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# The #longcovid revolution: A reflexive thematic analysis

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ABSTRACT

Research has identified long COVID as the first virtual patient-made condition (Callard and Perego, 2021). It originated from Twitter users sharing their experiences using the hashtag #longcovid. Over the first two years of the pandemic, long COVID affected as many as 17 million people in Europe (WHO, 2023). This study focuses on the initial #longcovid tweets in 2020 (as previous studies have focused on 2021–2022), from the first tweet in May to August 2020, when the World Health Organization recognised the condition.

We collected over 31,000 tweets containing #longcovid from Twitter. Using Braun and Clarke's reflexive thematic analysis (2020), informed by the first author's experience of long COVID and drawing on Ian Hacking's perspective on social constructionism (1999), we identified different grades of social constructionism in the tweets. The themes we generated reflected that long COVID was a multi-system, cyclical condition initially stigmatised and misunderstood. These findings align with existing literature (Ladds et al., 2020; Rushforth et al., 2021).

We add to the existing literature by suggesting that Twitter users raised awareness of long COVID by providing social consensus on their long COVID symptoms. Despite the challenge for traditional evidence-based medicine to capture the varied and intermittent symptoms, the social consensus highlighted that these variations were a consistent and collective experience. This social consensus fostered a collective social movement, overcoming stigma through supportive tweets and highlighting their healthcare needs using #researchrehabrecognition. The #longcovid movement's work was revolutionary, as it showed a revolutionary grade of social constructionism, because it brought about real-world change for long COVID sufferers in terms of recognition and the potential for healthcare provisions.

Twitter users' accounts expose the limitations of traditional evidence-based medicine in identifying new conditions. Future research on novel conditions should consider various research paradigms, such as Evidence-Based Medicine Plus (Greenhalgh et al., 2022).

## 1. Introduction

The term "long COVID" first entered public discourse in May 2020 when Dr. Elisa Perego shared #longcovid on Twitter (Callard and Perego, 2021; Perego and Callard, 2021). A hashtag (#) is a concept-labelling tool that encourages public and global sharing of the discussed concept by grouping conversations around it. Initially, #longcovid referred to Perego's experience of prolonged "cyclical, multiphasic and multisystem" symptoms of COVID-19 (Perego et al., 2020a, p.2). Twitter, with approximately 187 million users at the time, emerged as a platform for individuals with persistent COVID-19 symptoms to publicly share their experiences, symptoms, and concerns associated with living with the condition (Tankovska, 2021). Throughout the first two years of the pandemic, an estimated 17 million people in Europe, and even more worldwide, were suspected to have endured long COVID (WHO, 2023a). Given the imposition of mandatory social distancing measures, social media platforms like Twitter provided an avenue for individuals to connect and exchange their long COVID experiences. Consequently, global conversations on Twitter led to the emergence of long COVID as "the first illness created through patients finding one another on Twitter" (Perego and Callard, 2021, p.1), showcasing the potential for online community formation based on

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shared lived experiences (Santarossa et al., 2022).

Concurrently, another patient-defined term, ‘long hauler,’ was coined by Amy Watson, an American school teacher, to describe similar symptoms (COVID-19 Recovery Awareness, 2021). However, as this term was shared in a private group, it gained less publicity and traction in public discourse compared to ‘long COVID’ as an emerging diagnosis. Since ‘long COVID’ is the term predominantly used in existing literature, it will be used throughout the remainder of this article. It is important to note that ‘long COVID’ also incorporates the term ‘long hauler,’ as both are patient-coined terms for prolonged COVID-19 symptoms.

Perego’s #longcovid tweet challenged the initial expectation from the World Health Organization (WHO) that a COVID-19 infection would last on average for two weeks for people with mild infections (Perego et al., 2020a, 2021; WHO, 2020a). The WHO’s initial information largely depended on data from China, where COVID-19 originated. Early research focused on hospital admissions and did not continue beyond hospital discharge (Huang et al., 2022). Huang et al. (2022) noted this as a limitation and advised for further research in “outpatient, primary care, or community settings” to understand the full “spectrum of clinical severity” (p.2). Although the WHO and medical researchers were incognizant of longer-term sequelae, the use of #longcovid grew exponentially after Perego’s first tweet. Dr Tedros Adhanom Ghebreyesus, the WHO Director-General, was a Twitter user in 2020, and the use of #longcovid was noticed by him as he reshared the phrase (Ghebreyesus, 2023). On October 21st, 2020, Dr Ghebreyesus met in person with long COVID advocates to discuss their experiences of the condition. He summarised the meeting by showing support for patient-led research and patient-led activism for long COVID (Perego and Callard, 2021; Perego and Callard, 2021). He recognised patients’ requests for healthcare bodies to provide “recognition, rehabilitation and research” on long COVID (WHO, 2020b).

Once aware of long COVID, the WHO urgently pursued its medical recognition in the International Classification of Diseases (ICD-11), a “legally mandated health data standard” for medical nomenclature (WHO, 2023b). Given the lengthy process involved in adding a new condition to the ICD-11, the WHO expedited the recognition by applying an emergency code known as RA02. In September 2020, the ICD-11 defined long COVID as ‘post-COVID-19’ (WHO, 2023c). This new classification in the ICD-11 sent a clear signal to global healthcare organisations to promptly acknowledge and provide medical care for individuals with long COVID.

In this article, we examine the social construction of an online patient community on Twitter identified by the use of #longcovid. This community introduced long COVID as a health condition by publicly sharing and discussing #longcovid. The efforts of this community, over a brief three-month period, also created a clinical pathway for diagnosis. Therefore, we will examine the social construction of long COVID, as both a social and medical condition, by analysing from Perego’s first tweet containing #longcovid on May 20th, 2020, to Dr Ghebreyesus’ public recognition of long COVID on August 21st, 2020.

Our exploration of initial tweets differs from the work of Awoyemi et al. (2022), who conducted a sentiment analysis of long COVID descriptions on Twitter by extracting keywords. In their analysis, Awoyemi et al. (2022) examined 10,670 tweets from March 25, 2022, to April 1, 2022, over a seven-day period. However, to adequately assess the data longitudinally, this period may need to be extended. Their findings revealed that Twitter users expressed roughly equal sentiment towards long COVID, with 19.9% expressing positivity and 18.4% expressing negativity. Positivity was associated with trust, while negativity was associated with feelings of fear and sadness. Our study builds on the work of Awoyemi et al. (2022) by conducting manual analysis of tweets and utilising hashtags for tweet identification, rather than relying on keywords. Unlike hashtags, keywords are not shared with public intention and are more invasive in terms of Twitter users’ privacy (Twitter, 2023).

