicated that the government and policy makers should take prompt actions in building a safe and convenient vaccine reservation and rollout system, which requires both flexibility of the medical care system and the acceleration of digitalization in Japan. The public showed different attitudes toward vaccine brands. Policy makers should provide more evidence about the effectiveness and safety of vaccines and rebut fake news to build vaccine confidence.

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**KEYWORDS**

COVID-19; Japan; vaccine; Twitter; sentiment; latent dirichlet allocation; natural language processing



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## Introduction

A novel coronavirus causing COVID-19 was first identified in December 2019 [1]. As of February 24, 2022, the cumulative confirmed cases and deaths were approximately 426 million and 5.9 million, respectively, globally [2], of which 4,607,029 confirmed cases and 22,272 death cases were reported in Japan [3]. As of February 24, 2022, Japan had suffered 5 waves of infection and, as of this writing, was going through the sixth wave. During the fifth wave, the Tokyo Olympic Games were held, and infection cases had surged to 1,556,998 when the Games finished. The sixth wave began after the first local case of the Omicron variant and soon broke the records of cases and deaths in the fifth wave. The pandemic has had a significant adverse effect on individuals, governments, and the economy in Japan [4].

To end the worldwide pandemic, several COVID-19 vaccines were developed, and large-scale vaccination was called for to protect people across the world [5-7]. Japan's vaccination campaign was slower in the early stages than in other developed countries. Japan experienced significant delays in COVID-19 vaccinations, with a vaccination rate of less than 4% until May 21, 2021 [8]. Only 25.4% of the population was fully vaccinated by the opening of the Olympics on July 23, 2021, arousing widespread suspicions of the safety of the Olympics [9]. Several previous studies indicated vaccine hesitancy as a key factor in early-stage vaccination in Japan [10,11].

Vaccine hesitancy is one of the main risks to world health reported by the World Health Organization (WHO) [12,13]. According to the 5 C model of vaccine hesitancy [14,15], the slow progress of early vaccination campaigns in Japan might have resulted from the inconvenience of vaccination and low vaccine confidence. The inconveniences of vaccination included lagged regulatory approval of COVID-19 vaccines, delayed vaccine importation, and a low-efficiency vaccine rollout system [8]. Japan ranked among the countries with the lowest vaccine confidence in the world [16], which might have stemmed from the crisis of confidence toward the human papillomavirus (HPV) vaccine in 2013 [17]. A deeper understanding of vaccine hesitancy during the slow progress of vaccination can be instructive for the COVID-19 booster vaccination and vaccinations against future pandemics.

Classical surveys are often used to gather data on public attitudes toward vaccination [18-20] but are often costly and time-consuming and only reflect relatively short-term situations and limited samples. In contrast, social media research can be cheaper and is more practical for collecting almost real-time information on the opinions and sentiments of a large population. During the pandemic, social media was used to mine opinions and sentiments toward the COVID-19 vaccine in various countries, but there remains a gap regarding Japan. Several studies have linked social media activity to vaccine hesitancy and antivaccine campaigns [21-30]. Tangherlini and colleagues [21] analyzed vaccine hesitancy drivers on blogs and reported that parents may utilize these forums to spread vaccine opposition views to other parents. Bonnevie and colleagues [24] studied the evolution of vaccine resistance in the United States by analyzing Twitter discussion topics and found that prominent Twitter accounts were responsible for a significant percentage of vaccine opposition messages. Lyu and colleagues [25] argued that public discussion is driven by major events and that vaccine sentiment around COVID-19 has become increasingly positive in 6 countries, showing higher acceptance rates than previous vaccines. The findings of several studies indicate positive attitudes in Australia, the United Kingdom, and the United States, but more positivity is needed to boost vaccination rates [26,27]. Marcec and Likic [28] examined the sentiment toward different vaccine brands and found that the sentiment in some countries toward the AstraZeneca vaccine seems to be decreasing over time, while sentiment toward the Pfizer and Moderna vaccines has remained positive and stable. Yousefinaghani and colleagues [29] conducted a large-scale study of people's views of vaccines on Twitter. Chen and colleagues [30] summarized the topics of rumors on Twitter.

There were approximately 90.6 million Japanese social media users in 2020, accounting for 72.48% of the total population [31]. Moreover, the ongoing COVID-19 pandemic has led to the increasing use of social media as a venue for discussion of vaccine-related issues [32], and opinions of social media users may affect the opinions of others, resulting in vaccine hesitation or refusal [33].

This retrospective study aims to analyze the slow progress of early-stage vaccination in Japan by exploring the opinion and sentiment toward COVID-19 vaccines in Japanese tweets between August 1, 2020, and June 30, 2021, before and at the beginning of vaccination. We summarized the trends of the number of tweets and sentiments during the whole period. Regarding the reason for the slow vaccination process in Japan, the latent dirichlet allocation (LDA) topics of negative tweets since COVID-19 vaccination started were extracted. To investigate public attitudes toward different vaccine brands, sentiment and the top words of tweets related to 3 vaccine manufacturers were generated. The findings of this research can help governments, policy makers, and public health officials understand the factors that motivate and cause hesitance in the public toward vaccinations and provide evidence for planning, modifying, and implementing a tailored vaccine promotion strategy.

## Methods

### Data Extraction and Preprocessing

A large-scale COVID-19 Twitter chatter data set collected and maintained by Georgia State University's Panacea Lab [34] was used in this study. The data set was still being updated and included 1.3 billion tweets by February 24, 2022. The data were collected through the publicly available Twitter Stream application programming interface (API) by querying the keywords "coronavirus," "2019nCoV," and "corona virus" in all available languages between January and March 2020, and the keywords were expanded to "COVD19," "CoronavirusPandemic," "COVID-19," "2019nCoV," "CoronaOutbreak," "coronavirus," and "WuhanVirus" after that. The tweet IDs, posting date and time, and languages of all


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tweets were gathered from the query results and provided in the data set. We first extracted the IDs of tweets marked as Japanese (some were mixtures of Japanese and English) and then collected the tweets using the Python package Tweepy. In this study, 1,305,308 tweets marked as being in the Japanese language from August 1, 2020, to June 30, 2021, were downloaded. It was noticeable that some tweets containing both English and Japanese were also marked as being in the Japanese language in the data set. All the English words in the tweets were transferred to half-width and lowercase. The tweets were filtered by keywords (Multimedia Appendix 1, Table 1) related to vaccinations. After data cleaning, 144,101 tweets with selected keywords were used for further analysis. Official data on the number of infections, deaths, and vaccinated cases were collected from the website of the Ministry of Health, Labor and Welfare (MHLW) [35] and the Prime Minister of Japan and His Cabinet (PMOJ) [36].

Tokenization is a fundamental step in many natural language processing (NLP) methods, especially for languages like Japanese that are written without spaces between words. We tokenized all tweets and analyzed the unigram and bigram tokens. The website links, special characters, numbers, and “amp” (ampersands) were removed from the tweets before tokenization. The Python packages SpaCy and GiNZA were used to remove the Japanese and English stop words and implement tokenization. The tokenized words were joined by white space characters into text in the original order. The Python package scikit-learn was used to convert the white space–joined texts into unigram and bigram tokens and to calculate the counts of tokens.

**Table 1.** Examples of tweets of different sentiments, paraphrased to protect user privacy.

| Sentiment | Example |
|---|---|
| Positive | First vaccine! Muscle injection, surprisingly not painful. |
| Negative | I plan to get vaccinated, but in the absence of medium- and long-term verification, I remain concerned. |
| Neutral | Five vaccination sites are available for reservation in the Higashinari Ward. |
| Mixed | I heard that the Ministry of Education, Culture, Sports, Science and Technology will issue vaccination certificates for students planning to study abroad. That’s great, but isn’t the Ministry of Health, Labor and Welfare supposed to provide the vaccination certification? It's going to be confusing. |

### Sentiment Analysis

Lacking efficient models and labeled corpora for a mixture of Japanese and English, we did not propose or fine-tune a model for sentiment analysis. Instead, Amazon Web Services (AWS) supporting multiple languages was chosen for this task. The sentiment analysis includes 4 labels: positive, negative, neutral, and mixed. The positive ratio of tweets was defined as the number of positive tweets divided by the number of negative tweets within the same time period. For each tweet, the model predicts the label and provides the score for each label. Some examples of tweets of different sentiments are in Table 1.

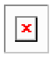
To determine the long-term tendency of the statistical data on public attitudes, we calculated the Pearson correlation coefficient (*r*) between the daily number of positive or negative tweets and the daily statistics for death, infection, and vaccinated cases using the Python package NumPy. The closer the absolute value of the *r* to 1, the stronger is the linear correlation between X and Y. In this study, we calculated the correlations before and after the start of vaccinations in Japan to determine whether vaccinations influenced the correlations.

### Latent Dirichlet Allocation

LDA is an unsupervised generative probabilistic model widely used in topic modeling [37]. LDA regards the documents in a corpus as generated from different topics, and each topic generates the documents following a Dirichlet distribution. We applied LDA modeling of vaccine-related tweets consistent with recent studies in other countries that included topic modeling [25,27]. We first generated the document-term matrix, which recorded the token frequencies in each tweet. All the tweets were put into a list, where each tweet was converted into unigrams and reconnected by spaces between neighboring tokens. A document-term matrix was generated on the reconnected tweets. Similar to [27], we also adopted the R package ldatuning [38] for topic number selection. The scores of 4 different metrics were calculated for the topic numbers from 2 to 50 (Figure S1 in Multimedia Appendix 2). The topic number with lower scores for the metrics of “Arun2010” [39] and “CaoJuan2009” [40] and higher scores for the metrics of “Griffiths2004” [41] and “Deveaud2014” [42] are more suitable for LDA modeling. In this study, “Deveaud2014” and “CaoJuan2009” reached the highest score on 6 topics. We built a 6-topic LDA model using the Python package scikit-learn for the tweets of negative sentiments from the first dose vaccination (February 17, 2021) in Japan to June 30, 2021. The results were made into bar plots of different topics to show the concerns during this period. The theme of each topic was summarized by 3 volunteers after a group meeting. The expectation of the number of tweets belonging to the *i*-th LDA topic was calculated by summing up the probability for each tweet generated by the *i*-th LDA topic.

### Peak Detection of Daily Trends

To provide an overview of the data, we plotted the trends of the daily number of total tweets and positive or negative tweets. For more precise analyses, the peaks in the data were labeled on the plots. For a human-like but objective selection, the peaks were determined by an algorithm with reference to the Weber-Fechner law [43] instead of human observation. The peaks of each month were selected using the following ratio:





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where $n_{day}$ is the number of tweets for the selected day and $n$ is the average number of daily tweets in the month. If the ratio $p_{day}$ is higher than a threshold λ, the number of tweets of that day is judged as a peak. We then selected the valid peaks from all the peaks. Peaks with less than $n_{min}$ tweets and peaks within $d$ days from the previous peak were discarded. In this study, λ=1.8, $d$=5, and $n_{min}$=200 for the total number of tweets, and $n_{min}$=40 for the number of positive or negative tweets. For all the detected peaks, we checked the tweets and provided the headline vaccine-related news in the tweets that day.

### Ethical Considerations

This study used publicly available and accessible tweets collected by Georgia State University's Panacea Lab allowing free download. We assert that our analysis is compliant with Twitter's usage policy in aggregate form without identifying specific individuals who made the Twitter posts. Also, the numbers of infections, deaths, and vaccinated cases downloaded from the MHLW and PMOJ are open government data. Therefore, the activities described do not meet the requirements of human subject research and did not require review by an institutional review board.

