Understanding Public Perceptions and Information Sharing Patterns about Long Covid: A Qualitative Analysis of Twitter Data

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Abstract

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Long Covid is a set of symptoms experienced by patients who previously acquired an acute SARS-CoV-2 infection. Interestingly, Long Covid is considered the first illness that has been identified and named by the patients experiencing these symptoms. Due to its novelty, there was a lack of guidance and knowledge regarding its severity and biological mechanisms. Consequently, this resulted in high levels of uncertainty among the public which largely shaped the types of conversations about Long Covid, especially on social media. With Long Covid continuing to be an emerging scientific topic coupled with the apparent lack of research regarding the public's need for Long Covid-related information, it necessitated formative research on the most salient conversations and opinions surrounding the illness. The top 100 most retweeted tweets containing the key phrase "Long Covid" from June 2020 to June 2022 were collected using the Twitter Streaming Application Programming Interface (API). The analysis included tracking rates of Long

Covid-related misinformation, using deductive analysis to recognize patterns of the ever-changing public perceptions about Long Covid, and identifying the most salient categories through content analysis. This study outlines the general patterns observed in how Twitter users discussed and communicated their opinions/knowledge about Long Covid. This study also found that information from ‘trusted’ and ‘credentialed’ healthcare influencers is treated as the objective truth, while information from political figures is considered biased. This is one of the first studies that examined how information about Long Covid was shared on Twitter during the height of the pandemic. However, more research is needed to determine effective ways to combat misinformation, especially among vulnerable populations.

INTRODUCTION

Long Covid is a term used to represent the myriad of symptoms that some people experience weeks, months, or even years, after a mild or severe acute SARS-CoV-2 infection.[1,2] These symptoms can manifest in multiple ways, such as tiredness or fatigue, chest pain, brain fog, sleep problems, depression or anxiety, and joint pain—similar to that of ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) patients.[1,2]

As of January 2023, 11% of adults who had COVID reported having Long Covid symptoms–a decrease from the 19% in June 2022.[2,3] Studies show that adults and children can suffer from Long Covid exhibiting similar symptoms, though kids are still less likely to develop such symptoms.[1,4]

As a result of its novelty and patient activism, the term 'Long Covid' was coined by patients experiencing post-acute COVID-19 sequelae.[5] This is reflected in the ways in which our knowledge and much of our understanding of Long Covid took shape early on, most of which were coming from patients themselves. Not long after, the *#LongCovid* was first used on Twitter by Elisa Perego on May 20, 2020. This term was soon adopted in print media and in academia, and by August 2020, it was a recognizable 'scientific object'.[5] Long Covid appears to be the first illness patients have collectively 'made' and 'identified', with many patients finding support groups and fellow 'long-haulers' on Twitter.

This was largely due to the lack of guidance and support that Long Covid patients received from public health agencies and in the health care setting. It was not until November 2020 that the CDC acknowledged the potential for long-term post-COVID infection symptoms.[6] Though it was finally acknowledged, there was very little information about its mechanisms, thus lacking the ability to create unified guidance and messaging during a critical time of the COVID-19 pandemic.

Additionally, Long Covid was severely under-researched as US only unveiled the National Action Research Plan on Long Covid in August 2022.[7] The plan resulted in high levels of uncertainty among the public which largely shaped the types of conversations about Long Covid, especially on social media. Unfortunately, the pace of science has been slower than the demand for information, particularly during times with high levels of uncertainty, such as a global pandemic.

Research shows that without proper guidance from trusted sources, people often turn to informal, less credible sources to obtain information to alleviate fears and anxiety—perceiving that any information is better than no information.[8–10] At the same time, this information-seeking behavior opens up opportunities for online rumoring, which is why we see the rampant spread of health misinformation/disinformation during public health crises[11,12]. As public health professionals, our best tool to prevent misinformation comes down to getting information early and quickly to the public.[10,13] However, we are faced numerous challenges when enacting pandemic-related public health measures, such as the increasing distrust of science and government.[10] This provides unique

challenges to public health authorities, especially when it is time to enact public health measures and emergency responses.[14] This was a huge problem throughout the COVID-19 pandemic (e.g., self-medicating with unsafe products, vaccine hesitancy), and is an ongoing issue with Long Covid.[15–17] We also saw this in the high rates of COVID-19 denialism both in the US and around the globe. Studies have evaluated the catastrophic effects of certain populations denying the reality of COVID-19, especially early on in the pandemic.[18-20] These erroneous claims were incredibly problematic, especially when public and global health officials tried to impose mitigative pandemic measures that many did not heed. This contributed to high numbers of cases and deaths, many of which could have been prevented.[19]

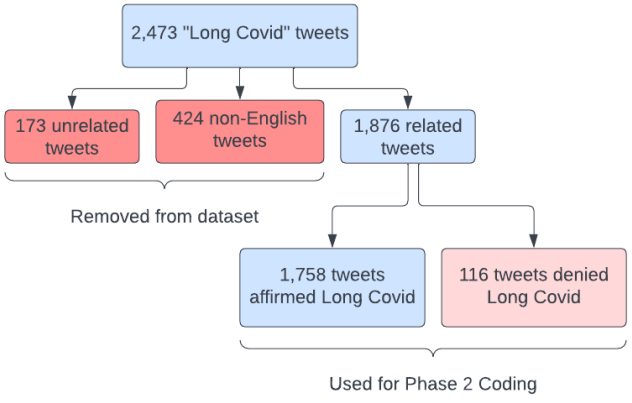
As of 2021, 48% of US adults report getting their news through social media sites. Interestingly, Twitter holds the highest proportion (55%) of its total user base that reports regularly obtaining their news from the social media site.[21] With such large portions of the country obtaining their information online, it is important to be aware of how health-related news is being shared/communicated as well as the general patterns observed within these online conversations. Very few studies have examined these publicly shared knowledge and experiences with an aim to understand public perceptions and misinformation patterns regarding Long Covid. Similar to disease surveillance, during public health emergencies, surveillance on digital information patterns is needed in order to properly respond as a trusted source of information. To do so effectively, it is critical to understand the different inaccurate information about certain public health topics, such as Long Covid, to minimize the potential harms promptly and efficiently for individuals and the larger public health.