Our study also differs from that of Santarossa et al. (2022), who explored the use of #longcovid and #longhauler after the formal recognition of long COVID as a diagnostic category by the WHO. Their analysis focused on 2500 tweets published from February 18, 2021, to February 23, 2021. They found that the phrases ‘support’ and ‘research’ appeared in 56.5% and 22.5% of #longcovid discourse, respectively. For #longhauler, the phrases ’symptoms’ and ‘building a community’ were found in 61.5% and 31.5% of conversations, respectively. Given the differing results, it is important to include both #longcovid and #longhauler in our study’s search strategy. Santarossa et al. (2022) noted that the limited time frame impacted their ability to assess tweets longitudinally and track the trending of hashtags over time, and they suggested that future research should address this limitation. Our study addresses this knowledge gap by collecting tweets containing #longcovid and #longhauler over a three-month period to gain insight into the initial understanding and conceptualization of long COVID by Twitter users.

## 2. Methods

### 2.1. Theoretical framework: social constructionism

Within sociological literature that considers the meanings and values that are often attached to illness experiences, it is widely accepted that health conditions are not solely defined by their biological properties and/or clinical status. Instead, meanings that patients give to their illness experiences are largely understood as valuable forms of knowledge that enable a more holistic recognition and treatment of the condition and its effects (Kanagasingam et al., 2022). These meanings can directly influence clinical practice by shaping how clinicians discuss the diagnosis with patients (Albury et al., 2022), increasing the capacity for mutual agreement on treatment options and any recommended lifestyle changes. Because this clinical assessment is, at least in part, dependent on the meanings that patients give to their illness, it cannot be understood to exist separately from socially constructed ideas of what illness is and how it is understood outside of clinical contexts. In other words, the value, and meanings that patients bring to their illness experiences are integral to good clinical care and often contribute to clinical recognition and understanding of illness and how best to treat it (Kanagasingam et al., 2022).

The conditions under which certain conditions gain clinical recognition and the speed at which they are treated are, arguably, politically determined and socially influenced (Mayes, 2016). Illnesses that gain public attention because of their perceived urgency are often prioritised by national health bodies over illnesses that are either not deemed urgent because they do not pose an immediate threat to public health or are seen as the result of ‘choice-driven’ health behaviours that individual lifestyle changes can presumably remedy (Berg et al., 2021). Unlike conditions such as Ebola that primarily affected African countries, COVID-19 was initially recognised as a potentially life-threatening condition for everyone who contracted it, including people with political power in Western countries. After COVID-19 was declared a global health emergency by the World Health Organisation in 2020, research funding to better understand the virus and how to treat it was institutionally ringfenced to ensure fast results (UKRI, 2022). Because of its transmissibility within and between nation-states, COVID-19 was widely understood as a threat to everyone, including those who would not ordinarily be perceived as vulnerable to severe illness from respiratory infections (i.e., young people and people with no underlying health conditions).

As a diagnosis that originated from a collective recognition of chronic symptoms amongst patients previously diagnosed with COVID-19, long COVID offers a new way of understanding how illness/disease is socially constructed. Rather than presenting with symptoms and allowing them to be recognised as indicative of a pre-existing clinical diagnosis, patients utilised their embodied awareness of the link between their symptoms and their experiences of COVID-19 to lobby for a new diagnosis that centred those experiences in clinical dialogue and assessment. In this way, their embodied awareness was enough to generate recognition of the need for research that would then clinically validate an illness experience they knew to be true, creating pathways for funding and social awareness of the potentially lasting effects of COVID-19. As a clinical diagnosis, long COVID is rooted in a patient-centred approach to healthcare that began with recognising the need to centre patient voices in clinical assessments. As such, the diagnostic pathway of long COVID demonstrates an alternative way of integrating lived experience and pathological properties to produce a diagnosis that reflects a holistic understanding of health conditions and their everyday effects.

This sentiment can be understood in relation to Hacking's (1999) comments on social constructionism, which define the theory as "ontologically subjective but epistemologically objective" (Hacking, 1999, p.22). Indeed, the hashtag #longcovid is ontologically subjective because it was created virtually by Twitter users to share their lived experiences. However, it is epistemologically objective because the term long COVID, through broad consensus, came to define the real-world suffering caused by a severe health condition with pathological properties (Greenhalgh et al., 2020). Because Hacking's framework explores the interconnected nature of lived experience and disease diagnosis, its focus on classifying illness in relation to both reflects current conceptualisations of long COVID and its effects on patients.

### 2.2. Analytical framework

We used a detailed application of Hacking's six grades of social constructionism to analyse a set of long COVID tweets (Table 1). In doing so, we sought to answer the following questions.

1. What were Twitter users' accounts of long COVID?
2. How did Twitter users describe their healthcare provisions for long COVID?

**Table 1**
The grades of social constructionism.

| Grade of social constructionism | Definition | Application to long COVID |
|---|---|---|
| Historical contestation | This reflects indifference or neither "good nor bad" representations (Hacking, 1999, p.19) of a socially constructed idea. | Tweets were examined for indifference towards the value of the term long COVID. |
| Ironic | An ironic commitment to social construction is the perception that the initial definition is "inevitable" because of the constraints of the "conceptual architecture" of society (Hacking, 1999, p.19). | Tweets were assessed for an ironic attitude that reflected a Twitter user's belief that they could not change societal values regarding the initial definition of COVID-19, which did not include long COVID symptoms. |
| Reformist | A reformist approach considers that the lack of awareness of a socially constructed idea is "quite bad". Although it is hard to shift societal consensus, a reformist tries to make small changes to improve the situation (Hacking, 1999, p.19). | Tweets were examined to see whether Twitter users acknowledged that the lack of awareness of long COVID was an issue and whether or not they tried to make small differences to the global perspective on long COVID in tweets that contained #longcovid. |
| Unmasking | Unmasking "strip[s]" an idea of its "false appeal or authority" to reveal the importance of the socially constructed term (Hacking, 1999, p.20). | Tweets were assessed to see whether, through the publication of their tweets, Twitter users were trying to raise awareness that the initial definition of COVID-19 was not fit for purpose and to raise awareness of their own term, long COVID. |
| Rebellious | This grade is an extension of unmasking, and it "actively maintains" and advocates continual unmasking of the socially constructed idea (Hacking, 1999, p. 20). | Tweets were analysed to see whether, once long COVID had been unmasked, Twitter users continued to support the term and its meaning. |
| Revolutionary | This grade builds upon the grade of rebellion by extrapolating the socially constructed idea from the "world of ideas" to physical reality (Hacking, 1999, p.20). | Tweets were reviewed to see whether, once the concept of long COVID had been established, Twitter users in their tweets pushed for real-world changes, such as healthcare provisions, to the lives of those experiencing long COVID. |

### 2.3. Governance and ethics

The Cambridge Psychology Research Ethics Committee (PRE.2021.007 (COV19)) granted ethical approval on May 16, 2021 with an agreement that tweets could be reported in full if anonymised.