## Results

### Overview of the Data

For a better understanding of the public attitude toward COVID-19 vaccines in Japan, we analyzed the trend and sentiments of vaccine-related tweets before and at the beginning of vaccination. We counted the number of vaccine-related tweets every day; the trends are shown in Figure 1. Headline news marking the milestones in Japan's vaccinations were marked on the curve. The number of daily vaccine-related tweets increased continuously over the whole time period. Before November 9, 2020, the number of daily vaccine-related tweets was around or below 200. The detected peaks were related to some important vaccine-related news. On August 11, 2020 (n=463; n indicates the number of tweets), Russia approved the world's first COVID-19 vaccine [44]. On August 25, 2020 (n=293), the Chinese government initiated the vaccinations of medical workers with self-developed vaccines. On September 9, 2020 (n=416), the AstraZeneca COVID-19 vaccine study was put on hold because of suspected adverse reactions in the participants. Two relatively small peaks (n= 292, n=274) were related to negative news about clinical trials in October 2020. The initial sharp peaks in the number of daily vaccine-related tweets were on November 9, 2020 (n=1006) and November 16, 2020 (n=606): Pfizer stated that its vaccine was 90% effective [5], and Moderna reported an effectiveness of 94.5%. The second surge in the number of daily tweets occurred on December 30, 2020 (n=1015), when a US nurse tested positive over a week after the first dose of vaccinations [45]. No additional peaks were detected in the following period, but the daily number of vaccine-related tweets continued increasing, especially after April 2021. This may be related to large-scale vaccinations in Japan, which is a long-term event across months.

We applied sentiment analysis to all tweets and counted the number of daily tweets for different sentiments in Figure S2 of Multimedia Appendix 2. About 85% of tweets displayed neutral sentiment, and negative sentiment overwhelmed positive sentiment in the other tweets. In Figure 2, we display the trends of positive and negative tweets with events. Negative sentiments mainly came from 3 aspects. The prompt response to vaccine rollout in other countries and news related to the side effects elicited negative public sentiment in Japan. Russia approved the first world's COVID-19 vaccine (August 11, 2020; n=47); China started to administer its self-developed vaccine to medical workers on August 25, 2020 (n=74). Negative news about vaccinations in other countries also caused negative sentiment in Japan. AstraZeneca and Johnson & Johnson paused their studies on September 9, 2020 (n=49), and October 13, 2020 (n=42); a nurse in the United States was infected after the first dose of vaccine on December 30, 2020 (n=127); and the WHO suggested that children should not be vaccinated in the current stage on June 22, 2021 (n=159). Negative sentiment also came from the severe infection situation and the local vaccination policy in Japan. Cases of infection and serious illness both reached the highest on record on January 21, 2021 (n=88); 10 prefectures extended the emergency statement on February 2, 2021 (n=114), and senior citizens started to get vaccinations on April 13, 2021 (n=114). In contrast, the high efficiency of the vaccine and the start of large-scale vaccinations in Japan triggered positive sentiment. On November 9, 2020 (n=83), and November 16, 2020 (n=41), Pfizer and Moderna announced their vaccines' effectiveness reached over 90% [46] and 94.5% [47], respectively, and on June 25, 2021 (n=42), a vaccine effect against the Delta variant was reported. On June 4, 2021 (n=61), the chief cabinet secretary announced the opening of vaccination appointments for workplaces and universities starting June 21, 2020. In addition, it is notable that the positive news about clinical trials also caused a peak of negative attitudes on November 9, 2020 (n=49).


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**Figure 1.** Trends of vaccine-related tweets with key events between August 1, 2020, and June 30, 2021. The red points indicate detected peaks, and the green points indicate important events related to vaccinations in Japan.

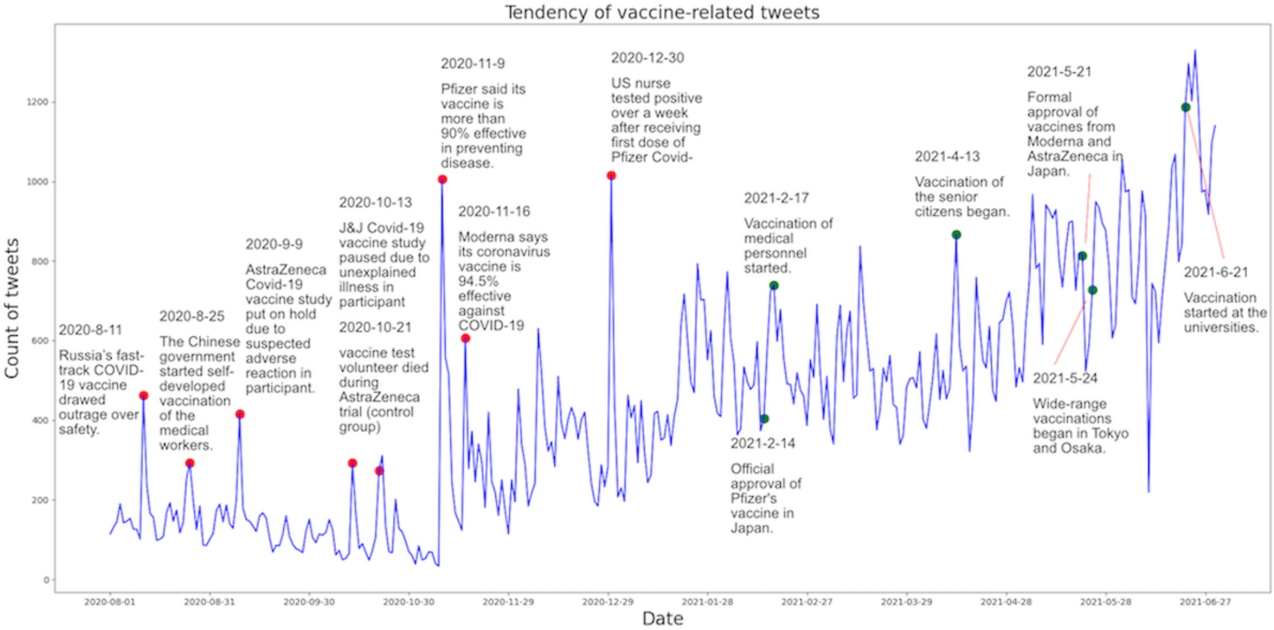
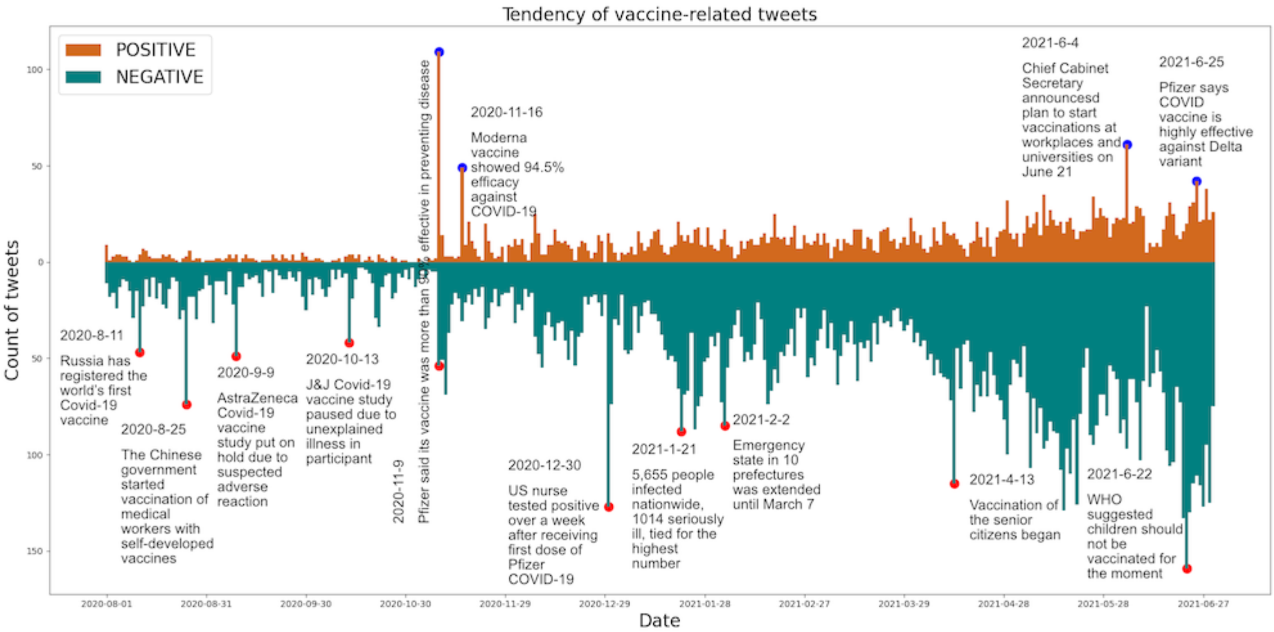



**Figure 2.** Trends of positive and negative sentiments between August 1, 2020, and June 30, 2021. The headline news related to the peaks are labeled.




### Correlation of Total Tweets and Positive or Negative Tweets With Cases, Deaths, and Vaccinations

As shown in Figures 3 and 4, we calculated the correlation coefficients of total tweets and positive or negative tweets with the daily death, infection, and vaccinated cases, both before and after the first vaccination in Japan (February 17, 2020, dashed line in Figure 4). As Table 2 shows, the daily number of tweets showed correlations with the numbers of deaths, cases, and vaccinations ($r$=0.642, 0.405, and 0.686, respectively; $r$=0.715 after the first vaccination); negative sentiment was strongly correlated with deaths ($r$=0.691) and cases ($r$=0.500) before the first vaccination, but they later decreased to 0.305 and 0.293, respectively. The correlation between negative sentiment and vaccinations was slightly higher than the correlation with positive sentiment after the first vaccination.


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**Figure 3.** Trends of daily number of tweets with the daily numbers of (A) cases, (B) deaths, and (C) vaccinations.

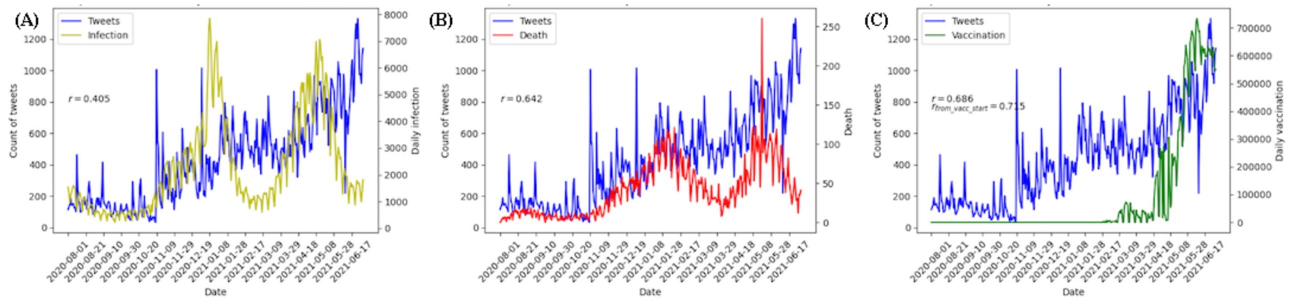


**Figure 4.** Trends of positive and negative sentiment together with the daily number of (A) cases, (B) deaths, and (C) vaccinations. The dashed line indicates the first day of vaccinations in Japan (February 17, 2020).

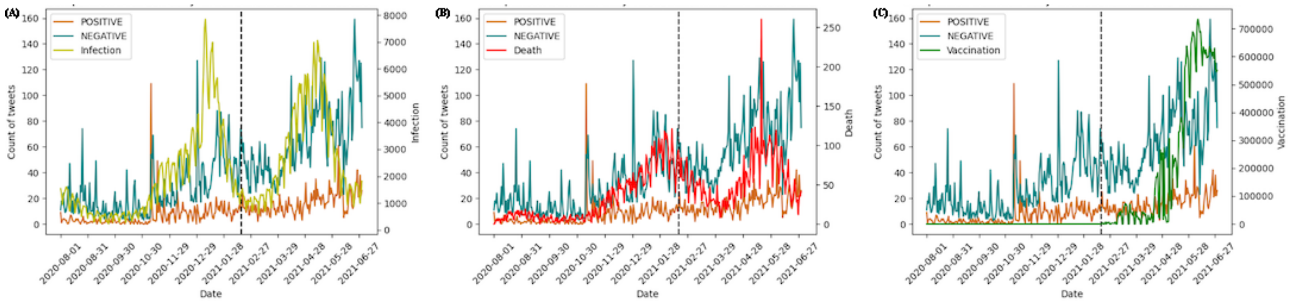


**Table 2.** The correlations of positive and negative sentiment with daily deaths, cases, and vaccinations before and after the first vaccination in Japan.

| Case types | Positive sentiment | | Negative sentiment | |
|---|---|---|---|---|
| | Before, *r* | After, *r* | Before, *r* | After, *r* |
| Death cases | 0.309 | 0.350 | 0.691[a] | 0.305 |
| Infection cases | 0.242 | 0.147 | 0.500[a] | 0.293 |
| Vaccinated cases | N/A[b] | 0.532[a] | N/A[b] | 0.575[a] |

[a]$r \geq 0.5$.