This study aims to answer the following question:

- What were the most salient opinions and misinformation about Long Covid on Twitter between June 2020 and June 2022, and how have these patterns changed over time?

METHODS

Data Collection



This data was obtained by the University of Washington's Center for an Informed Public (CIP) through ongoing data collection using the Twitter Streaming Application Programming Interface (API). CIP has been collecting COVID-19-related data since January 23, 2020. From the tweets collected by the CIP, we queried the 100 topmost retweeted tweets per month containing key phrase "Long Covid" from June 2020 to June 2022–

totaling 2,473 tweets. June 2020 only had 73 total tweets that contained the key term 'Long Covid' that had at least one retweet.

Qualitative Coding

All 2,473 tweets were manually coded, following a two-dimension coding system.[22] For the purpose of this study, Long Covid denialism will be considered as proxy measure for Long Covid-related misinformation. Misinformation is challenging to measure and keep track of given the ever-changing nature of our knowledge regarding Long Covid.

Phase 1 Coding

Example Unrelated: "This week, India registered 500,000 coronavirus cases but its peak is not predicted until November. "It is going to be a *long Covid* season in India", one expert said."
Example Unable to Code: "Survivors! Setelah negatif dari COVID-19 ternyata kita gak selalu bebas dari keluhan lho. Ada yang namanya Long COVID. Kayak apa sih *Long COVID*? Apa aja keluhan2nya?"
Example Affirm: "As of today I ~officially~ have long COVID (as recognized by the CDC), so I wanna take a second to explain what's happening."
Example Deny: "There is no 'Long Covid'. You were permanently injured by blood clotting, because you were denied treatment in order to protect the Emergency Use Authorization. Wake up… they are not your friends."

All 2,473 tweets were manually coded using four mutually exclusive codes: *Unrelated*, *Unable to code*, *Affirm*, and *Deny*. All tweets that were coded as *Unrelated* or *Unable to Code* were removed from the data as they were either not relevant to the study or were non-English tweets. Roughly 20% (473 tweets) of all tweets were coded by two coders, utilizing consensus coding. Out of the 2,473 tweets, 173 were unrelated, 424 were non-English tweets, 1,758 affirmed Long Covid, and 116 denied Long Covid. The 1,876 tweets meeting the eligibility as relevant moved forward to Phase 2 Coding.

Phase 2 Coding

Rigorous notes were taken during Phase 1 of coding to help develop an inductive codebook to be used for Phase 2. The codebook consists of ten code groups with a total of 32 unique codes (Appendix 1). Roughly 15% (~289 tweets) of all tweets were coded by two individuals with an intercoder reliability score of 0.71.

Data Analysis

Using the coding results from Phase 1, we tracked the rate of denial throughout the study timeline. Denial rates were calculated by taking the number of tweets coded as *Deny* divided by the total number of relevant tweets per month (*no. of denial tweets per month / total no. of related tweets per month * 100*). Specific months where denial rates peaked were flagged for further analysis of that month's denial tweets.

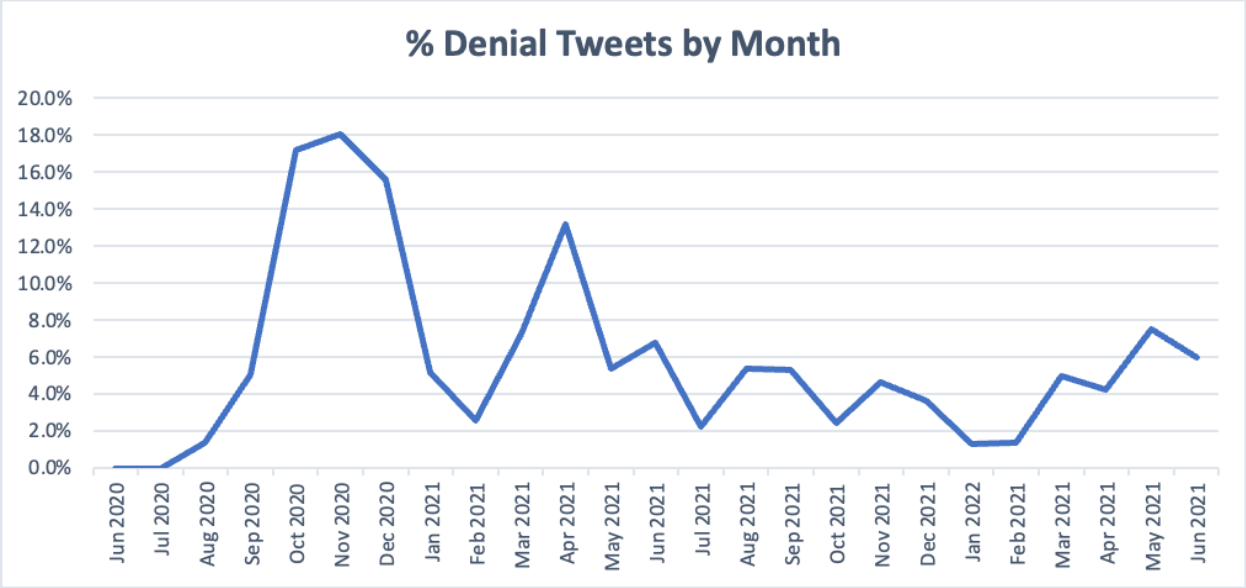
The code groups created for Phase 2 coding were primarily designed to help recognize patterns regarding public perceptions and opinions throughout the study timeline. Some example groups are 'Call to Action', 'Personal Illness Stories', and 'Criticism' (Appendix 1). Based on these code groups, code frequency was analyzed to determine any observable patterns within the data–employing a deductive content analysis. The timeline was divided into 6-month segments–*June to December 2020, January to June 2021, July to December 2021,* and *January to June 2022.*