### 2.4. Data collection and sampling

All historical tweets used for this study were in the public domain. These refer to those published more than seven days before the collection date (Twitter, 2021a, 2021b). MT collected historical tweets by creating an academic Twitter account from which she generated a 'bearer token'. This token was inserted into the software Python alongside commands (Appendix 1) that led to retrieving historical tweets from Twitter's latest Application Programming Interface (API), known as the V2 archive. This was a novel approach because earlier archives would only permit the collection of tweets that had been posted during the previous seven days (Boyd and Crawford, 2012, p.666). The V2 archive was an efficient, effective, and accessible option and was designed specifically for use by researchers in COVID-19 studies (Chen, 2021).

The search identified tweets that used two terms: #longcovid OR #longhauler. MT collected tweets posted between 00:00:00 20/05/20 and 00:00:00 22/08/20 as this period covered the three months from Perego's initial tweet about long COVID to the first public use of the diagnostic term long COVID by the WHO Director-General. Tweets used included all geographic regions and languages, including, but not limited to, the U.K., Germany, France, Spain, the U.S.A and Japan. MT used Google Translate to decode non-English content. Search terms were not included with more limited geographical circulation, such as #apresj20, (the French equivalent of long COVID), and neither were medical terms for long COVID (i.e., post-COVID-19 syndrome (WHO, 2019)) in order to focus on global, patient-made terms. Twitter keywords and retweets were excluded because keywords are not intended for a public audience like hashtags, and retweets can lead to duplication of the same tweet (Bravo and Hoffman-Goetz, 2015).

Applying this strategy yielded a sampling frame of 31,016 tweets, from which a random sample of 1000 non-replaced (and therefore non-duplicated) tweets was selected (Appendix 2). Information power theory encourages consideration of the aims, sample specificity, underlying theory, quality of dialogue and analysis strategy. Information power theory and these considerations were applied to this study to justify the quantity of tweets (Malterud et al., 2016). Pilot work by MT further refined the sample. Tweets were reviewed for inclusion by MT and HB, and 26 tweets were excluded following a discussion of their relevance (Fig. 1). Of these 26 tweets, one failed to discuss long COVID, 21 did not contain data, and four had been shared outside the study timeframe. For ease of identification, the 974 tweets that were used in the final analysis were numbered chronologically and labelled as Tweet 1 (T1) to (T974).

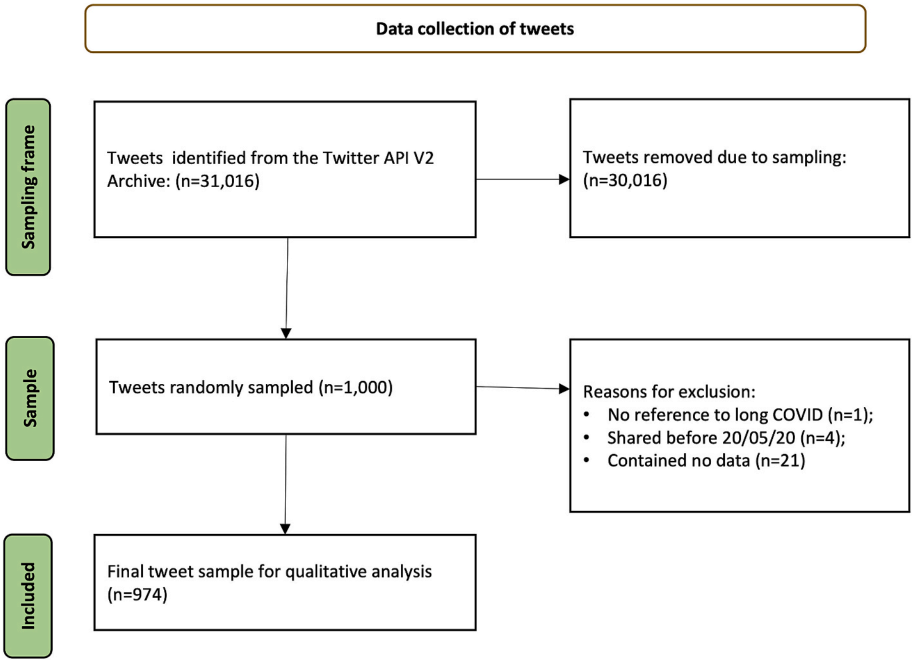

**Fig. 1.** The data collection process and inclusion and exclusion of tweets.

### 2.5. *Reflexive thematic analysis*

Reflexive thematic analysis (RTA) is a branch of thematic analysis designed by Braun and Clarke (2020, 2006). All approaches to thematic analysis "aim to identify and make sense of patterns of meaning across a dataset" (Braun and Clarke, 2020, p. 4), which aligns well with this study's aim to understand the accounts given by Twitter users of long COVID and their subsequent experiences of healthcare. RTA is particularly appropriate in this context because it does not prescribe the use of any specific methodology. The "flexibility" this offers enables researchers to embrace various supporting theories when analysing the data (Braun and Clarke, 2020, p.4), in this case, social constructionism.

This study began while MT experienced long COVID symptoms. RTA enabled her to reflect on how her research was being shaped by her own experience of being a doctor. She questioned how and why patients had identified long COVID ahead of various medical bodies and in turn, the process through which traditional evidence-based medicine typically came to recognise medical conditions. She was influenced by Kirsti Malterud (2006), also an academic general practitioner, and her work on the social construction of clinical knowledge. For instance, Malterud (2006) noted the "inadequacy of a confined biomedical approach, where only questions and phenomena that can be controlled, measured and counted are regarded as [medically] valid" (p.292). MT felt this could explain why there was initially such a delay before long COVID was recognised, since many sufferers, including herself, could not access COVID-19 diagnostic testing at the start of the pandemic and therefore did not, initially, fit the diagnostic requirements of a biomedical approach to validation.