[b]The first vaccination in Japan was February 17, 2020, so we calculated the correlation before and after that day, respectively.

### Topic Modeling of Negative Tweets After Vaccination Started

To analyze the problems at the early stage in Japan regarding public attitude, LDA topics were extracted from negative tweets after the first dose of vaccination in Japan. The top 10 keywords for each of the 6 LDA topics are shown in Figure 5. Topic 1 might be related to worries on the safety of vaccines. The theme of Topic 2 could be concerns about the risk of infection during the Tokyo Olympics. Topic 3 might show dissatisfaction of the public with the slow vaccination process in Japan compared with other countries. The top keywords in Topic 4 indicate discussions of the effectiveness of different vaccine brands. Topic 5 was related to the vaccine reservation system and telephone scams toward senior citizens during the vaccination process. Topic 6 indicated diffidence on the safety of the vaccines, especially regarding the injections of children and medical staff.

The expectations of the numbers of tweets generated for each topic are shown in Figure 6. Expectations of the number of tweets generated by Topic 4 (2165) and Topic 3 (2062) were the highest, and the expectation of tweets generated by Topic 5 (815) was the lowest. The sum of the expectations of Topics 1 (1087) and 6 (1338) was slightly larger than that of Topic 4.


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**Figure 5.** Top 10 keywords (translated into English) for each of the 6 topics of the latent dirichlet allocation (LDA) model built on negative tweets after vaccination started. The weights can be regarded as the pseudo counts of the keywords in each topic.

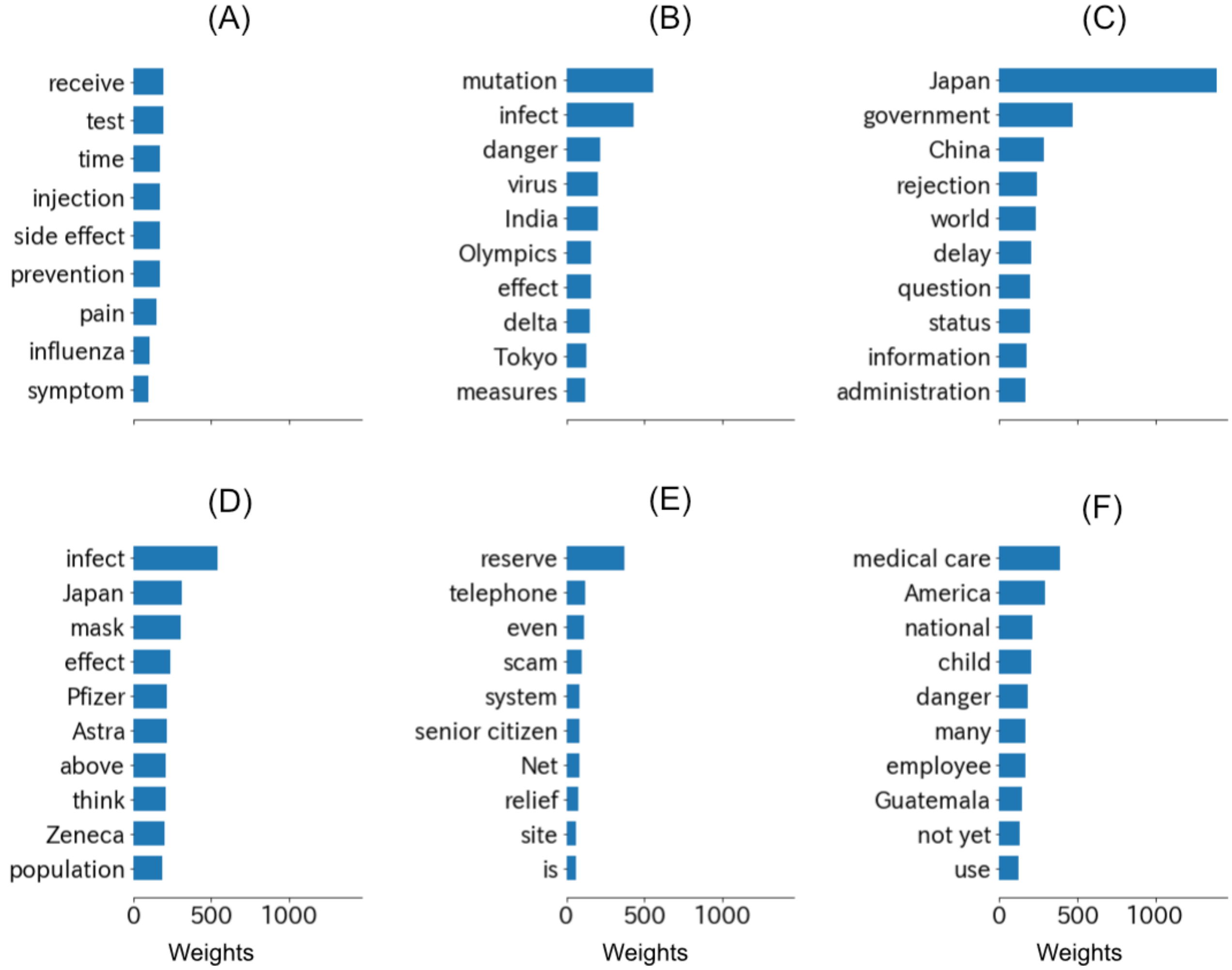
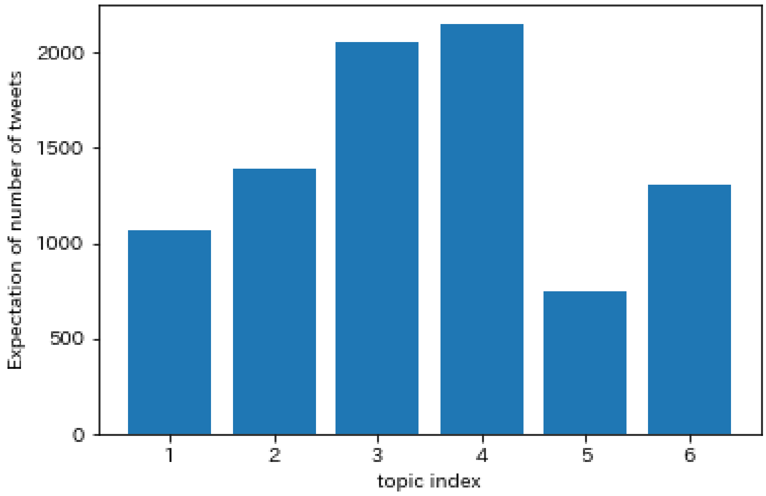



**Figure 6.** Expectation of number of tweets generated for each latent dirichlet allocation (LDA) topic.




### Three Manufacturers' Vaccines

We analyzed the public attitudes toward the 3 vaccine brands approved by the Japanese government. The numbers of related tweets, in descending order, were 12,089 for Pfizer, 7300 for AstraZeneca, and 3338 for Moderna. As shown in Figure 7, public concerns about the 3 vaccines showed temporal variations. AstraZeneca vaccines showed an overall upward trend with peaks in September 2020 and March 2021 and a gradual decline after March 2021. The Pfizer vaccine received greater attention than the others from October 2020 to February 2021 and reached a peak in November 2020. Moderna appeared less in discussions, but since March 2021, the number of related tweets has continued to grow along with those for the Pfizer vaccine. As for the positive ratio of tweets related to the 3



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manufacturers, the positive ratios for all 3 vaccines were lower than 0.5, meaning that the sentiment toward all the vaccine brands was negative. AstraZeneca had the lowest (0.19) average positive ratio, while Moderna had the highest (0.36).

We analyzed the top 10 words in the tweets related to each vaccine brand. As shown in Figure 8, the discussion of all 3 vaccines mainly concerned effectiveness and side effects. According to the term frequencies of the top words for different manufactures, Pfizer was discussed more often than AstraZeneca and Moderna combined. There were also differences in the keywords of different vaccines. For Pfizer, the keywords were mainly about effectiveness and supplements. For AstraZeneca and Moderna, the top keywords also included severe side effects and thrombosis for AstraZeneca and heart disease for Moderna. It is also noticeable that "thrombus" ranked second in the top keywords of AstraZeneca.

**Figure 7.** (A) Monthly number and (B) positive ratio of tweets related to the Pfizer, AstraZeneca, and Moderna vaccines between August 1, 2020, and June 30, 2021.

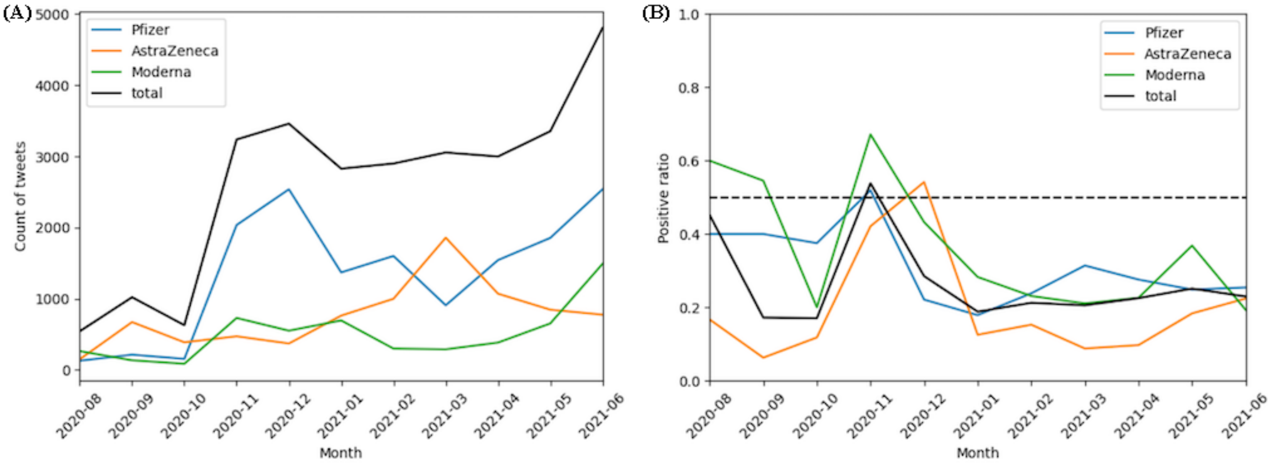
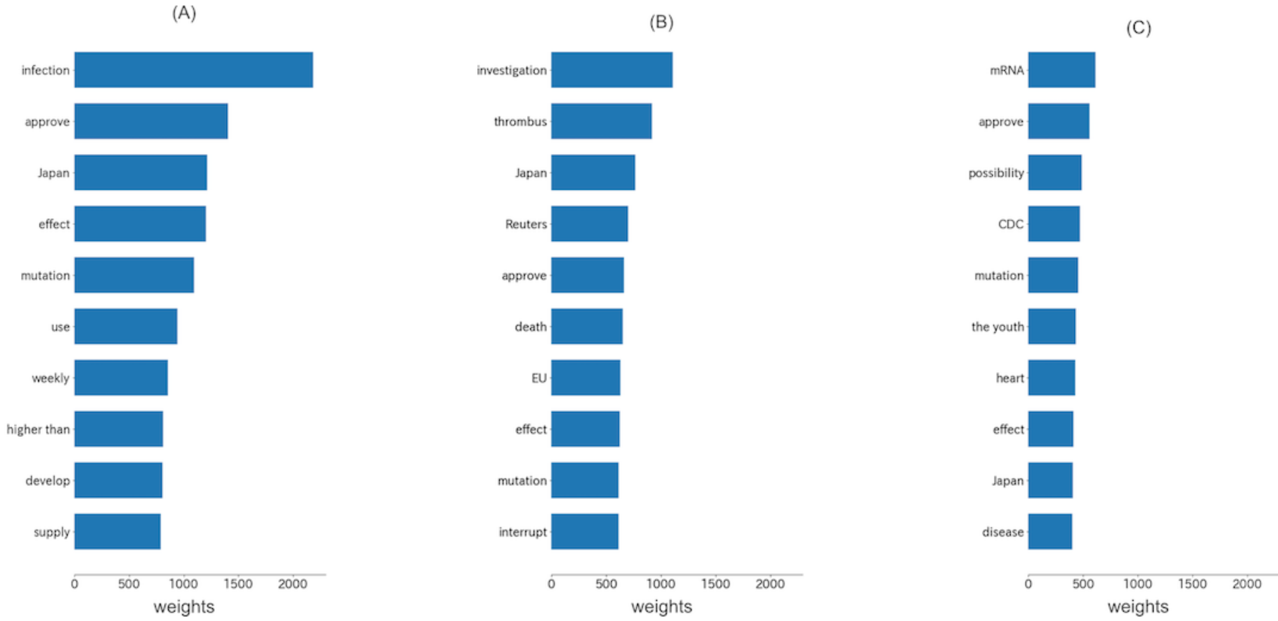



**Figure 8.** Top 10 words (translated into English) of tweets associated with the (A) Pfizer, (B) AstraZeneca, and (C) Moderna vaccines.