Phase 2 tweets were also content analyzed based on key recognizable categories observed in the data. Throughout this process, salient topics were developed relating to how Long Covid information was shared and discussed on Twitter from June 2020 to June 2022.

RESULTS

Phase 1 Coding Results

Using the results from Phase 1 of coding, we are able to determine when, within the study timeline, Long Covid denialism peaked.



Percentage of denial tweets peaked from October to December 2020 at 17.2%, 18.06%, and 15.58%, respectively. A smaller peak also occurred in April 2021 at 13.6%.

Further analysis of all the denial tweets within these four peaks was conducted, unveiling some interesting patterns that reflect the increased spread of misinformation soon after a supposed "trusted" entity shares Long Covid-related information.

October and November 2020

A review of the denial tweets between October and November 2020 shows that the majority of these tweets were in response to three tweets made by Matt Hancock, who at the time was the UK's Secretary of State for Health and Social Care.[23] There were a number of tweets in response to Matt Hancock's tweet about Long Covid. The responses included dismissing long covid as being a serious health issue altogether or in comparison to the flu, cancer, and dementia.

> **@MattHancock** (October 18, 2020): Younger, non-hospitalised #coronavirus patients are experiencing the debilitating impacts of long COVID
> Whatever your age, it's vital you follow the guidelines to protect yourself, your community & our NHS.
> #HandsFaceSpace
>
> > Response quote tweeting Matt Hancock's October 18 tweet:
> > **@BurnsideNotTosh** (October 19, 2020): The number of deaths and cases aren't justifying our actions, quick let's scramble around for something else.
>
> **@MattHancock** (October 21, 2020): Today, I visited a long Covid clinic to talk to patients with this devastating condition
> To anyone of any age, catching Covid can be very serious - we should all do our bit to avoid that.
> Remember: #HandsFaceSpace & #GetATest if you have #coronavirus symptoms
>
> > Response quote tweeting Matt Hancock's October 21 tweet:
> > **@allisonpearson** (October 21, 2020) Pernicious rubbish from our Health Secretary. Flu is more serious for young people than Covid. Flu kills around 12 children and teenagers every year. Covid mainly kills the very old and is not "very serious to anyone of any age"!
>
> **@MattHancock** (November 16, 2020): This virus remains a potent threat to anyone of any age & any background
> I'm very pleased to confirm that the NHS will have a network of 40 long Covid clinics in place by the end of the month to help those suffering from long Covid.
>
> > Response quote tweeting Matt Hancock's November 16 tweet:
> > **@LozzaFox** (November 16, 2020): Long Covid? What a fear mongering numpty. What about long dementia? or long cancer? or long toothache? Honestly, you're not in a bond movie.

Based on the response elicited by Matt Hancock, it appears that UK citizens were particularly untrusting and doubtful about the information being provided by a political figure.

December 2020

Approximately a third of the denial tweets on December 2020 were from Alex Berenson, who The Atlantic described as the 'Pandemic Wrongest Man'.[24] Most of his tweets imply or theorize that Long Covid is made up.

> **@AlexBerenson** (December 11, 2020): Notice you've heard nothing about "long Covid" for the last month? That's because positive test and death counts are up so the CNNs aren't stuck with Plan B. Don't worry, as the wave breaks long Covid will be back.

These tweets came soon after Dr. Fauci from the CDC discussed the need to understand Long Covid symptoms in November 2020.[6] These responses show that some people are convinced that Long Covid is a fearmongering tactic used to justify lockdowns and other COVID-19-related mandates/guidelines.

April 2021

All denial tweets in April 2021 centered around invalidating Long Covid symptoms or implying that Long Covid is non-COVID-19 infection-related. Long Covid, as a disease, was highly muddied with increasing doubt about its legitimacy and severity.

Some are implying that Long Covid symptoms are caused by lockdown burnout:

> **@spencermorgan93** (April 1, 2021): You haven't got long covid. You just feel like sh*t cos you been locked up for a year and had all the good aspects of life taken away

While some believe that Long Covid symptoms are made up by those who have it:

> **@KismetandHope** (April 6, 2021): The idea of long covid is a hypochondriac's wet dream.

Phase 2 Coding Results

General Patterns Observed from June 2020 to June 2022

As we moved through the pandemic and learned more about Long Covid, the opinions and types of conversations that Twitter users changed over time. In the beginning, people were eager to provide Long Covid-related information and resources through sharing links and personal experiences. Later on, we see that people started calling for more support from the government, criticizing public health measures, and bringing up the long-term implications of Long Covid to our society. Below is a timeline of how these conversations shifted throughout the 2-year study timeline. See Appendix 2 for supporting quotes.

May 2020

#LongCovid was first used by Elisa Perego on Twitter as a contraction of long-term Covid illness, to summarize her experience of disease as cyclical, progressive, and multiphasic.