While conducting RTA , MT coded collaboratively with two researchers without experience of long COVID, and this collaboration supported reflexive discussions. As sometimes, it was hard for MT to disentangle voicing her own experiences from those of Twitter users. Hence, the collaborators provided a sounding board for the reflective process. MT and HB followed Braun and Clarke's (2020) guidance on RTA by conducting "open and organic" (p.9) coding, which led to the development of themes. These themes were subsequently discussed with BC and then all collaborators.

## 3. Results

Analysis of the tweets led to the identification of six themes.

(a) individual long recovery;
(b) invisible illness;
(c) unexpected cohort;
(d) validation through quantification;
(e) the need for support and research; and
(f) recognition from health services.

Fig. 2 below illustrates how these themes relate to Hacking's grades of social constructionism. Themes (a) to (d) (identified in the blue petals) reflect how participants experienced being ill with long COVID. These themes addressed research question one regarding Twitter users' accounts of long COVID by reflecting long COVID could be an isolating and invisible experience (as shown by (a) and (b)) and unexpected, given the original lack of awareness of long COVID (c). In addition, Twitter users began defining themselves by their duration of long COVID symptoms, highlighting that the initial two-week definition was inadequate. They also began requesting a numerical understanding of their condition by counting the incidence of sufferers (d). Themes (e) and (f) (shown in the grey petals) address research question two and reflect participants' concerns about healthcare provisions. The grey petals demonstrate that Twitter users sought support, research, and recognition from health bodies.

The grades and themes were purposefully overlapped in this flower-like shape to reflect the complexity of the data. The general progression of long COVID's social construction was from ironic to historical contestation and, therefore, chronological. However, different grades of commitment to social constructionism were posted at similar times. Therefore, overlapping the petals represents the trend for chronological progression whilst also being mindful that the progression was not always linear.

### (a) Individual long recovery: an ironic grade of social constructionism

Twitter users described isolating, lengthy, and frightening

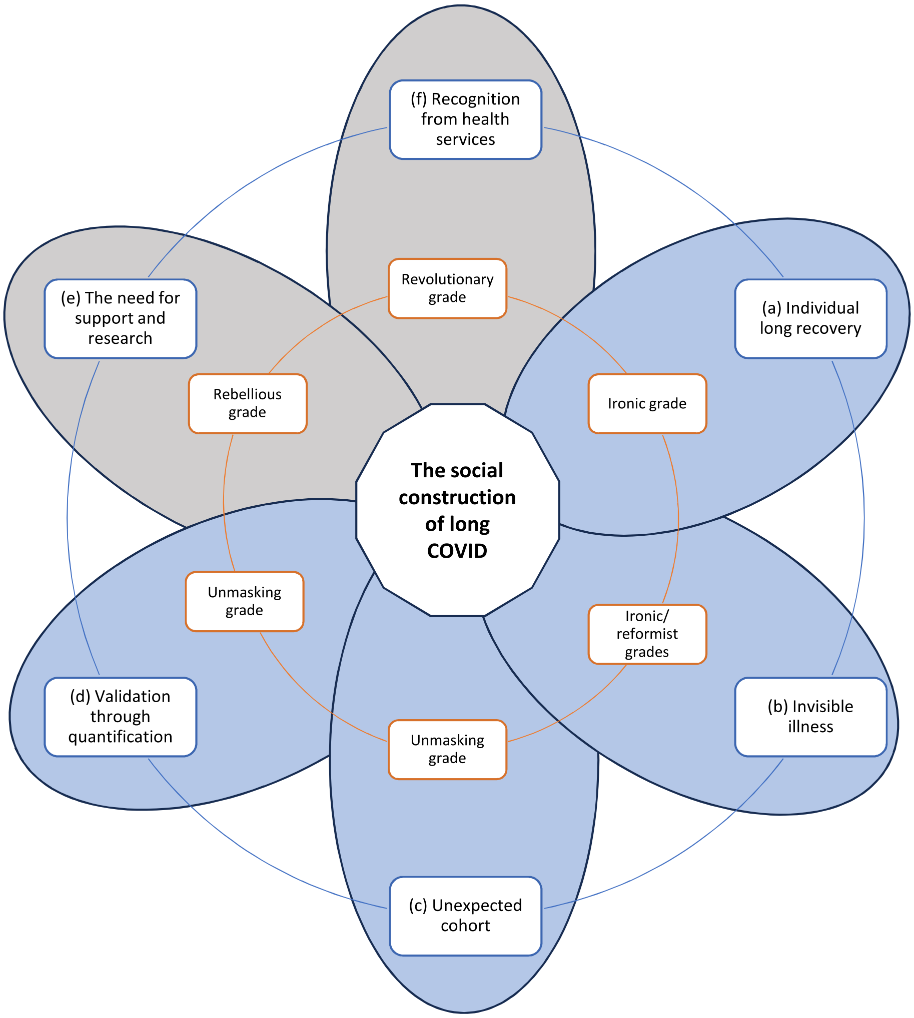

**Fig. 2.** Illustration of the six themes that were generated according to Hacking's 1999 framework of social constructionism.

experiences of long COVID, which presented an array of physical and psychological symptoms (see T322), including “tachycardia, hair loss, vision blur, numb arms” (T420), “anxiety” (T143) and “mood abnormalities” (T454). Other studies have noted these multisystem symptoms (Ladds et al., 2020; Heiberg et al., 2022). One participant from Ladds et al. (2020) reported widespread neuropathy: “I've been left with nerve issues, like really horrible nerve … stabbing pains in my hands and feet and I can't move my toes anymore” (p.4-5). Another participant, from Heiberg et al. (2022), commented that as well as respiratory and cardiac issues, “the worst trauma has been that I've got a post-traumatic stress syndrome.” (p. 698), reflecting the psychological impact of long COVID.

A key symptom that participants routinely discussed was “brain fog” (T204, T894). Heiberg et al. (2022) defined brain fog as a variety of cognitive challenges, which could include “attention deficits, lack of ability to focus over time, and challenges in performing executive functions” (p. 699). This symptom was experienced across cultures. In an otherwise Spanish tweet, it was labelled "#brainfogg" (T655); in French, it was referred to as “brouillard cérébral/cognitif” (T831, T888). Callan et al. (2022) suggested that brain fog could lead to “profound psychological, occupational and social impact[s]" and feelings of “guilt and shame” (p.4) as brain fog impacted the participants' abilities to socialise and work.