## Discussion

### Principal Findings

This study examined long-term Japanese public opinion and sentiment, covering discussions from August 1, 2020, through June 30, 2021, when multiple vaccines were available yet only 13.6% of the population was fully vaccinated in Japan. We evaluated the trends and sentiments of vaccine-related tweets in Japanese. The overall number of tweets continued to increase after the start of large-scale vaccinations in Japan, which might have been primarily driven by critical events related to the vaccines. The sentiments of most tweets were neutral, with negative sentiment exceeding positive sentiment in volume. The correlations between the sentiments and the daily cases, deaths, and vaccinations were calculated. We also checked the LDA topics of negative sentiment since the vaccination started to identify the problems of vaccination at the early stage. Finally, we analyzed the trends in public sentiment about 3 vaccine brands (Pfizer, Moderna, and AstraZeneca), which showed a temporal shift as clinical trials moved forward, but whose core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remained effective and secure. The top words for tweets related to each brand were also collected.

Our results show that negative sentiment outweighed positive sentiment in Japan, whereas most previous studies of other countries demonstrated more positive sentiment on social media [26,27,29]. The negative sentiment exhibited by our results is consistent with the findings of some previous survey studies in Japan [48-52], and we provided fine-grained and more practical evidence. We observed a decrease in the correlations of negative sentiment with numbers of cases and deaths in Table 2, for which the direct reason is the decrease in the numbers of cases and deaths and the abnormal increase in negative sentiment. The decrease in the numbers of cases and deaths may result from the effect of emergency statements and vaccinations, but the increase in negative sentiment might have stemmed from the frequent negative news about the messy process of vaccinations, including busy phone lines, website crashes, and incorrectly administered vaccinations in this period. We also found that the same event could trigger positive and negative sentiments in Japan. On November 9, 2020, when Pfizer reported that its vaccine was more than 90% effective, the peak of both positive and negative sentiments might indicate public expectation of its effectiveness and concerns about its safety. We presume that the negative sentiment was caused by the accumulation of negative news from different vaccines during clinical trials. There was a downward trend in both deaths and infections after the first dose, contrary to the trend of a consistent increase in the number of tweets.

The LDA topics of negative tweets reflected public concerns at the early stage of vaccination. Topics 1 and 6 concern the safety of vaccines. The sum of the expectations of the 2 topics was overwhelmingly greater than those of the other topics, which indicates that concerns about side effects might have outweighed the fear of infection at the beginning of the vaccination process. Similar results showing higher concerns about vaccine safety than the risk of infection can be found in classical surveys in other countries [53,54]. Topic 3 showed dissatisfaction with the slow vaccination process in Japan. This result is consistent with a survey-based study indicating disappointment of the Japanese public because of better performance during COVID-19 in neighboring countries [55]. Topic 2 showed pessimistic attitudes toward the Olympics, especially under the threat of a mutated virus, which is consistent with the results of a survey on the attitudes toward the Tokyo Olympics in several countries [9]. The expectation of the number of tweets generated by Topic 5 was the lowest, but the theme of Topic 5 directly indicated some problems during the vaccination process. The vaccine rollout system was inefficient at first in Japan [8], and people found it hard to reserve COVID-19 vaccines even though supplementation of vaccines was sufficient [56]. The reservation difficulties also provided a chance for telephone scams [57], which might have increased distrust in the vaccination process.

The sentiments and top words differed slightly across the vaccine brands, but the core remained effective and secure. Compared to the other 2 vaccines, the public tended to focus on the effectiveness of Pfizer in preventing infection, as opposed to Moderna, which tended to focus more on its effectiveness against mutated viruses and its mRNA development technology. The average percentage of positive sentiment for AstraZeneca was the lowest, similar to results in other countries [28]. The top words for both AstraZeneca and Moderna showed strong concerns among the public about the severe side effects of the vaccines. Furthermore, we found that "fake news" or misleading headlines caused public panic and widespread negative sentiment. For example, on October 21, 2020, numerous media outlets reported that the clinical trial of the AstraZeneca vaccine had led to the death of a Brazilian volunteer, which continued to trigger public panic even though the next day it was reported that the volunteer had not received the vaccine [58].

## Implications and Recommendations

The popularity of social media platforms coupled with NLP strategies benefits the government by enabling the monitoring of close-to-real-time public sentiment regarding vaccine information. This can inform more effective policy making and establish confidence toward vaccines so as to maximize vaccine uptake. Some of our findings provide new evidence and inspiration to academic researchers and can assist policy makers in capturing the relevant information needed in real time.

Our study provides Japanese public opinion and sentiment toward the COVID-19 vaccine with dynamic and unmodified expression. Japan ranked among the countries with the lowest vaccine confidence in the world, which might be linked to the HPV vaccine safety scares that started in 2013. However, the way in which the HPV vaccine scare was approached by health officials indicates continuing issues with the Japanese vaccination program that need resolving. Correspondingly, our findings indicate that the Japanese public showed significant negative sentiment before and at the beginning of vaccinations.

The LDA model of the negative tweets during the early stage of vaccination suggested some factors related to the slow vaccination process, which all indicated the importance of the swift action of the government and policy makers during the vaccination process. The strong concerns regarding the safety of vaccines at the beginning of the vaccination process suggest the necessity of building vaccine confidence. Swift and fair feedback on vaccine safety by policy makers could be especially important in the early stages of vaccination. Comparison with the vaccination process in other countries indicated the expectation of a prompt vaccination process in Japan. The claims regarding problems with the reservation system and vaccine-related telephone scams showed the urgency of building a convenient and safe pipeline for vaccine distribution and reservation, presenting the challenge of both the flexibility of the medical care system [8] and the acceleration of the digitalization process [59] in Japan. Concerns about the Olympics were also caused by the slow progress of anti-epidemic measures and the vaccination process but also showed the need for risk evaluation by policy makers balancing public health and other factors [60].

The public was concerned about the severe side effects of vaccines and was easily affected by fake or misleading news about the vaccines. To build vaccination confidence, it is also important to respond to concerns about the different vaccine manufacturers and respond to fake news in detail.



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### Limitations

Our study has several limitations. First, as Twitter penetration is only 58.2 million (42.3% of the total population) people in Japan, our data may not be representative of the entire population, especially the older generations. Second, according to Twitter's user privacy protection principles, our study could not further examine the demographic characteristics of users, such as age, gender, and geographic location. Third, due to the limitations of Japanese resources for sentiment analysis, we used AWS without training on data, so our findings might have been influenced by the accuracy of the model. Eventually, only a small number of people was vaccinated during our study period, especially older adults and health care workers. So, most of the tweets posted by users were based on information from the internet and news rather than direct experience with vaccinations. Accordingly, further in-depth studies are needed in the future.

### Conclusions

This study identified the Japanese public opinions and sentiments expressed on Twitter before and at the beginning of vaccination. The public attitude toward vaccination in Japan was negative, and the concerns about side effects might have outweighed the fear of infection at the beginning of the vaccination process, which reflected the necessity of boosting vaccine confidence. LDA topics of the negative tweets at the early stage of vaccination indicated that the government and policy makers should take prompt actions in constructing a safe and convenient vaccine reservation and rollout system, which requires both the flexibility of the medical care system and the acceleration of digitalization in Japan. People showed different attitudes toward the 3 vaccine brands. Policy makers should provide more evidence about the effectiveness and safety of vaccines and rebut fake news to build vaccine confidence.


## Acknowledgments

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## Conflicts of Interest

None declared.

Multimedia Appendix 1
These are translation tables between English and Japanese.
[XLSX File (Microsoft Excel File), 66 KB - infodemiology_v2i1e32335_app1.xlsx ]

Multimedia Appendix 2
Supplementary figures.
[DOCX File , 314 KB - infodemiology_v2i1e32335_app2.docx ]

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## Abbreviations

**API:** application programming interface
**AWS:** Amazon Web Services
**HPV:** human papillomavirus
**LDA:** latent dirichlet allocation
**MHLW:** Ministry of Health, Labor and Welfare
**NLP:** natural language processing
**PMOJ:** Prime Minister of Japan and His Cabinet
**WHO:** World Health Organization


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Original Paper

# Identifying the Socioeconomic, Demographic, and Political Determinants of Social Mobility and Their Effects on COVID-19 Cases and Deaths: Evidence From US Counties

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## Abstract

**Background:** The spread of COVID-19 at the local level is significantly impacted by population mobility. The U.S. has had extremely high per capita COVID-19 case and death rates. Efficient nonpharmaceutical interventions to control the spread of COVID-19 depend on our understanding of the determinants of public mobility.

**Objective:** This study used publicly available Google data and machine learning to investigate population mobility across a sample of US counties. Statistical analysis was used to examine the socioeconomic, demographic, and political determinants of mobility and the corresponding patterns of per capita COVID-19 case and death rates.

**Methods:** Daily Google population mobility data for 1085 US counties from March 1 to December 31, 2020, were clustered based on differences in mobility patterns using K-means clustering methods. Social mobility indicators (retail, grocery and pharmacy, workplace, and residence) were compared across clusters. Statistical differences in socioeconomic, demographic, and political variables between clusters were explored to identify determinants of mobility. Clusters were matched with daily per capita COVID-19 cases and deaths.

**Results:** Our results grouped US counties into 4 Google mobility clusters. Clusters with more population mobility had a higher percentage of the population aged 65 years and over, a greater population share of Whites with less than high school and college education, a larger percentage of the population with less than a college education, a lower percentage of the population using public transit to work, and a smaller share of voters who voted for Clinton during the 2016 presidential election. Furthermore, clusters with greater population mobility experienced a sharp increase in per capita COVID-19 case and death rates from November to December 2020.

**Conclusions:** Republican-leaning counties that are characterized by certain demographic characteristics had higher increases in social mobility and ultimately experienced a more significant incidence of COVID-19 during the latter part of 2020.

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**KEYWORDS**
COVID-19; cases; deaths; mobility; Google mobility data; clustering



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## Introduction

In March 2020, COVID-19 was acknowledged by the World Health Organization (WHO) to be a global pandemic [1]. Since then, governments worldwide have implemented a series of lockdown measures intended to reduce the spread of the disease. The efficacy of these measures, in the absence of a vaccine or effective therapy, has varied across countries. Initial evidence on lockdown measures implemented in China suggested that reducing interpersonal physical contact or reducing the movement of the population is an effective means to control the spread of the virus [2]. These findings spurred national and subnational policies restricting population mobility, including social distancing (physical distancing between people who are not from the same household) [3] and stay-at-home (SAH) or shelter-in-place (SIP) orders, which required people to stay at home except for essential activities [4,5].

In addition to the direct impacts of such policies, evaluating the effects of demographic and socioeconomic factors on population mobility is also important as there were non-pandemic-related events that significantly impacted public movements in the U.S. after the first wave of the pandemic. Specifically, the summer of 2020 witnessed many demonstrations and public rallies in the U.S. in response to a series of events, including the death of George Floyd. Social distancing receded into the background despite rising caseloads and deaths due to COVID-19. The initial decline in public movement that occurred during the early months of the pandemic was succeeded by rapid increases in social mobility through much of the U.S. [6]. Increases in social mobility also occurred as many jurisdictions modified their SAH orders, allowed more businesses to reopen, and relaxed rules on social distancing [7]. This rise in mobility has been linked to higher COVID-19 cases in these regions [8]. Public mobility may have also increased during fall 2020 because of public rallies and social gatherings associated with the US presidential election.