June 2020

42% of all tweets from Jun to Dec 2020 shared Long Covid information through links remained constant throughout the whole study timeline. These are usually linked to research studies, news articles, videos, podcasts, and talks.

14% of all tweets from Jun to Dec 2020 were calling on the government for more support, guidance, and information about Long Covid.

Tweets about the personal experiences with Long Covid accounted for 9% of all tweets from Jun to Dec 2020. Long Covid patients shared their symptoms, experiences, and general thoughts with others as a way to increase awareness of the disease.

January 2021

As we learn more about the incidence and severity of Long Covid, more people started voicing their **criticisms of the poor COVID-19 pandemic guidelines, lack of action from the government, and poor Long Covid-related public messaging – accounting for 18% of all tweets from Jan to Jun 2021.**

Long Covid in children also became a topic of interest on Twitter, with **9% of all tweets from Jan to Jun 2021 showing concern about the impact of Long Covid on children**. This is largely in response to UK's decision to re-open schools for in-person classes.[25]

July 2021

As we enter the second half of 2021, **more people started talking about the vaccine as it relates to Long Covid**. We see this given that the vaccine has now become available to the general population. **75% of all vaccine-related tweets framed the COVID-19 vaccine as a way to prevent Long Covid.**

The conversations about Long Covid started including **heavy use of statistics**, most of which were uncited. **83% of all tweets including Long Covid-related statistics from July to Dec 2021 were uncited**.

January 2022

About 8% of all tweets from Jan to June 2022 described the personal experiences of Long Covid patients and their family members. These tweets, unlike early on in June 2020, were less about bringing awareness to Long Covid, and more about discussing their experiences with the **illness as a cautionary tale.**

Sharing of Long Covid-related information remained constant throughout the pandemic, which speaks to the **continued collective sensemaking** around the topic. **About 31% of all tweets from Jan to Jun 2022 shared Long Covid-related information.**

June 2022

Phase 2 Coding Results - Categories

The following five categories were developed through content analysis that outlines specific phenomena that were observed within the data. These categories explore the co-optation of the term 'Long Covid', the importance of credentialed healthcare influencers in disseminating Long Covid-related information, the disappointment regarding poor handling of the disease, the conversation about the COVID-19 vaccine as it relates to Long Covid, and the increasing distrust in government entities and public health agencies.

I. Long Covid as a topic was co-opted by several groups to push forward different agendas

ME/CFS PATIENTS: 17% of all personal illness stories were from ME/CFS patients. Long Covid and CFS share similar symptoms (e.g., brain fog, fatigue, difficulty performing daily tasks, etc.)[1,2] With the increased attention that Long Covid was receiving, ME/CFS patients took to Twitter to voice their grievances for being ignored in the healthcare settings for years. Some were frustrated at the amount of attention that Long Covid had as a new illness.

> **@kbeanie93** (February 16, 2021): People didn't give a shit when I was diagnosed with M.E over 10 years ago. People didn't give a shit when I had post viral fatigue after glandular fever before that. But now it's 'Long Covid' it's suddenly all over the media and some kind of national tragedy?

While some were hopeful that the number of resources and attention given to Long Covid patients can open up doors for those who have been suffering from ME/CFS for years.

> **@KarimKhan_IMHA** (July 18, 2020): This will not go unnoticed by our friends in these two communties: people living with ME community, people living with CFS. Let's hope one outcome of #COVID19 is to advance our understanding and most importantly treatment of other conditions.

ANTI-LOCKDOWN GROUPS: Approximately 18% of all denial tweets claimed that Long Covid symptoms are merely the effects of lockdown measures, emphasizing the long-term effects of isolation on mental health. Long Covid has been renamed as 'Long Lockdown':

> **@PatrickBehSci** (December 18, 2020): Depression, fatigue, anxiety, brain fog, etc are all symptoms of LONG LOCKDOWN. Isolation and confinement is mentally debilitating. They are blaming it on Covid so they can keep the scam going indefinitely. Lockdown = "long Covid" = more lockdown. QT @Telegraph: People suffering with debilitating effects of long Covid could be at risk of self-harm or suicide

> **@HerdImmunity12** (June 24, 2021): We hear in the UK today that the government are reporting that 2 million Brits are suffering from 'Long Covid'. Depression, tiredness, no energy and feeling lifeless. Wrong, it's the condition 'Long Lockdown'. This comes from enforcing masks, dictatorship and tyranny.

ANTI-VAXXERS: Vaccine hesitancy was a huge challenge in managing the pandemic. 16% of all denial tweets implied that Long Covid is a vaccine harm. Given that we knew very little about the biological mechanisms and causes of Long Covid, this topic became a huge talking point among the anti-vaccine community.

> **@Nick_Pye** (January 2, 2021): Is "long covid" a ready-made excuse for all future illness caused by rushed, untested, unnecessary vaccines?

> **@beverleyturner** (April 20, 2022): The problem is.... "Long Covid" symptoms are annoyingly identical to "long vaccine harm"... Which is infuriating for sufferers and baffling for doctors, but marvellous for the indemnified drug companies. Just. Bloody. Marvellous for them...

Interestingly, we see a pattern of how the term 'Long Covid' was coopted to describe alternative explanations for lingering symptoms, as we see with 'Long Lockdown' and 'Long Vaccine.'

II. Healthcare Providers and Researchers' tweets were key assets in providing Long Covid information

Healthcare providers and researchers, particularly those who are verified on Twitter, served as Long Covid 'fact-givers'. Most of their tweets are in the form of Twitter threads to provide more context on the situation with Long Covid, especially sharing about current incidences, new studies, and correcting misinformation.