Furthermore, “brain fog,” coupled with multi-organ symptoms, presented in a relapsing and remitting cycle. This cyclical experience of illness was also identified by Rushforth et al. (2021). It was illustrated in T472: “You think you're getting better, only to be hit again”, leading to concern amongst participants that they might never recover. This theme encompassed those who described long COVID in terms of social constructionism with an ironic attitude. Hacking's (1999) definition of irony differs from its colloquial use. Referring to Table 1., an ironic commitment to social constructionism is the perception that the initial definition of long COVID is “inevitable” because of the constraints of the “conceptual architecture” of society (Hacking, 1999, p.19). Here, Twitter users felt hopeless about the prospects of a better future and therefore, held an ironic grade of social constructionism. For instance, one participant stated: “there is no end in sight” (T459) and did not express the belief that neither the experience of long COVID nor the recognition for long COVID would change.

> T322, posted 18/07/2020.
>
> “5 months. I still can't breathe. My heart rate hits 145 easy when I'm laying down multiple times a day If I dare eat anything with calorie intake. I'm on two blood pressure meds and I'm 24. I'm also severely anaemic. My body feels shattered. #LongCovid”

### (b) Invisible illness: ironic and reformist grades of social constructionism

The second theme is a direct quote from T278 and reflects participants' reports of the stigma associated with their experiences of long COVID. Participant T699 reported its impact on their immediate and extended social network: “it makes me want to cry in frustration when workplaces, friends, family, and doctors say it’s no big deal, that if you’re young you’ll be better in two weeks” (T699). T743 expressed concern that widespread stigma could impact any person that contracted long COVID, “are you ready, too, to be ill for months in #LongCovid? To risk disability and permanent damage? To lose your job for it?” (T743).

Similar to the theme (a) Individual long recovery, theme (b) Invisible illness also reflects an ironic attitude to social constructionism. For example, T699 reflects Hacking’s (1999) definition of irony because it offers no sign that the person felt able to change societal values regarding the initial definition of COVID-19, i.e., to encompass long COVID.

By contrast, in T278 (below), the writer pleaded for help to increase the public acknowledgement of long COVID and therefore shift away from the helplessness of an ironic grade of social constructionism. Instead, it suggests the development of a reformist approach, which considers that the lack of awareness of a socially constructed idea is “quite bad” (Hacking, 1999, p.19). A reformist approach recognises it is hard to shift societal consensus, yet still tries to make small changes to improve the situation (Hacking, 1999).

T278, posted 15/07/2020.

> “@X There is a huge problem and history of sufferers of invisible illness being disbelieved. Please help us generate empathy, not judgement by being aware of this blind spot. #LongCovid …”

Furthermore, the presence of these two grades of social constructionism in one theme is reflected in the overlapping petals of Fig. 2. It shows that the process that led to the social construction of long COVID on Twitter was organic, not linear.

### (c) Unexpected cohort: an unmasking grade of social constructionism

Participants described surprise and concern regarding their observations that many people who developed long COVID, many of whom were severely affected, were young and previously “fit and healthy.” Some participants commented that “relatively young, formerly quite healthy friends” (T58) and “previously healthy and active people of all ages” (T126) were contracting long COVID. Furthermore, Twitter users emphasised that this was a shared experience, “I have friends, including relatively young, formerly quite healthy friends, in the same boat.” (T58). A sense of camaraderie, support and warmth was shared about this collective experience, “I’m so sorry. for what it’s worth, you are not alone! #LongCovid and me got your back if you ever wanna shout out” (T442).

However, this acknowledgement of an unexpected cohort directly conflicts with the WHO’s initial suggestion that those who might be severely affected would be mainly immunocompromised and elderly patients (see T58). This discord between lived experience and the expectations of healthcare providers led to Twitter users *unmasking* the initial definition of COVID-19, stripping it of its “false appeal or authority” to reveal the importance of the term ‘long COVID’ (Hacking, 1999, p.20). The term highlighted the protracted suffering of those with long COVID, which was unknown to the WHO at the time.

T58, posted 25/06/2020.

> “This is definitely a thing. A very serious thing. I have friends, including relatively young, formerly quite healthy friends, in the same boat. #LongHauler #COVID19 Broadway actor, COVID-19 survivor talks about lingering symptoms 3 months later URL”

### (d) Validation through quantification: an unmasking grade of social constructionism

At the start of the pandemic, the mortality rates and incidence of acute infections of COVID-19 were reported daily in the U.K. (ONS, 2020). By contrast, healthcare systems initially failed to register the incidence of long COVID as a medical condition. Twitter users highlighted this omission. One person featured in this study, for instance, pointed out that “there are no numbers to express just how life-wrecking this thing is” (T733), while others raised concerns regarding the limited input from healthcare systems (T713).

T713, posted 08/08/2020.

> “I think the issue of #LongCovid is very important, and I think you are right - establishing some numbers around those sufferers would be a very good idea. I hope the authorities get onto it. If not, I hope it’ll make it to the top of my to do heap”

Regarding social constructionism, T713 shows elements of rebellious commitment, as the Twitter user sought to “actively maintain” the unmasking of long COVID, regardless of whether or not healthcare systems undertook this role themselves (Hacking, 1999, p.20).

### (e) The need for support and research: a rebellious grade of social constructionism

Building on this rebellious strand of online discourse, participants began to advocate for their own unmet healthcare needs. Twitter users developed another patient-coined term, #rehabresearchrecognition, to spread the exigency for rehabilitation, further research and for recognition of long COVID (see T748). This overarching hashtag was collectively produced as an amalgamation of the tweet contents "#recognition #rehab #research”, “rehabresearchrecognition” and "\rehab\research \recognition” (T126, T148, T176, T216, T243, T748 and T966). By sharing #rehabresearchrecognition, Twitter users attempted to shift the medical community’s awareness of the issue from an abstract concept to a recognised medical condition that demanded physical healthcare tailored to patients’ needs.

T748, posted 10/08/2020.