A growing amount of research has used mobility data from social media platforms (Google, Twitter, and Facebook) and mobile phone providers to understand changes in mobility during the pandemic [9,10], the relationship between population mobility and the spread of COVID-19 cases [8-18], and the effects of nonpharmaceutical interventions (NPIs) on mobility [5,19,20]. The consensus from these studies is that increased mobility is associated with higher COVID-19 case counts. Badr et al [15] used cell phone data from 25 counties provided by Teralytics and found that reduced mobility patterns are associated with reduced COVID-19 incidence rates. Using mobile phone data from Safegraph, Gao et al [20] similarly found that lower mobility (more time at home) is associated with a reduced spread of COVID-19 across states. Glaeser et al [19] also used Safegraph data and found reduced mobility to be correlated with lower cases for some US cities. Using Google data from different jurisdictions, other studies found a positive correlation between mobility and COVID-19 case counts [11,12,14,17]. These studies are, however, limited; they investigated social mobility across a small number of US counties during the early days of the pandemic. As such, they were unable to capture socioeconomic, demographic, and political determinants of mobility [21-25].

We evaluated the determinants and consequences of population movements in 1089 US counties from the start of the pandemic to December 2020. This study contributes to the literature by using clustering analysis and other tools to evaluate the impacts of different socioeconomic and demographic characteristics on social mobility in a sample of US counties. We also investigated the effects of such mobility decisions on daily per capita COVID-19 cases and deaths. Social mobility was measured through the use of Google mobility indicators at retail and recreational venues, grocery and pharmacy stores, workplaces, and residences. Robust statistical findings based on such analysis would inform policymakers in crafting efficient and effective NPIs that could curb the spread of COVID-19.

Our results demonstrate that clusters with higher mobility at retail outlets, grocery and pharmacy stores, and workplaces and a lower duration of stay at residences also have a higher percentage of population aged 65 years and over, a larger population share of Whites with less than high school and college education, a higher percentage of the population with less than a college education, a lower percentage of the population using public transit to work, and a smaller share of voters who voted for Clinton during the 2016 presidential election relative to other clusters. The clusters with higher mobility also experienced pronounced increases in per capita COVID-19 daily case and death rates from November to December 2020. These findings are consistent with other studies that suggest that Trump-leaning counties experienced increases in social mobility and less stringent policies after the first wave of the pandemic, which was succeeded by higher levels of disease severity during the latter months of 2020.

## Methods

### Data

#### *COVID-19 Incidence Data*

The daily numbers of confirmed cases and deaths due to COVID-19 at the county level were downloaded from the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU) [26]. For the 1089 counties in our sample, the mean (SD) of confirmed cases and deaths (both per 100,000 of population) were 1541.27 (1905.59) and 33.72 (44.78), respectively. Figure 1 reveals the distribution of counties in our sample. There is a significant concentration of counties in the East, Northeast, and certain southern states. There are fewer counties from the midwestern and southwestern parts of the United States. This is because Google mobility data (discussed later) are less available for counties with lower population density. This is a limitation of our analysis.



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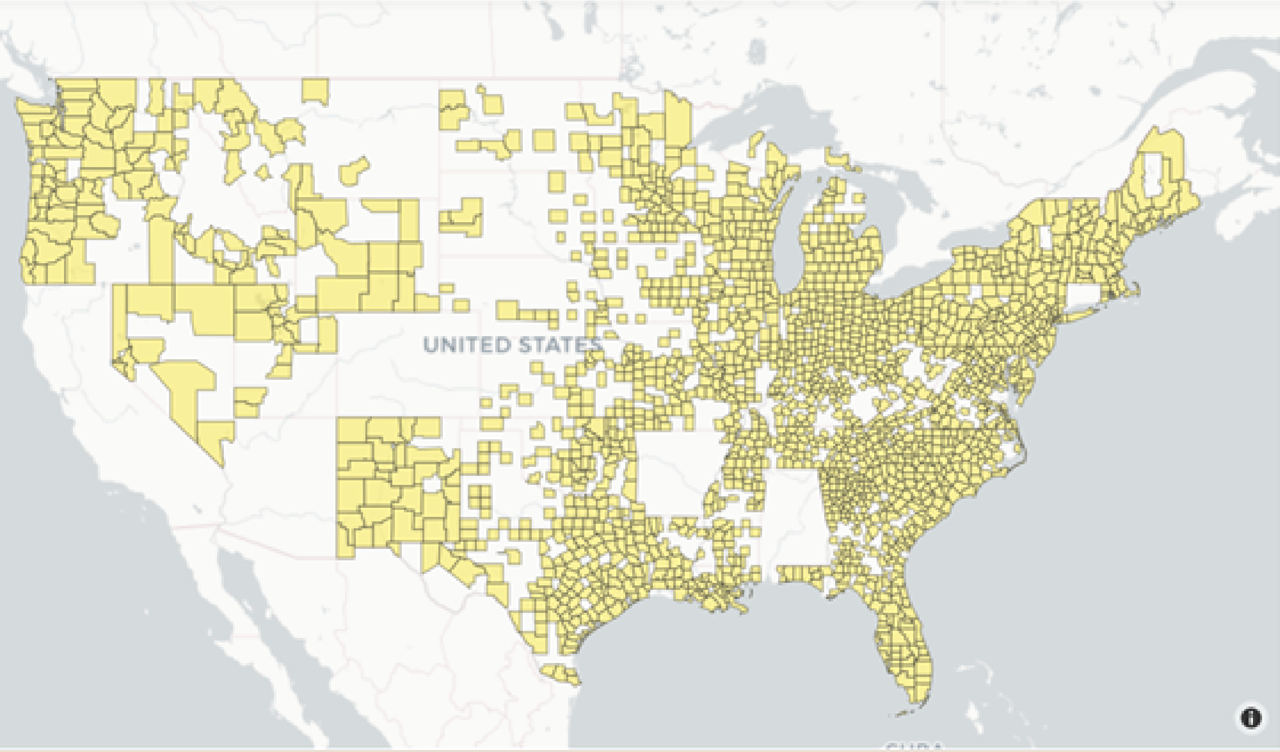
**Figure 1.** Geographic distribution of counties.




### Population Mobility

Data on population mobility were obtained from Google's COVID-19 *Community Mobility Reports*. Google creates social mobility data from users who have turned on the Location History setting of Google accounts on their phones and have agreed to share this information. Google mobility indicators are with respect to population-level daily visits to grocery and pharmacy stores, which include grocery markets, food warehouses, farmers' markets, specialty food shops, drug stores, and pharmacies; parks, which consist of local parks, national parks, public beaches, marinas, dog parks, plazas, and public gardens; transit stations, comprising subway, bus, and train stations; retail stores and recreation outlets consisting of places such as restaurants, cafes, shopping centers, theme parks, museums, libraries, and movie theaters; and workplaces. The Google mobility data also provide an index on the duration of stay at residences. Google mobility indicators for transit hubs and parks were omitted because of large numbers of missing values for the counties included in this study.

A prepandemic baseline mobility value was determined using the median mobility for each day of the week from January 3 to February 6, 2020 [27]. Subsequent mobility values were normalized to baseline. Counties with missing values less than or equal to 10% for each indicator were selected for the study. Missing values were replaced by the average from 3 prior days. The availability of Google data determined which counties we used in our analysis. The final data set contained observations for 1089 counties, which is roughly 35% of the total number of counties (N=3142) in the United States. Daily values were available for the first and second waves of the pandemic from March 11 to December 31, 2020.

With the exception of the residential index, daily values for each index were calculated relative to baseline, which was defined as the median for the corresponding day of the week, during the 5-week period from January 3 to February 6, 2020. Hence, each daily value is the percentage change in the social mobility category relative to its baseline, which shows how the number of visits to different destinations in a day have changed in percentage terms since the onset of the pandemic. The Google residential index represents the duration of stay at an individual's residence relative to the 5-week baseline. The values in this index are the percentage differences in time spent at home relative to the baseline period.

### County-Level Socioeconomic, Demographic, and Political Data

The 2016 census data were collected by the Massachusetts Institute of Technology (MIT) Election Data and Science Lab [18]. These data were supplemented by county variables collected by other studies [23,25]. To validate that our samples were representative of all US counties, we compiled summary statistics of socioeconomic and demographic variables between our sample and all counties (Table 1). In summary, there did not seem to be significant differences in most variables between all counties and our sample. The exception is population, where our sample mean was more than 2.5 times that of the mean for all counties. In a similar vein, although all counties have 58% of the population in rural areas, the corresponding statistic for our sample was only approximately 31%. These discrepancies can be explained by the fact that Google's social mobility indicators are only available for counties with larger populations that are more densely populated. This is consistent with the visualization of counties in our sample from Figure 1.



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**Table 1.** Sample statistics of census variables for all counties and our sample based on daily values.

| Variable | All counties | | | Our sample | | |
|---|---|---|---|---|---|---|
| | Mean (SD) | Minimum | Maximum | Mean (SD) | Minimum | Maximum |
| **Politics** | | | | | | |
| Population voting for Trump in 2016 (%) | 28.13 (8.44) | 1.93 | 76.32 | 24.28 (7.22) | 2.63 | 66.42 |
| Population voting for Clinton in 2016 (%) | 14.07 (7.41) | 0 | 49.02 | 17.18 (7.33) | 2.73 | 42.86 |
| Registered voters as population (%) | 74.86 (5.31) | 43.14 | 95.08 | 73.49 (5.14) | 47.33 | 90.63 |
| **Demographics** | | | | | | |
| Whites (%) | 77.36 (19.74) | 0.76 | 100.00 | 73.57 (18.63) | 2.78 | 97.34 |
| African Americans (%) | 8.96 (14.5) | 0 | 86.19 | 9.96 (12.21) | 0.09 | 76.55 |
| Hispanics (%) | 8.99 (13.66) | 0 | 98.96 | 11.03 (13.41) | 0.68 | 95.48 |
| Foreign born (%) | 4.62 (5.63) | 0 | 52.23 | 7.12 (6.81) | 0.40 | 52.23 |
| Females (%) | 49.98 (2.33) | 21.51 | 58.50 | 50.62 (1.30) | 38.76 | 56.03 |
| Population aged 29 years and under (%) | 37.34 (5.44) | 11.84 | 70.98 | 39.24 (4.98) | 13.64 | 61.69 |
| Population aged 65 years and older (%) | 17.63 (4.44) | 3.86 | 53.11 | 15.57 (3.93) | 6.95 | 53.11 |
| Less than high school education (%) | 14.23 (6.54) | 1.28 | 51.48 | 12.44 (5.26) | 2.08 | 41.34 |
| Less than college education (%) | 79.22 (9.14) | 19.79 | 97.02 | 73.98 (10.11) | 26.34 | 90.86 |
| Whites with less than high school education (%) | 11.04 (5.33) | 0 | 41.76 | 9.11 (3.92) | 0.97 | 25.57 |
| Whites with less than college education (%) | 77.00 (10.36) | 9.19 | 95.92 | 71.28 (11.58) | 15.30 | 89.96 |
| **Socioeconomics** | | | | | | |
| Median household income (US $) | 47,817.60 (12482.4) | 18,972.00 | 125,672.00 | 53,798.50 (13905.9) | 28,452.00 | 125,672.00 |
| Rural population (%) | 58.48 (31.45) | 0 | 100.00 | 31.733 (22.08) | 0 | 100.00 |
| Population density (number of people per square mile) | 582.71 (3761.83) | 0.26 | 179,922.30 | 1397.32 (6127.90) | 6.22 | 179,922.30 |
| Hospitals per 100,000 of population (number of hospitals per 100,000 of population) | 0.61 (0.94) | 0 | 10.56 | 0.25 (0.166) | 0 | 1.61 |
| Poverty rate (%) | 15.16 (6.07) | 2.60 | 48.40 | 13.35 (4.87) | 2.60 | 37.30 |
| Population without health insurance (%) | 0.09 (0.05) | 0.01 | 1.62 | 0.09 (0.06) | 0.02 | 1.62 |
| Share of population using public transit for commuting to work (%) | 0 (0.01) | 0 | 0.26 | 0.01 (0.02) | 0 | 0.26 |