> **@DrZoeHyde** (March 12, 2021): I completely agree. It's now clear children are much more affected than first thought. Data from the UK's Office for National Statistics puts the 5-week prevalence of persistent symptoms at 13% in children aged 2-11 years. Children get long COVID, too. https://t.co/ebDo69pOIF QT @fitterhappierAJ: My opinion is that kids need a vaccine to protect themselves, not simply so that we all reach a 'herd immunity' threshold.

> **@dgurdasani1** (January 24, 2022): This is misinformation - please report. 'Healthy' 5 yr olds *do not* face 'zero' risk from this virus- many have developed long COVID. Hospitalisations are the highest they've been in this age gp & more children have died of COVID-19 than any other preventable childhood illness. QT @JuliaHB1: The abject state of the replies to this tweet from one of the many lunatics on Indie SAGE. Dear God. The include the claim that not jabbing healthy 5 year olds against a virus they face zero risk from means they are "lambs to the slaughter". These people have lost their minds.

Some key players include *@DrEricDing, @chrischirp, @DrZoeHyde, and @dgurdasani1*. Between the four of them, they share over 1 million Twitter followers. Between these four accounts, they were responsible for 9% of the topmost retweeted tweets from June 2020 to June 2022.

III. Overall disappointment with poor public communication about Long Covid

Throughout the pandemic, there was no clear and unified messaging about Long Covid from the government or public health agencies. As a result, we find that people grew increasingly frustrated about the lack of acknowledgment and public communication about the illness.

> **@RaviHVJ** (February 15, 2022): The simple truth is that Long Covid is incredibly inconvenient for those in power. #LongCovid profoundly conflicts with the current rush to return things to "normalcy," for recognizing the risks posed by Long Covid would make the prevailing mass infection policy untenable.

People were particularly unhappy with the messaging around "Living with COVID" and "getting back to normal" as they failed to acknowledge the health and economic burden that Long Covid brings. "Living with COVID" potentially meant letting COVID cases run wild, thus increasing the number of individuals suffering from Long Covid.

> **@elisaperego78** (March 29, 2022): Even at the most basic level, "living with covid" is unsustainable from an economic view point. People can't be sick, repeatedly, for weeks every year. And yes, we know #LongCovid / long-term health effects are not rare. It means prolonged or permanent disability for millions

IV. Long Covid and the COVID-19 Vaccine

There were two main conversations about the COVID-19 vaccine as it relates to Long Covid: 1) the vaccine will prevent or reduce your likelihood of getting Long Covid, and 2) Long Covid is a vaccine injury.

For the most part, we see tweets citing that getting the COVID-19 vaccine is the most effective way to prevent Long Covid.

> **@DrTomFrieden** (July 20, 2021): One of the best reasons to get vaccinated is to avoid long Covid. Many young, healthy people are suffering from debilitating symptoms months after Covid infection. The most certain way not to get long Covid is to not get Covid.

Similarly, other Long Covid patients have claimed that the vaccine has helped with symptom management, though most were anecdotal.

> **@MaraGay** (February 24, 2021): This is both anecdotal and early, but many long covid survivors are feeling significantly better after receiving their first vaccine dose. Including me. Fascinating.

On the other hand, some tweets are implying that Long Covid is an injury sustained from getting the COVID-19 mRNA vaccine, or that vaccine injury is being covered up as Long Covid.

> **@DarylMakk** (May 10, 2022): Long covid is a term they made up to cover up the side effect of the jab #changemymind #VaccineSideEffects

> **@peterrowen_** (October 30, 2021): Word from an insider - vaccine injury in Irish hospitals is currently being intentionally mislabelled as 'long covid'

V. Long Covid denial tweets were rooted in distrust and doubt

Tweets that denied that Long Covid, bottom line, showed that trust is an important feature of public communication. Without the baseline of trust and respect, people will question the accuracy and credibility of the information provided, regardless of who or where the information is coming from.

> **@eyed_loon** (August 3, 2021): The true long covid:
> I no longer trust doctors
> I no longer trust the NHS
> I no longer trust MSM
> I no longer trust the police
> I no longer trust vaccines
> I never trusted politicians and I was right not to.

It is also important to emphasize that there was a clear 'us' versus 'them' mentality that was present in many of the denial tweets. The concept of 'they' was assigned as the enemy of truth, thus anything that 'they' tell you is actually untrue. 'They' is usually implied to be the government, society, or a general higher entity.

> **@airstripone84** (January 2, 2021): Covid - what we know so far;
> They're lying about masks
> They're lying about deaths
> They're lying about impact on NHS
> They're lying about the testing
> They're lying about risk to health
> They're lying about 'long covid'
> They're lying about vaccines
> Any questions?

DISCUSSION

Evident in our deep dive into months with peak rates of denial, we find that information from political leaders and government agencies does not necessarily receive the response that we would hope for. This is clear given the increased rates of Long Covid denial after former UK Minister of Health, Matt Hancock, delivered messages regarding the threat of Long Covid.

Early on in the pandemic, Long Covid was initially introduced by Long Covid patients, sharing their first-hand experiences with the disease. Soon after, users began calling for more information and action from the government while also sharing cited Long Covid-related information. When those calls to action went unanswered, tweets shifted to criticisms about how the pandemic was handled and the poor public messaging about Long Covid. In the second half of 2021 when the prevalence of Long Covid increased, tweets urged others to take Long Covid more seriously, to get vaccinated, and to continue adhering to guidelines in an effort to protect others, especially children, from getting Long Covid. As mandates and guidelines started to be lifted and "living with COVID" became the new motto, Long Covid patients shared again their horror stories with Long Covid, particularly to serve as a cautionary tale for others.