> “@X @X @X @X Thank you for speaking so candidly about your health. The 16,000 in our #LongCovid Facebook group are crying out for #RehabResearchRecognition URL”

### (f) Recognition from health services: a revolutionary grade of social constructionism

In subsequent tweets, participants commented on how medical bodies gradually became aware of long COVID. For instance: “Thankfully, the medical establishment is waking up to the threat of #LongCovid” (T843). They also commented on key healthcare actors such as Dr Anthony Fauci, then director of the National Institute of Allergy and Infectious Diseases at the US National Institutes of Health and chief medical adviser to US President Donald Trump, and Dr Tedros Ghebreyesus becoming aware of the condition. Various tweets suggested that Fauci and Ghebreyesus had signalled agreement with Twitter users that COVID-19 symptoms could be severe and persist beyond two weeks. T204, for instance, reports Fauci saying that “there are chat groups that you just click on and see people who recovered that really do not get back to normal. They report symptoms such as brain fog, difficulty concentrating, fatigue, that resemble the symptoms of ME [myalgic encephalomyelitis]”. Similarly, T967 reports similar support from Ghebreyesus.

T967, posted 21/08/20.

> “My message to these [long covid] patients was: we hear you loud and clear, and we are committed to working with countries to ensure

> you receive the services you need, and to advancing research to serve you better"

This theme demonstrates a revolutionary commitment to the social construction of long COVID among the participants in this study, given that their efforts helped to bring about real-world change that key healthcare actors then led. This understanding is supported by T967, in which Ghebreyesus highlighted the need for improved healthcare and research on long COVID and pledged that the WHO would work with healthcare groups globally to provide this.

### *3.1. Outlying data: a historical grade of social constructionism*

Generally, the dataset reflected warmth and support for the existence of, and concern regarding, long COVID. Only four of the 974 tweets, T764, T824, T866 and T963, all posted between the 11th and August 21, 2020, did not. These all reflected a historical contestation for the social construction of long COVID, and this commitment only became apparent at the end of the dataset. For example, T764 suggested indifference towards long COVID "@X What's so bad about the new infections? There will be many more, but very few get sick and even less seriously ill. Why this fear?" Here, this Twitter user suggested that long COVID was rare and likely milder than sufferers were reporting.

> T764
>
> "@X What's so bad about the new infections? There will be many more, but very few get sick and even less seriously ill. Why this fear?"

For this study, these tweets were classified as outliers because they received minimal engagement from other Twitter users. This may have been because #longcovid was still a new term, perhaps only being shared by those seeking a community for their active symptoms and concerns. This potentially contrasted with Twitter users outside the long COVID community, who were only beginning to become aware of the term due to its increasing use on Twitter. Therefore, we suggest that these outlying tweets came from Twitter users who were not suffering from long COVID and were questioning the term's legitimacy.

## 4. Discussion

Twitter users were instrumental in achieving medical recognition for long COVID. Our results show that Twitter users who tweeted the term #longcovid in the first three months reached a quick consensus on their experiences of the condition, whilst healthcare bodies remained unaware of it. Many initial tweets containing #longcovid described an illness encompassing persistent, multi-organ symptoms that returned cyclically, features which were also identified in qualitative studies at the start of the pandemic. Ladds et al. (2020), described long COVID as a "multisystem disease with evidence of cardiac, respiratory, or neurological end-organ damage manifesting in a variety of ways" (p.2), while Rushforth et al. (2021) found that participants interviewed between May–June 2020 reported a "recurrent cycle of partial recovery followed by deterioration" (p.5). There was, therefore, ample evidence for the cyclical and multi-organ symptoms that Twitter users described in tweets as debilitating and disabling. Despite these challenging symptoms, however, many reported that whilst healthcare bodies were unaware of long COVID, their symptoms were disbelieved.

Twitter users felt their long COVID symptoms were disbelieved by many, such as friends, family, healthcare professionals or colleagues, to the extent that they felt their illness was "invisible" to others (T278). This lack of awareness and invisibility could lead to misunderstanding and stigmatisation of long COVID symptoms. This finding aligned with long COVID patients' stories that were submitted to an online website during a similar time frame (April–September 2020), which described the undervaluation of such symptoms and illness experiences as an epistemic injustice (Ireson et al., 2022). A British union-led study also found a lack of awareness in the workplace, which reported that many workers faced discrimination or were disadvantaged because their employers contested the status of long COVID as a medical condition (TUC, 2021).

In addition, this union-led study noted that many with long COVID found that their symptoms persisted for more than 12 months. Eventually, this would lead to a new classification of disability under the provisions of the UK Equality Act 2010 (TUC, 2021). Initially, however, this newfound disability was overlooked by healthcare bodies. For instance, Twitter users were concerned that their experiences of long COVID did not match the WHO's original viewpoint that COVID-19 would be mild for the general population (WHO, 2020a). They raised these concerns, stating that young, fit, healthy people also fell severely ill with long COVID. Interestingly, in an essay published on the May 8, 2020, just before the establishment of the hashtag #longcovid, Callard (2020) expressed these same concerns, namely that long COVID was being misrepresented as a mild and brief condition, given its potential severity. Therefore, Twitter users' attempts to raise awareness at the time were similar to growing concerns about prolonged symptoms in the existing literature.

Twitter users were also concerned that healthcare bodies might not adequately provide healthcare provisions or invest in research on long COVID due to a lack of awareness. Therefore, they campaigned for their healthcare needs using the hashtag #researchrehabrecognition. Their requests for specialised healthcare and research into the longer sequelae of COVID-19 were also raised in subsequent articles commenting on the initial management of long COVID (Callard, 2020; Ladds et al., 2020; Perego and Callard, 2021; Rushforth et al., 2021). With hindsight, it is clear that Twitter users were instrumental in achieving medical recognition for the condition. For instance, when guidelines were being developed for clinicians caring for patients who were affected, one honoured the efforts to which these Twitter users had gone to reach public consensus regarding their experiences by using the patient-coined term "long COVID" (Greenhalgh et al., 2020). In summary, this study supports the existing findings that Twitter users' accounts of, and their requests for greater healthcare support for their long COVID resembled literature being published simultaneously, both in terms of the types and duration of symptoms described and regarding the disbelief with which sufferers were confronted due to a general lack of awareness.

### *4.1. New findings*

We suggest that this study adds to the existing literature on long COVID as its findings show that Twitter facilitated the formation of a collective social movement that reached social consensus on the meaning of the term long COVID. According to Millward and Takhar (2019), a collective social movement is a way to challenge injustice. In this case, the injustice was the disbelief and stigma experienced by Twitter users in response to their long COVID symptoms. For a social movement to be successful, Millward and Takhar (2019) argue that "emotions effectively make movements move" (p.6). Through its public and open system, Twitter's social network enabled the sharing of these emotions among previously unassociated users, from everyday citizens to high-profile figures such as the Director-General of the WHO. The openness of Twitter enabled unassociated users to connect and share emotional experiences. It differed from methods used on other social networking sites (i.e., Facebook and Slack), which contained closed groups for long COVID sufferers that restricted public sharing. Twitter's unique properties as a social media site on which accounts of long COVID could be disseminated publicly were identified by Santarossa et al. (2022), who highlighted the "decentralisation" (p.13) of Twitter discourse on long COVID during their social network analysis. This decentralisation suggests that Twitter users had "no single opinion leader" because there was "a free flow of information between the users" (Santarossa et al., 2022, p.13). This free flow of information reflects the "working utopia" of a collective social movement, which enables sharing of emotions, such as those accompanying accounts of long COVID.