## Clustering

Figure 2 summarizes our methodology for identifying different clusters of counties using Google mobility indicators. Clustering is an unsupervised learning technique that partitions a data set into groups or clusters based on similarity measures. This study leveraged partitioning-based algorithms, which divided the data set into partitions, where each partition was a cluster. For each county included in this study, data were clustered based on a combination of the daily values of the 4 Google mobility indicators. To identify the different clusters of counties, we performed 2 steps [28]:

1. Compressing the multidimensional time series data to extract the latent variables using deep neural networks
2. Using K-means clustering to identify the different clusters of counties based on latent variables' representations



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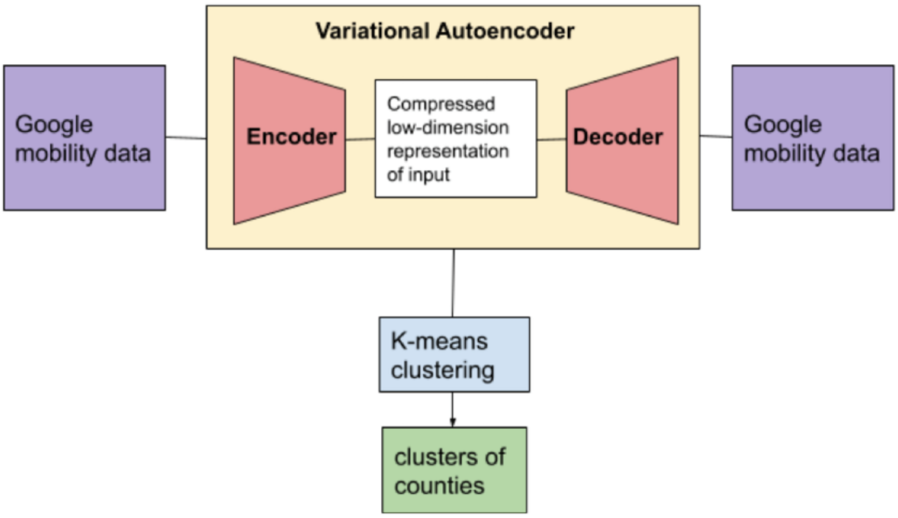
**Figure 2.** Methodology for identifying different clusters of counties using a variational autoencoder.



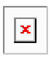

To compress the multidimensional time series, we implemented the variational autoencoder (VAE) architecture based on long short-term memory (LSTM) [29-31]. The principal concept of this generative approach is to project high-dimensional data into latent variables. Our model comprised 4 blocks [32]:

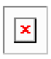
1. Encoder: Defined by the LSTM layers, the multidimensional time series input (x) are fed into the LSTM.
2. Encoder to latent layer: Defined by a linear layer, which identifies the mean and SDs of the last hidden layer of the encoder. During the training process, the multigaussian distributions are defined and reparametrized iteratively by the mean and SDs derived from latent vectors.
3. Latent layer to decoder layer: The latent variables (z) are sampled from the distribution and pass through a linear layer to identify the decoder input.
4. Decoder: Defined by the LSTM layers, which uses latent variables (z) to reconstruct the original data [33].

Identifying the true posterior distribution is intractable [33]. Therefore, to construct the original data, the probabilistic encoder model was approximated by normal distribution p(z|x)N(0,1) and used as a probability decoder [30,33]. Hence, the reconstruction of input was defined by sampling from the distribution of latent variables (z).

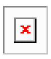
To evaluate the performance of the model, the loss function was defined as follows:

- The divergence from the approximated distribution and the true distribution

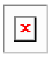




- The mean squared error loss calculated the difference between original and reconstructed input data



- The total loss is defined as sum of 2 losses:



The model was trained in Python 3.6 using the Keras library [34] with the Adam optimizer. The batch size and number of the epochs were set to 10 and 100, respectively. The number of nodes for encoder and decoder hidden layers was set to 500. The dimensionality of latent variables was set to 3. We also implemented the L1 and L2 regularizers to avoid overfitting. To evaluate the performance of the model, the VAE total loss was used to identify the reconstruction error between encoder input and decoder output.

Once the model was trained and the encoder, decoder, and VAE were constructed, the output of the encoder model was selected as the representation of the multidimensional patterns of each county. K-means clustering was used to identify the similar segmentation of the counties. To identify the optimum number of clusters as well as the homogeneity of data points within each cluster, the elbow method [35] and the silhouette score [36] were used.

## Explaining the Socioeconomic Characteristics of Similar Counties

To compare the socioeconomic characteristics of the counties in each cluster, the 2016 MIT election data were used as input, while the classes were the cluster labels. The data were divided into training and testing sets with a 70:30 split, respectively. The random forest classifier [37] with 10 k-fold cross-validations was used to build the predictive models. The area under the curve (AUC) of the model was calculated, and the most important features associated with the cluster numbers were defined as the parameters describing the characteristics of counties in each cluster. Feature scores of different census variables for the clusters were computed, which yielded an idea of the relative importance of different socioeconomic and demographic factors for explaining the different clusters. Figure 3 summarizes our approach.


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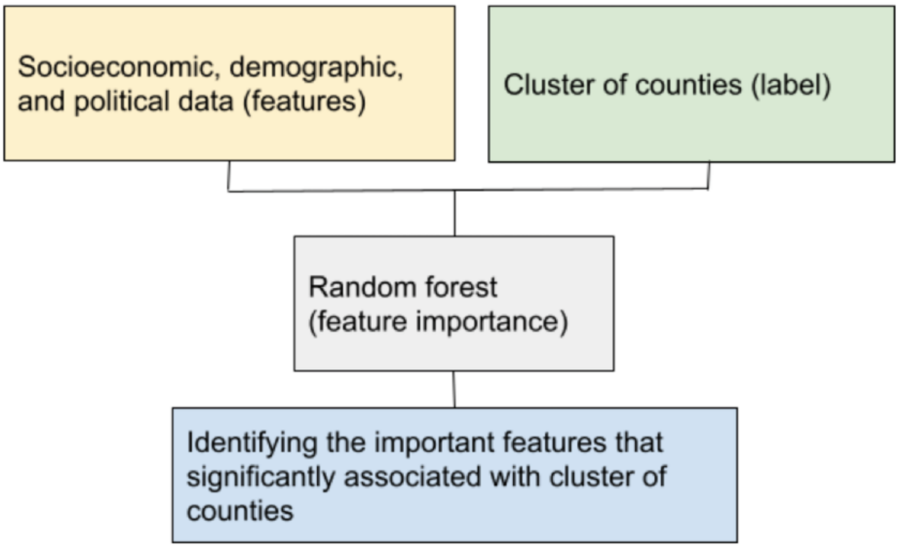
**Figure 3.** Framework to identify the socioeconomic characteristics of different clusters of counties using random forest feature importance.

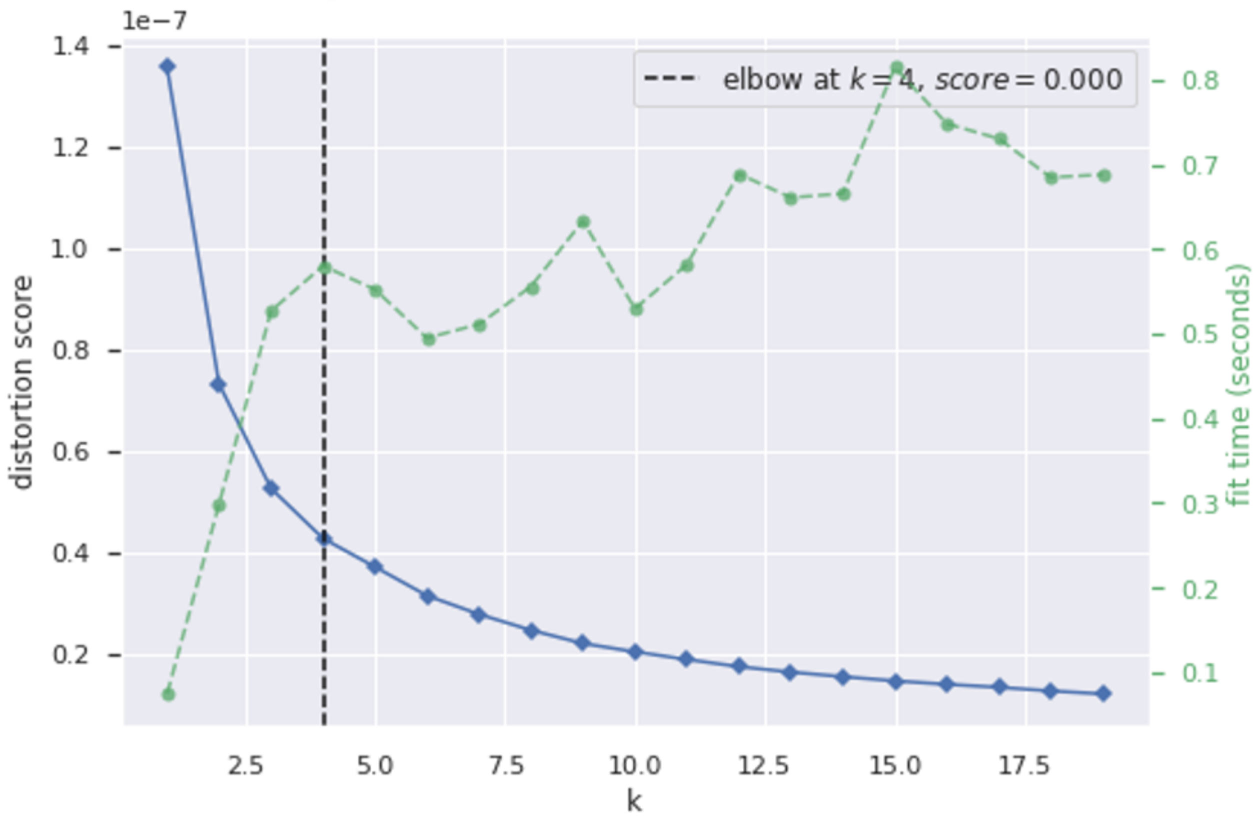



## Results

### Clustering

This study leveraged a partitioning-based deep learning model to cluster counties based on similarities in social mobility. For each county included in this study, data were clustered based on a combination of the daily values of the 4 Google mobility indicators (retail, grocery and pharmacy, workplace, and residence). The multidimensional time series of Google social mobility indicators from 1089 counties was divided into training and testing sets and fed into the VAE model. The result demonstrated a loss of 0.08. The latent variables were extracted as the output of the encoder. The K-means clustering algorithm identified 4 social mobility clusters. The number of counties in these clusters, which were termed as 0, 1, 2, and 3, were 215, 338, 473, and 59, respectively. Figure 4 gives the distortion scores of the K-means clustering.

**Figure 4.** Distortion score elbow for K-means clustering.





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## Google Social Mobility Trends

Across all clusters, visits to retail stores fell significantly after the start of the pandemic until around mid-April, followed by a steady increase and plateauing in early July (Figure 5). Visits to retail outlets began to decline again in late September but then began an upward trend starting on Thanksgiving weekend until the end of December. Retail social mobility values were the highest for cluster 0, followed by clusters 2 and 1, with cluster 3 having the lowest social mobility. Grocery and pharmacy mobility trends reflected those seen for retail social movements but were less pronounced (Figure 6). Cluster 0 had the highest values of grocery mobility, followed by clusters 2, 1, and 3. Workplace mobility showed an initial decline at the start of the pandemic, followed by a steady increase from early May onward (Figure 7). Spikes in mobility were observed during the weekend, which did not significantly decline relative to prepandemic observations. County clusters followed the same order, with cluster 0 having the greatest mobility, followed by clusters 2, 1, and 3.