The most common categories that were identified were, 1) 'Long Covid' as a heavily co-opted term due to its novel nature, 2) credentialed healthcare influencers as key sources of Long Covid-related information, 3) expressed disappointment regarding poor handling of the disease, 4) Long Covid and the COVID-19 vaccine, and 5) distrust in government entities and public health agencies.

The idea of trusted sources of information has been extensively reviewed in the literature.[26-28] Healthcare providers, for example, have been found as 'influencers and providers of vital information to the public in clinical encounters and this influence seems to expand through Twitter threads. However, the findings from this study show that similar credibility cannot be observed from an official source, such as a government official or agency. The study found that the public does not view government officials as imparting objective truth, and in fact, can elicit a negative response from the public, shedding some lights into what a 'trusted source' looks like on social media. Verified Twitter accounts of health influencers were key sources of information and were often heavily retweeted. However, we found that there were very few politicians or government officials in the top 100 most retweeted tweets per month. The few instances when they were, it was often met with negative responses or countered by high rates of misinformation. This study shows that there is an opportunity to utilize the help of Twitter 'influencers' in order to increase the reach and credibility of public health messaging.

The study also found that the term 'Long Covid' being a crowdsourced term opened it up to be easily co-opted by other groups with different agenda as shown with emergence of new terms, such as 'Long Vaccine' and 'Long Lockdown'. This may also be a result of the fact that very little scientific information and public health guidance were provided to the general public. Uncertainty

and lack of information were still our biggest challenges with Long Covid and how we continue to communicate it.

Chronic Fatigue Syndrome and Long Covid

ME/CFS has been a highly overlooked condition for decades. ME/CFS patients' symptoms have been ignored and invalidated for years. Perhaps a better understanding of Chronic Fatigue Syndrome is one of the positives that came out of the Long Covid conversation. In this study, we found ME/CFS patients were highly involved in the Long Covid conversation on Twitter as advocates for their chronic illness. They were partly responsible for bringing light on the similarities of CFS to Long Covid–mirroring the same trajectory of Long Covid patients advocating for themselves. Given the similarities between Long Covid and ME/CFS symptoms, new research discoveries about Long Covid can provide the answers that ME/CFS patients have been looking for.[29,30] This can provide a standardized diagnostic protocol for both Long Covid and ME/CFS patients in the future which will drastically improve healthcare experiences. However, this would not have been possible without the ME/CFS patients who have advocated for more attention to their illness.

Limitations

The study data was limited to English tweets, primarily from the US and UK which limits the overall understanding of the Long Covid information shared, especially within the global context. Non-English tweets, which accounted for 17% of the original 2,473 tweets, were not analyzed for this study. Though these tweets were not included in the study, it is still important to emphasize that Long Covid is a global phenomenon that affects people worldwide. Additionally, the term 'Long Covid' is likely one of the many terms used to describe post-acute viral infection sequelae. Before this term was invented and adopted, other terms may have been used to describe the same symptoms, including 'post-acute COVID infection sequelae' (PACS).

CONCLUSION

As we enter the fourth year of the COVID-19 pandemic, still very little is known about Long Covid. We currently do not have a universal clinical definition for Long Covid, we do not have a standardized diagnosis protocol, nor do we have a clear picture of its prevalence.[33] With very little information available for the general public, especially for those suffering from Long Covid, we will likely continue to see significant shifts in how Long Covid is talked about and discussed online. More research needs to be done in order to better understand Long Covid as a disease and as a public health topic. Additionally, as we learn more about Long Covid, we must be proactive in communicating through different channels to reach as many people as possible. When it comes to addressing the public, especially on social media, the role of 'trusted' and 'credentialed' influencers should be considered as an effective channel to reach a fairly large digital audience. Interestingly, their reach is far more effective than those who have ties with the government or government agencies. In this case, these influencers are likely seen as unbiased sources of

information and are more aware of the importance of the interpersonal relationship with the target audience.

This paper contributed to the slowly growing body of research about Long Covid infodemiology (i.e., information epidemiology). This study provides some formative knowledge on how information about Long Covid has been shared in a way where we can reflect on our shortcomings as public health officials during a global pandemic. This is among the first studies that examined how information about Long Covid was shared on Twitter during the height of the pandemic.

However, more research needs to be done to determine effective ways to combat misinformation, especially among vulnerable populations. Minoritized populations are often the last to receive vital information and resources, so there is a need to increase outreach to these communities in times of uncertainty. Additionally, it would be helpful to learn about the discussions regarding government distrust and continue to learn how to address this to ensure desirable health outcomes.

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APPENDIX

Appendix 1 - Final Phase 2 Codebook

Code Name	Code Definition	Notes/Examples
1.0 Personal Illness Stories	DO NOT USE FOR CODING	
1.1 First-hand Experience	Mention of personal experience with long covid symptoms; reserved for tweets from people with or claim to have long covid	
1.2 Second-hand Experience/Accounts	Mention of personal experience working with or taking care of others who have long covid symptoms; reserved for doctors, nurses, healthcare workers, family members, and friends of those who have long covid	e.g., "I work with long covid patients and it's hard to diagnose them without a previous positive covid test."
1.3 Hearsay	Mention of someone else's experience with long covid; does not include their own experience	e.g., "my friend has long covid and can't even get out of bed in the morning"
1.4 Other Illnesses	Any mention of other illnesses, such as ME and other chronic illnesses; especially from people suffering from ME or chronic fatigue syndrome (CFS)	
2.0 Call to Action	DO NOT USE FOR CODING	
2.1 Government/Public Health Action	Tweets calling for the government (and specific health sectors) to do more to improve strategies to control and prevent long covid cases, provide more guidance on long covid, etc. Use this code for any tweets that is asking the government to do something regarding long covid	
2.2 Societal	Tweets calling for more people to recognize	e.g., tweets asking people