(Millward and Takhar, 2019, p.6).

We suggest that the success of this collective social movement was fuelled by the initial emotional support and positive reception to tweets containing the hashtag #longcovid. For instance, earlier in the dataset, T442 offers warmth and support, "I'm so sorry. for what it's worth, you are not alone! #LongCovid and me got your back if you ever wanna shout out". This initial, collective emotional support spearheaded the later campaign for recognition and healthcare, which appeared towards the end of the dataset through the new hashtag #researchrehabrecognition. Before this point was reached, Twitter users widely shared the individual terms #research, #rehabilitation, and #recognition. Eventually, users amalgamated the three terms into the grouped hashtag above. The evolution of hashtags demonstrated the collective decision-making process aimed at challenging the injustice faced by long COVID sufferers due to their initial lack of medical recognition and healthcare provisions.

The contents of the tweets mirrored the transitory stages of social constructionism. At first, many Twitter users felt an ironic attitude towards the existing social construction of long COVID, in which the degree of stigma and disbelief seemed insurmountable. Subsequently, users shifted to an "unmasking" phase, which contributed to the legitimisation of long COVID as a medical diagnosis. Finally, the collective will this inspired created a revolutionary attitude towards long COVID. This attitude shift made it possible to gain recognition from health bodies and explore the potential for developing healthcare provisions (Hacking, 1999). None of this would have been achievable, and there would have been no transition from an invisible illness to a recognised one, without the initial emotional support that was presented in the early tweets. Therefore, we propose that the positivity offered in the early tweets comprised the initial currency of the collective social movement and led to its success.

This success aligns with Hacking's (1999) perspective on social constructionism, whereby Hacking defined the theory as "ontologically subjective but epistemologically objective" (Hacking, 1999, p.22). Although the hashtag #longcovid was ontologically subjective, created virtually by Twitter users, it became epistemologically objective through a broad consensus that defined the real-world suffering caused by long COVID (Greenhalgh et al., 2020). Hacking's (1999) work on social constructionism advises that the power of social construction lies in its ability to highlight the plight of a minority group, such as those with long COVID initially. Indeed, traditional evidence-based information on long COVID was initially lacking for various pandemic-related reasons (Rushforth et al., 2021), such as the inability of researchers to collect data in person due to social distancing. Nevertheless, real-world experiences of long COVID are legitimate, regardless of whether healthcare bodies can explain them. Djulbegovic and Guyatt (2019) still take this argument further: that consensus is a better alternative when evidence-based medicine is lacking, as it was at the start of the pandemic. This principle is arguably exhibited by the process through which tweets containing #longcovid gradually resulted in a collective social movement and eventually in the changed recognition status of long COVID sufferers.

We propose that the initial evidence-based approach to questions about long COVID also presented another obstacle to its recognition. Healthcare bodies tend to lean towards positivist paradigms when defining a new condition, encouraging an objective approach. An example of this is the Bradford Hill (1965) criteria for epidemiologic evidence, which form a nine-point checklist for consideration.

(1) strength of association,
(2) consistency of the observed association,
(3) specificity,
(4) temporality,
(5) biological gradient,
(6) plausibility,
(7) coherence,
(8) experiment, and
(9) analogy.

This set of criteria can be applied to investigate the possibility of a quantitative, causal relationship between the virus severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), which causes COVID-19, and long COVID symptoms.

Long COVID did not initially fulfil Bradford Hill's criteria, and we propose that this finding hindered the opportunities for health bodies to become cognizant of long COVID and respond with appropriate medical care. An initial lack of diagnostic testing reduced the chance of medical bodies finding a strong association between positive COVID-19 tests and long COVID symptoms, thereby preventing them from fulfilling criterion 1 (Greenhalgh et al., 2020). As this study shows, symptoms of long COVID varied because they impacted multiple bodily systems and were inconsistent due to their cyclical nature, which led to difficulties in consistently observing symptoms (failure to meet criterion 2), attributing them specifically to long COVID (criterion 3), and link such symptoms over time (criterion 4). Furthermore, due to the rapid nature of the unprecedented pandemic, there were insufficient resources to conduct fast clinical trials (criterion 8) to an appropriate ethical standard to assess: the biological gradient (criterion 5), the strength of the effect size, or to identify coherence (criterion 7) between laboratory and real-world findings (Greenhalgh et al., 2022). Given the limited understanding of post-viral syndromes, such as ME (also known as chronic fatigue syndrome (CFS)), there was limited medical consensus either on the use of such syndromes as analogies (criterion 9) for long COVID or on the plausibility (criterion 6) of underlying mechanisms for post-viral sequelae (Missailidis et al., 2019). Ultimately, applying the Bradford Hill criteria to show a cause-effect relationship between SARS-CoV-2 and long COVID proved impossible early in the pandemic. This indicates that there is a significant blind-spot in evidence-based medicine that prevents medical observation and recognition of some new medical conditions.

In this way, the collective social movement was crucial in clinically recognising this condition because it provided consensus on a definition of long COVID and overcame the blind-spot of traditional evidence-based medicine. Although the symptoms were varied and intermittent, our sample for this study of nearly 1000 tweets showed that this variety was a uniform experience. One tweet would not have been enough to construct long COVID socially; rather, thousands of tweets over several months were needed to provide social consensus on the meaning of the term. The subsequent collective consensus achieved by the social movement was compelling enough to demonstrate to healthcare bodies, including the WHO, that long COVID was a genuine condition, with individuals truly suffering from its effects, despite the absence of traditional evidence-based medicine. Moreover, the efforts of the #longcovid movement translated into concrete real-world advancements, such as medical recognition and acknowledgement of the healthcare needs specific to long COVID. These tangible outcomes exemplify a revolutionary grade of social constructionism (Hacking, 1999). Hence, we assert that the successes of the #longcovid movement were truly transformative and revolutionary in nature.