**Figure 5.** Google retail mobility.


**Figure 6.** Google grocery and pharmacy mobility.

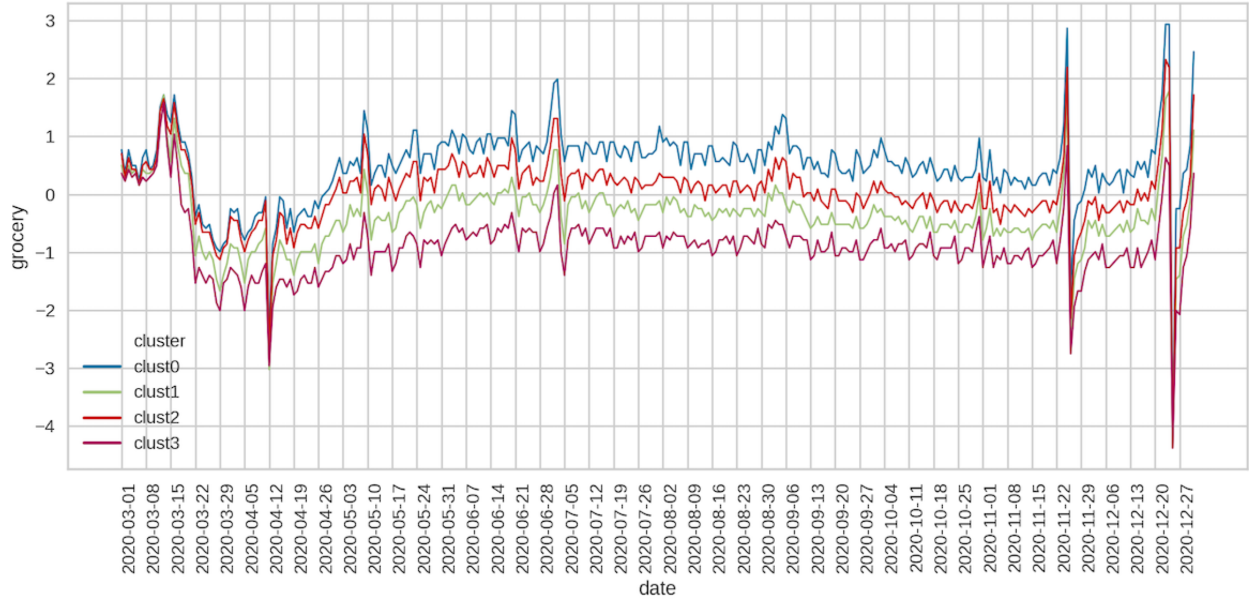




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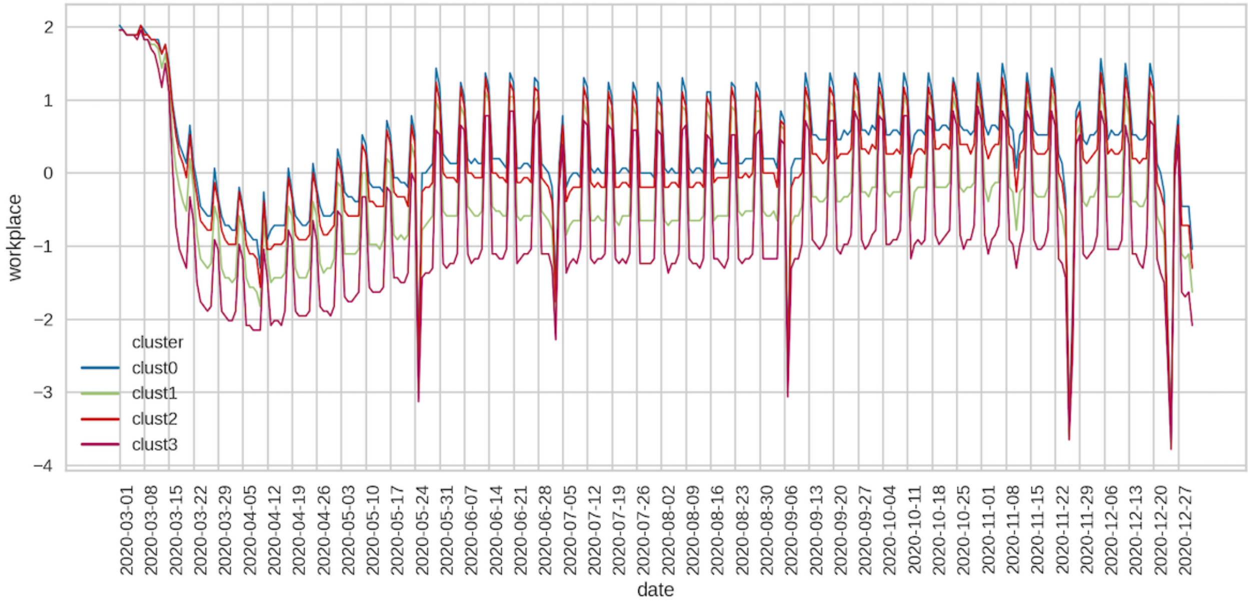
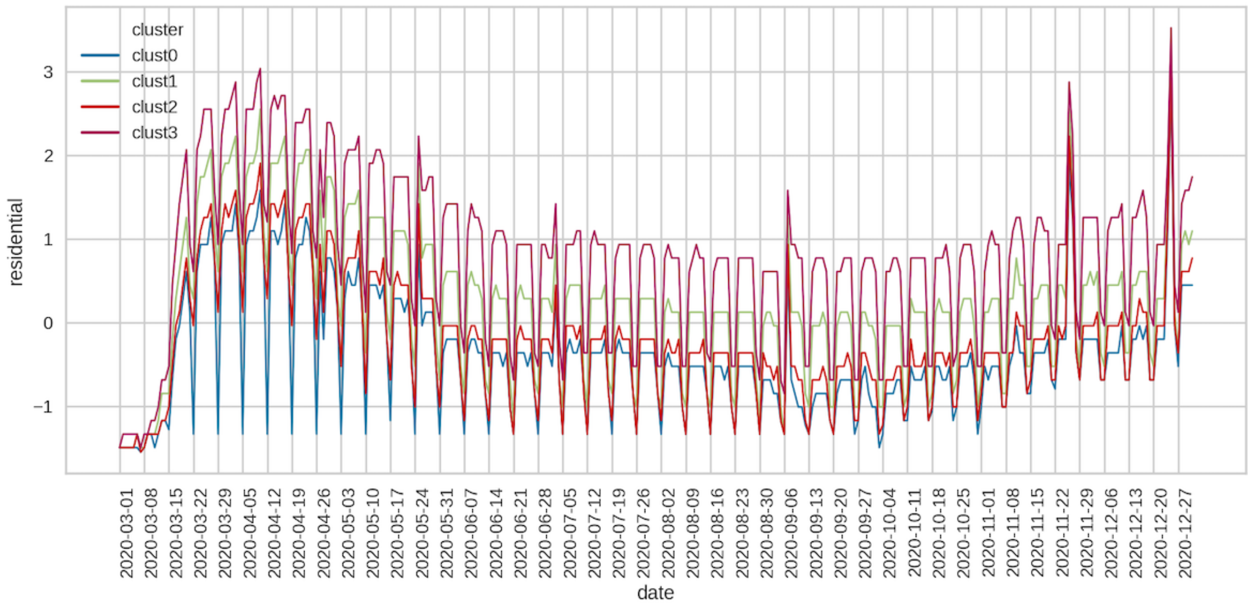
**Figure 7.** Google workplace mobility.




Finally, residential mobility followed a reverse pattern relative to the other indicators, with cluster 3 having the highest mobility, followed by clusters 1, 2, and 0 (Figure 8). Residential mobility was highest during the onset of the pandemic, followed by a decreasing trend during spring and summer. From late September onward, residential mobility began to increase, and this trend continued until the end of the sample period. The spikes in mobility captured the weekend effects. Our social mobility data indicated differences in mobility between clusters, with counties in cluster 0 having the highest retail, grocery, and workplace mobility and the lowest residential mobility. In contrast, counties in cluster 3 had the lowest social mobility and the highest residential mobility.

**Figure 8.** Residential mobility.




## Relationship Between Google Social Mobility Indicators and County Characteristics

To determine whether county characteristics are correlated with differences in social mobility between the clusters, we obtained socioeconomic, demographic, and political data from each county from 2016 census data [18]. These data included 2016 election returns, race, median income, total population, percentage of rural areas, and education level of the population for age and race. These data were supplemented by county variables collected by other studies [23,25].

A random forest classifier was used to generate feature scores of different socioeconomic and demographic characteristics of the counties included in each cluster, across all 4 clusters (mean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receiver operating characteristic [ROC] AUC 0.871). Table 2 contains the feature scores of all county-level variables.

The top 10 variables in terms of feature scores were percentage of the population aged 65 years and over (0.41715), percentage of females (0.08784), percentage of Whites (0.03869), percentage of Whites with less than college education (0.03772), percentage of Hispanics (0.03369), percentage of Whites with less than high school education (0.03178), percentage of the population using public transit (0.02967), county unemployment rate (0.02759), proportion of voters for Clinton in 2016 (0.02737), and percentage of the population with less than high school population (0.02719). Hence, although political preference and population composition were important, it is important to note the significance of 3 educational variables among the top 10, with the percentage of the population with less than college education being the 11th variable in terms of feature score.

To explore the top 11 socioeconomic, demographic, and political variables impacting social mobility further, we determined the mean population percentage for each county-level variable across clusters (Table 3). The table also contains results of statistical tests of significance of sample means between clusters. The Z test of sample means was performed to compare the significance of different county-level variables for different clusters. Results demonstrated several variable similarities for clusters with the highest social mobility. The percentage of the population aged 65 years and over, Whites, the percentage of whites with less than high school and college education, and the percentage of the overall population with less than college education were higher in counties defined by clusters 0 and 2. Tests of equality of sample proportions and means confirmed that there was a statistically significant difference between clusters 0 and 2 versus clusters 1 and 3 for these population variables. In contrast, the percentage of Hispanics, percentage of the population using public transit for work, and percentage voting for Clinton in 2016 were lower in clusters 0 and 2 relative to clusters 1 and 3. There was no consistent, significant difference across clusters for the percentage of females, population with less than high school education, and unemployment rates.

**Table 2.** Feature scores of county-level variables.

| Feature | Score |
|---|---|
| Percentage aged 65 years and older | 0.41715 |
| Percentage of females | 0.08784 |
| Percentage of Whites | 0.03869 |
| Percentage of Whites with less than college education | 0.03772 |
| Percentage of Hispanics | 0.03369 |
| Percentage of Whites with less than high school education | 0.03178 |
| Percentage of population using public transit for commuting to work | 0.02967 |
| Unemployment rate | 0.02759 |
| Percentage voting for Clinton in 2016 | 0.02737 |
| Percentage with less than high school education | 0.02719 |
| Percentage with less than college education | 0.02429 |
| Hospitals per 100,000 of population | 0.02385 |
| Percentage of rural population | 0.0221 |
| Population density | 0.02178 |
| Percentage of foreign born | 0.02118 |
| Poverty rate | 0.02051 |
| Percent without health insurance | 0.02003 |
| Percentage voting for Trump in 2016 | 0.01992 |
| Median household income | 0.01911 |
| Percentage aged under 29 years | 0.01852 |
| Registered voters as a percentage of population | 0.01682 |
| Percentage of African Americans | 0.01319 |


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**Table 3.** Differences in county-level variables across clusters.

| Variable | Sample mean (%) | | | | *P* value of sample means between clusters | | | |
|---|---|---|---|---|---|---|---|---|
| | Cluster 0 | Cluster 1 | Cluster 2 | Cluster 3 | Clusters 0 and 1 | Clusters 0 and 3 | Clusters 1 and 2 | Clusters 2 and 3 |
| Population aged 65 years and older | 17.10 | 14.20 | 16.20 | 13.00 | <.01 | <.01 | <.01 | <.01 |
| Females | 50.40 | 50.70 | 50.70 | 50.40 | .01 | .99 | .99 | .23 |
| White | 81.50 | 66.30 | 77.10 | 58.60 | <.01 | <.01 | <.01 | <.01 |
| Whites with less than college education | 78.20 | 65.00 | 75.20 | 51.10 | <.01 | <.01 | <.01 | <.01 |
| Hispanics | 6.90 | 15.50 | 8.20 | 19.80 | <.01 | <.01 | <.01 | <.01 |
| Whites with less than high school education | 11.20 | 7.10 | 10.10 | 5.10 | <.01 | <.01 | <.01 | <.01 |
| Population using public transit for commuting to work | 0.30 | 1.20 | 0.30 | 3.70 | <.01 | <.01 | <.01 | <.01 |
| Unemployment rate | 7.50 | 7.20 | 7.40 | 6.30 | .06 | <.01 | .06 | <.01 |
| Voting for Clinton in 2016 | 13.80 | 20.10 | 15.30 | 27.20 | <.01 | <.01 | <.01 | <.01 |
| Less than high school education | 13.50 | 11.70 | 12.60 | 11.50 | <.01 | .02 | .01 | .17 |
| Less than college education | 79.50 | 69.20 | 76.90 | 58.50 | <.01 | <.01 | <.01 | <.01 |

## Trends in Daily Cases/Deaths by Cluster

Given that policies restricting population mobility were established to curb the spread of COVID-19, we sought to determine whether county clusters with higher social mobility indicators (clusters 0 and 2) reported elevated viral cases and deaths. The daily number of confirmed cases and deaths due to COVID-19 at the county level was obtained from the CSSE at the JHU. We determined the median daily per capita cases (Figure 9) and deaths (Figure 10) by cluster. During the first months of the pandemic, per capita daily cases were quite comparable across clusters (Figure 9). There was a visible divergence that occurred at the beginning of October (onset of the second pandemic wave), with daily cases rising sharply in clusters 0, 1, and 2 relative to cluster 3. For the remainder of the period examined, cluster 0 had the highest number of daily cases, followed by clusters 2 and 1. Cluster 3 retained relatively lower daily cases. Interestingly, clusters 0 and 2 had lower daily deaths until the beginning of September (Figure 10). Daily deaths in these clusters then increased rapidly, and by the beginning of October, per capita deaths in clusters 0, 1, and 2 were higher than in cluster 3.