	long covid as a larger issue, take long covid more seriously, or asking for people to increase awareness and vigilance of long covid	to take this disease more seriously
2.3 Individual	Tweets calling for individuals to mask more or to continue adhering to covid guidelines in order to prevent long covid (i.e., individual responsibility)	
2.4 Research/Information	Tweets asking that more research be done to better understand long covid or tweets asking for more information about long covid	can also be used for any tweets that are asking an open question about long covid
3.0 Criticism	DO NOT USE FOR CODING	
3.1 Lack of Information and Action about Long Covid	Tweets criticizing or complaining about the general lack of information and action from the government and other public health agencies regarding long covid	exclude tweets that are directly asking for an action to be done -- those will go under the 'call to action' category
3.2 Lack of Acknowledgement and Public Messaging	Tweets specifically criticizing that people, healthcare professionals, or the government aren't taking long covid seriously enough; criticizing the government or other public health entities for lack of public messaging about the dangers of long covid; use for any mention of how poorly the dangers of long covid has been communication to the publics	can encapsulate any criticism about communication or the lack thereof
3.3 COVID-19 Guidelines	Tweets complaining, criticizing, or disagreeing with new or current covid-related guidelines (e.g., herd immunity, school reopening, lockdown, mask mandates, vaccine mandates, etc.) as it relates to long covid; use for tweets that imply that mandates (masking, social distancing, lockdown, etc) is necessary to control COVID-19 transmission, thus controlling long covid rates	e.g., "We should not be re-opening schools yet because kids are going to get long covid"
4.0 Request for Support	DO NOT USE FOR CODING	
4.1 Support Groups or Advice	Tweets advertising or looking for long covid support groups; mentions of being in a support group or needing support	can be for tweets offering support and/or advice OR long covid patients (or

		loved ones of long covid patients) asking for support and/or advice
4.2 Financial Support	Tweets asking for financial support from others (e.g., crowdsourced funding) due to the financial burden brought on by long covid	do not use to code any tweets asking the government to provide more funding to mitigate/prevent long covid--code those as call to action-->government action
5.0 Collective Sensemaking	DO NOT USE FOR CODING	
5.1 Long Covid Information	Mentions of what we currently know about long covid or sharing any current or new information about long covid (e.g., symptoms, manifestations, etc.)	NOT USED FOR CODING
5.1.1 Cited Sources	Long covid information tweets that include links to scientific papers, news articles, government websites, etc.	different from provision of educational materials: these tweets are specific to tweets that may have provided information about long covid and adding a link to provide a source (e.g., "Long covid symptoms include fatigue, brain fog, shortness of breath. https//pubmed.org")
5.1.2 Uncited Sources	Long covid information tweets that do not include the source of this information	
5.2 Statistics Sharing	Tweets that include statistics about long covid prevalence or incidence	NOT USED FOR CODING e.g., “1 in 5 people will get long covid”, “100,000 children in the UK have long covid”
5.2.1 Cited Sources	Statistics sharing tweets that include links to scientific papers, news articles, government websites, etc. to back up the numbers mentioned	different from provision of educational materials: these tweets are specific to tweets that may have

		provided statistics about long covid and adding a link to provide a source (e.g., "1 in 10 people who get COVID suffer from long covid https//pubmed.org")
5.2.2 Uncited Sources	Statistics sharing tweets that do not include their source of statistical information	
5.3 Provision of Educational Materials	Tweets sharing links to any long covid resources, such as talks, panels, podcasts, videos, articles, briefings, policy discussions, general resources, etc. with the intention of providing more information about long covid to the general public; can also be used for tweets recruiting long covid patients to participate in a study	different from long covid information--cited sources: these tweets are specifically sharing an article (e.g., quoting a specific sentence as their tweet plus a link to the specific resource)
5.4 Correcting Misinformation/Misconceptions	Tweets specifically addressing misconceptions or misinformation about long covid; can also be used for tweets calling out misinformation	
5.5 Alternative Treatments	Tweets mentioning any alternative treatments for long covid (e.g., ivermectin)	exclude any mentions of the vaccine - must be coded under one of the COVID-19 vaccine codes
6.0 Long Covid in Children	Mentions of long covid in children (e.g., prevalence, severity, experiences, etc.); can be double coded with statistics sharing or long covid information	
7.0 COVID-19 Vaccine	DO NOT USE FOR CODING	
7.1 Vaccine as Prevention and Treatment for Long Covid	Tweets claiming that the COVID-19 vaccine can treat or cure long covid; do not code as alternative treatments	
7.2 Vaccine Does Not Prevent Long Covid	Mentions of the COVID-19 vaccine not preventing long covid	
7.3 Long Covid as a Vaccine Injury	Tweets claiming, explicitly or implicitly, claiming that long covid is caused by the COVID-19 vaccine	
7.4 Long Covid as Cautionary Tale to Increase Vaccine	Tweets talking about the horrors of long covid (e.g., prevalence, poor experiences,	