**Figure 9.** Daily cases per 100,000 residents.

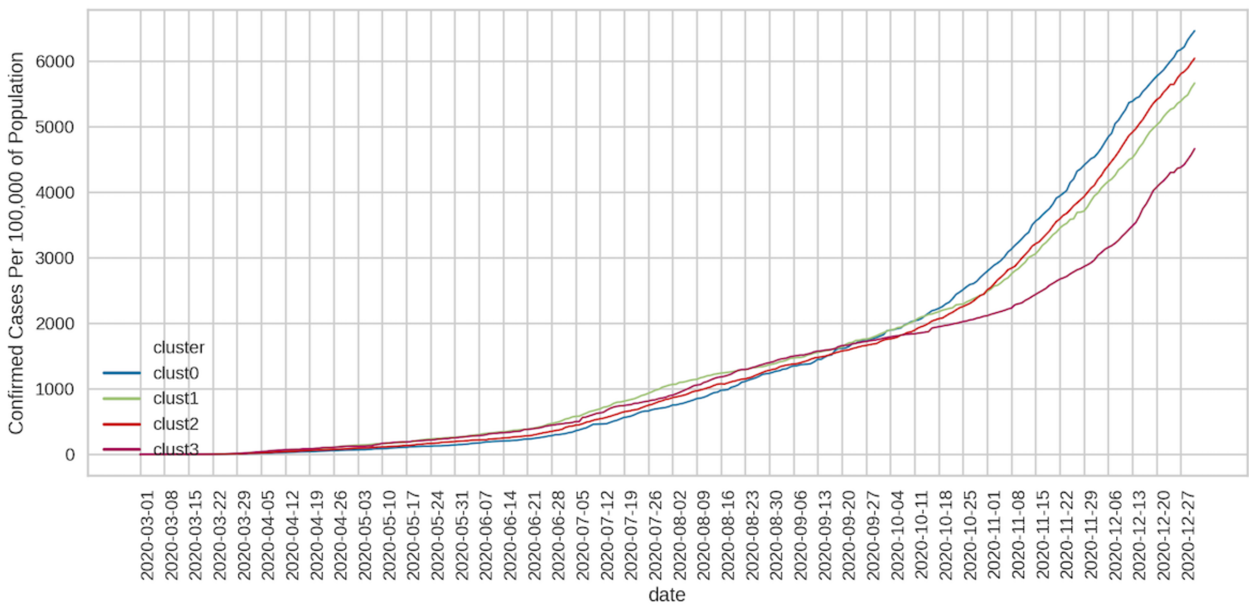




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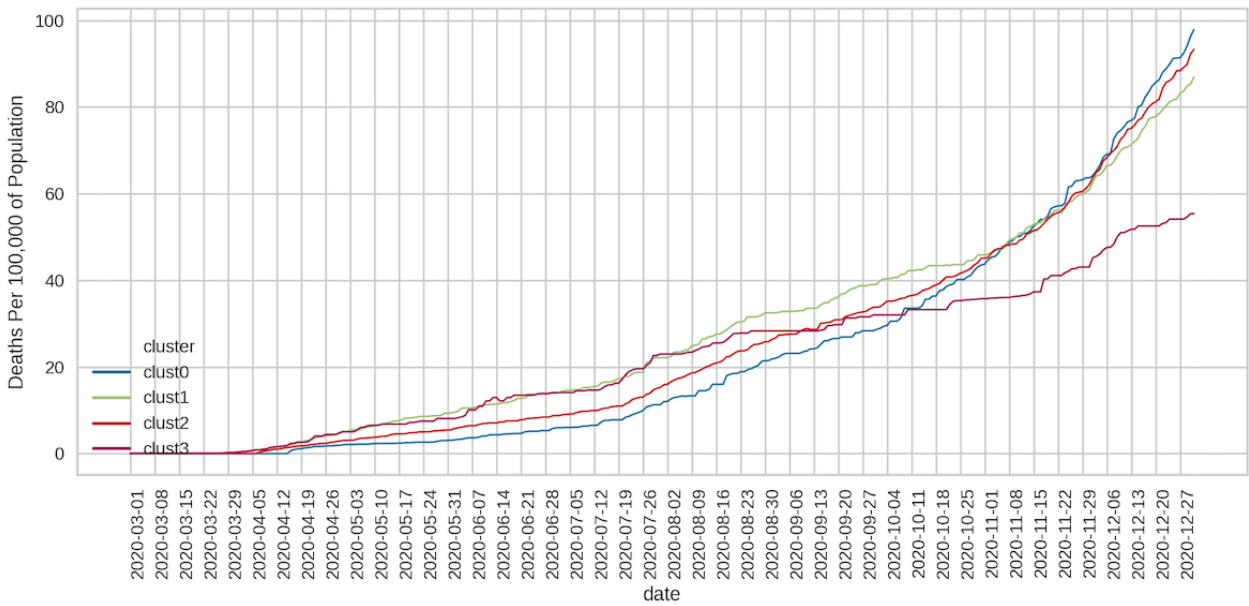
**Figure 10.** Daily deaths per 100,000 residents.




# Discussion

## Principal Findings

This study aimed to assess the effect of county-level characteristics on population mobility and the consequences of this mobility on the spread of COVID-19. To the best of our knowledge, this is the first study that has used unsupervised machine learning to understand differences in population mobility across US counties during the first and second waves of the pandemic and determine the relative importance of a wide array of socioeconomic, demographic, and political variables in defining different mobility-based clusters.

Our results demonstrate that of the 4 clusters defined by Google social mobility indicators, the clusters with higher retail, grocery, and work mobility (and lower residential mobility) had several similar population characteristics. Specifically, counties with greater social mobility also had a higher percentage of the population aged 65 years and over, Whites with less than high school and college education, and overall population with less than college education. Counties in these 2 clusters also had a lower share of the population that is Hispanic, the percentage of the population using public transit to work, and the share of voters who voted for Clinton during the 2016 presidential election. Research does suggest that Whites with less than college education constituted a significant voting block for Trump during the 2016 election [38]. In line with this, the 2 clusters with the greatest social mobility also experienced higher per capita COVID-19 case and death rates during most of November and December 2020. These results are consistent with Xie and Li [39], who also used county-level data during the early days of the pandemic and found lower education levels to be correlated with higher infection rates.

The significant increase in COVID-19 cases and deaths in clusters 0 and 2 during November and December 2020 could be a consequence of public rallies and general disregard for social distancing and safety protocols by pro-Trump voters [40]. Although we cannot prove this, the majority of counties in these clusters were Republican leaning during the 2016 presidential election. Moreover, our finding of higher per capita daily COVID-19 cases and deaths in such counties is consistent with other studies. Desmet and Wacziarg [41] found that early on during the pandemic, Republican counties actually experienced lower COVID-19 cases and therefore had lax attitudes toward mask wearing, social distancing, and lockdown measures. However, as the pandemic spread to Trump-leaning counties, population preferences for less stringent social distancing policies had already been formed, making it difficult for policymakers to implement stricter restrictions on social mobility. As a result, this led to greater disease severity in Trump-leaning counties. In a similar vein, Allcott et al [42] found that areas with more Republicans engaged in less social distancing, controlling for other factors, including public policies. In summary, these findings corroborate our own results. Social mobility in the aftermath of the first wave of the pandemic was much higher in Republican counties, which ultimately resulted in higher COVID-19 cases and associated deaths relative to other counties that were Democrat leaning.

Social media is increasingly being used to capture population movements and understand their corresponding impacts on COVID-19 incidence. Social media–based data, including those presented here, have some limitations. Specifically, there is the possibility of sample selection bias if Google Maps users have specific demographic characteristics and are not distributed uniformly across the population. However, data from Statista indicate that in the U.S., Google Maps had 154 million users in April 2018 [43]. Further, published research has done a comparison of Google mobility data against corresponding cellular-generated information by other providers and has found a close correspondence. Specifically, Szocska et al [44] constructed a mobility index and an SAH/resting index based on data on almost all phone subscribers in Hungary and found a close correlation with corresponding Google mobility indices at the national level. There are also a significant number of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published studies that have used Google mobility data to capture population movements for different countries and have found them to be important in predicting movements in COVID-19 (Bryant and Elofsson [11], Askitas et al [45], and Stevens et al [46]). For these reasons, we think there is a high likelihood that Google mobility data do reflect population movements. However, Google mobility data do not include information on certain types of public movements, such as election rallies or community gatherings.

Our research demonstrates the usefulness of publicly available Google mobility data and unsupervised machine learning methods in establishing relationships between county-level characteristics, mobility decisions, and COVID-19 incidence. These findings have important implications for policymakers and public health officials in understanding the effects of NPIs, as the efficacy of such measures on mobility is influenced by underlying socioeconomic, demographic, and political ideology characteristics. The use of Google data enables researchers to assess the types of public movements that are most contributory to COVID-19 spread.

The results of this study provide a unique lens on the potential of machine learning to understand social mobility behaviors. These findings are critical for public health organizations trying to understand the levels of mobility in their counties, in addition to providing insights into some of the underlying factors (ie, social determinants of health) contributing to regional differences in COVID-19 caseloads.

### Conclusion

Our results emphasize a role for machine learning methods in public health. Publicly available Google data, in conjunction with census data, can be used to understand the socioeconomic, demographic, and political determinants driving population mobility choices across US counties. This knowledge can assist policymakers in developing NPIs to restrict viral spread during the COVID-19 pandemic.

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## Conflicts of Interest

None declared.

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## Abbreviations

**AUC:** area under the curve
**CSSE:** Center for Systems Science and Engineering
**JHU:** Johns Hopkins University
**LSTM:** long short-term memory
**MIT:** Massachusetts Institute of Technology
**NPI:** nonpharmaceutical intervention
**SAH:** stay-at-home
**SIP:** shelter-in-place
**VAE:** variational autoencoder

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Corrigenda and Addenda

# Correction: Health Literacy, Equity, and Communication in the COVID-19 Era of Misinformation: Emergence of Health Information Professionals in Infodemic Management

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***(JMIR Infodemiology 2022;2(1):e35012)*** doi:10.2196/35012

In “Health Literacy, Equity, and Communication in the COVID-19 Era of Misinformation: Emergence of Health Information Professionals in Infodemic Management” (JMIR Infodemiology 2022;2(1):e35014) the authors noted one error.

In the originally published article, the degrees of author Deneice Marshall appeared as “BA, MA, Dip Education.”

In the corrected version, these degrees have been revised to “BSc, MSc, Dip Education”

The correction will appear in the online version of the paper on the JMIR Publications website on May 31, 2022 together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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