Uptake	etc.) as a way to encourage people to get the COVID-19 vaccine	
8.0 Concerns about Long Covid Long-Term Impact	DO NOT USE FOR CODING	
8.1 Economic Burden/Impact	Mention of the economic impacts brought on by long covid (e.g., staff shortages, bad economy, etc.); long covid as a burden to the healthcare system; mention of long covid being a huge problem in the health sector	
8.2 Long Covid as a Mass Disabling Event	Tweets claiming that long covid is a disability, and that it will leave many people disabled; any implication that long covid is a disability	e.g., "long covid is going to leave a whole generation disabled"
9.0 Alternative Explanations	DO NOT USE FOR CODING	
9.1 Long Covid as Made Up Phenomenon	Tweets claiming/implying that long covid is made up for any given reason (e.g., long covid is a fearmongering tactic utilized by the government to control the public, long covid is a strategy for the government to push pro lockdown sentiments, etc.)	
9.2 Long Covid is Not Serious and Can be Explained by Other Reasons	Tweets claiming/implying that long covid is not serious or as bad as we think; includes tweets claiming that long covid is a symptom of other things (e.g., anxiety/depression from long lockdown); includes tweets that there are more challenging issues that we need to focus on	
9.3 Long Covid is Psychosomatic	Tweets claiming that long covid is only a psychosomatic disease or that long covid is only a disease that affects hypochondriacs or unhealthy people; tweets claiming that long covid is an excuse for people to get sick days or disability checks	
10.0 Other	Catch-all code for all tweets that do not fit within the other code/categories	

Appendix 2 – Supporting Quotes for Changes in Pattern Timeline

Time	Pattern	Supporting Quotes
June 2020 to December 2020	**42% of all tweets from Jun to Dec 2020 shared Long Covid information through links**	**@InstituteGC** (October 5, 2020): There's still much we don't know about #COVID19, including the impact of 'long covid'. This

	remained constant throughout the whole study timeline. These are usually linked to research studies, news articles, videos, podcasts, and talks.	paper examines @KingsCollegeLon's symptoms study & other emerging evidence, to understand the scope & scale of the problem and its role in the risk of the virus https://t.co/DrUqcOm59j
	Tweets about the personal experiences with Long Covid accounted for 9% of all tweets from Jun to Dec 2020. Long Covid patients shared their symptoms, experiences, and general thoughts with others as a way to increase awareness of the disease.	**@Julia_SCI** (September 16, 2020): Two months later and I'm having a very low energy, fatigue day. I'm slow to get up, I feel light headed and get tunnel vision. Joints feel stiff. I'm just tired of being tired. Please keep wearing your masks and staying home. You really don't want this. QT @NatureNews: Months after infection with SARS-CoV-2, some people are still battling crushing fatigue, lung damage and other symptoms of 'long COVID'.
	14% of all tweets from Jun to Dec 2020 were calling on the government for more support, guidance, and information about Long Covid.	**@PoliticsPollss** (August 25, 2020): Boris Johnson must meet families whose relatives have been killed by coronavirus and fund research into the longer-term effects, known as "long Covid", to help the pandemic's forgotten victims, MPs have said. Should the PM meet and fund research for the families? #LongCovid
January 2021 to June 2021	As we learn more about the incidence and severity of Long Covid, more people started voicing their **criticisms of the poor COVID-19 pandemic guidelines, lack of action from the government, and poor Long Covid-related public messaging – accounting for 18% of all tweets from Jan to Jun 2021.**	**@AndyMcDonaldMP** (February 9, 2021): 112,000+ British citizens dead, tens of thousands with long Covid & many with permanent damage to vital organs. Yet the government says that the coronavirus isn't a 'serious' workplace risk. Is it any wonder the UK is suffering the highest death toll in the world? https://t.co/AbjFCHYPLw
	Long Covid in children also became a topic of interest on Twitter, with **9% of all tweets from Jan to Jun 2021 showing concern about the impact of Long Covid on children**. This is largely in response to UK's decision to re-open schools for in-person classes.[21]	**@KatyJayne101** (April 7, 2021): This is your reminder that Gavin Williamson re-opened schools without adequate safety measures in place. 43,000 children and 114,000 teaching staff in the UK are living with long Covid. Williamson claims that kids "lack discipline & order." Its high time for Williamson to go.
July 2021 to December 2021	As we enter the second half of 2021, **more people started talking about the vaccine as it relates to Long Covid**. We see this given that the vaccine has	**@DrTomFrieden** (July 20, 2021): One of the best reasons to get vaccinated is to avoid long Covid. Many young, healthy people are suffering from debilitating symptoms months

	now become available to the general population. **75% of all vaccine-related tweets framed the COVID-19 vaccine as a way to prevent Long Covid.**	after Covid infection. The most certain way not to get long Covid is to not get Covid.
	The conversations about Long Covid started including **heavy use of statistics**, most of which were uncited. **83% of all tweets including Long Covid-related statistics from July to Dec 2021 were uncited**.	**@jbritt06** (September 20, 2021): I keep hearing about the worker shortage, but no interrogation into the 700K ppl we lost, and the effect of long covid on the 40M positive cases
January 2022 to June 2022	**About 8% of all tweets from Jan to June 2022 described the personal experiences of Long Covid patients and their family members**. These tweets, unlike early on in June 2020, were less about bringing awareness to Long Covid, and more about discussing their experiences with the **illness as a cautionary tale.**	**@MLS_Dave** (February 23, 2022): I've have #LongCovid for 2 yrs exacerbated by Omicron in Jan. 2 yrs ago I could do 1000 push-ups an hr & intense heavy & speed bag workouts. Now I have a cardiologist, rheumatologist, neurologist & urologist, & I'm doing better than many others with long covid. Think about that.
	Sharing of Long Covid-related information remained constant throughout the pandemic, which speaks to the **continued collective sensemaking** around the topic. **About 31% of all tweets from Jan to Jun 2022 shared Long Covid-related information.**	**@PamBelluck** (May 18, 2022): NEW: A study of over 78,000 people who received a specific medical diagnostic code for long Covid found that most hadn't needed hospitalization for their initial infection and nearly a third had no pre-existing medical issues. https://t.co/vA0XGjfnz5