However, we cannot ignore the emergence of negative remarks about long COVID in the temporal tail-end of tweets. This outlying data potentially reflects the fact that public discussion of long COVID, including on Twitter, had shifted from its initially positive reception. As #longcovid began to gain public traction, it also rose to the attention of those with a more sceptical attitude towards the condition ("long COVID deniers"), and so the hashtag also rose in notoriety. It remains to be seen whether either the platform or the discourse continues to offer the kind of positive "working utopia" (Millward and Takhar, 2019, p.6) that facilitated the collective social movement identified in this study. Awoyemi et al. (2022), in 2022 conducted a sentiment analysis of tweets, which identified tweets showed similar levels of positivity (19.90%) and negativity (18.39%) toward long COVID. We are concerned that if the hashtag #longcovid is no longer shared with the warmth and empathy that characterised its conception, it may weaken the medical recognition of the term and impede real-world changes for long COVID sufferers. Therefore, while Twitter played an important role in bringing social and medical recognition to long COVID, further research beyond Twitter is necessary.

### *4.2. Future research*

To consider other ways, beyond Twitter, in which long COVID is likely to be considered by healthcare bodies, it is helpful to contextualise it with the social construction of other illnesses. Swoboda (2006) argued that "all new illnesses are socially constructed" (p. 234) but that the resultant medical recognition from healthcare bodies varies. Healthcare bodies easily recognise diseases such as HIV (Swoboda, 2006) and COVID-19 because their causal mechanisms are supported by quantitative evidence. By contrast, diseases for which limited quantitative evidence can be gathered to explain their causal mechanisms, such as ME/CFS, have been contested (Swoboda, 2006). In this way, maintaining the attention of healthcare bodies arguably depends on how long COVID is defined in quantitative research.

We propose that future research should address long COVID both quantitatively and qualitatively. This is to ensure that lived experience of long COVID is not overlooked so that medical treatment developed quantitatively is suitable for those experiencing long COVID. Therefore, we support revisiting the applicability of Bradford Hill's criteria in the case of long COVID from a quantitative perspective. With the lifting of mandatory social distancing measures in the U.K., it is now easier to conduct high-quality quantitative research in both hospital and community settings. Ongoing randomised control trials, such as the hospital-based RECOVERY trial and the community-based PANORAMIC trial, are evaluating treatment options for COVID-19 and its sequelae (RECOVERY Collaborative Group et al., 2021; PANORAMIC trial group, 2022). Additionally, mixed-methods research incorporating qualitative perspectives, such as the LOCOMOTION study, aims to improve long COVID care pathways in partnership with patients (Sivan et al., 2022).

These ongoing studies, along with our own findings supported by sociological theory, contribute to the current debates on expanding evidence-based medicine. These debates advocate for the integration of multiple research paradigms, including those covered by the social sciences, which are often excluded from traditional evidence-based medicine. This integration results in an enhanced approach known as evidence-based medicine plus (EBM+), which is more inclusive of patient lived experience (Greenhalgh et al., 2022). Therefore, we argue that further quantitative and qualitative research, as defined by EBM+, is needed on long COVID to ensure a comprehensive and holistic understanding of the lives of those affected by long COVID.

### *4.3. Limitations*

One limitation of our sample is that the participants' demographics, such as age and gender were unknown. This could lead to exclusion or over-inclusion of certain demographics, as well as the inclusion of tweets generated by bots, rather than human users. Furthermore, some people living with long COVID do not use Twitter. Therefore, our results have limited generalisability and cannot be understood to represent all experiences of long COVID. To address these factors, future studies could consider capturing the demographics of Twitter users, such as conducting surveys or extracting demographic characteristics from public profiles. Additionally, the inclusion of bot screening software can help distinguish human experiences from automated or non-human content.

## 5. Conclusion

In this study, we collected 31,016 tweets with the hashtags #longcovid and #longhauler shared on Twitter between 20/05/20 and 21/08/20. Adopting a social constructionism framework, we aimed to assess the development of long COVID as a recognised medical condition on Twitter, starting from a single tweet. From our analysis of 974 tweets within the sampling frame, we observed that Twitter users initially portrayed long COVID as a relentless, multi-organ, and disabling condition. However, these accounts faced stigma and discrimination due to the lack of awareness among the general public and healthcare bodies at that time.

These early Twitter user accounts of long COVID, predating its official recognition, were later substantiated by studies documenting the initial experiences of long COVID. Our study contributes to the existing literature by highlighting how the hashtag #longcovid facilitated the formation of a collective social movement, leading to social consensus regarding the symptoms of long COVID. This social consensus played a vital role in gaining medical recognition for long COVID, despite the initial limitations of traditional evidence-based medicine during the early stages of the pandemic.

Furthermore, the collective social movement established a shared understanding of the healthcare needs of long COVID sufferers. Twitter users effectively campaigned for these needs using the hashtag #researchrehabrecognition, which caught the attention of the Director-General of the World Health Organization (WHO), who acknowledged and addressed these concerns. Therefore, the #longcovid movement's work was revolutionary, as it showed a revolutionary grade of social constructionism (Hacking, 1999), because it brought about real-world change for long COVID sufferers in terms of recognition and the potential for healthcare provisions.

Given the limitations of traditional evidence-based medicine in identifying and understanding new conditions, our study suggests that future research on long COVID would greatly benefit from adopting an Evidence-Based Medicine Plus (EBM+) approach. This approach would consider both medical bodies' expertise and patients' perspectives to develop comprehensive and effective healthcare provisions for long COVID.

## Credit author statement

**Melody Turner**: Conceptualization, Methodology, Software, Validation, Investigation, Data curation, Formal analysis, Writing - Original Draft, Visualization **Helen Beckwith:** Methodology, Validation, Formal analysis, Writing - Review & Editing, Supervision **Tanisha Spratt**: Methodology, Writing - Review & Editing **Elvira Perez Vallejos:** Writing - Review & Editing, Supervision **Barry Coughlan:** Methodology, Software, Formal analysis, Writing - Review & Editing, Supervision.

## Declaration of competing interest

Nil to declare.

## Data availability

We have shared the commands used to collect the data (See Appendix 1), which can be used to retrieve the same data from Twitter's Application Programming Interface (API) with Twitter's permission.

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## Appendices.

### *Appendix I*

*Python Command for Sampling Frame*

```
pip3 install twarc twarc-csv
twarc2 configure.
Please enter your Bearer Token:
twarc2 search –archive –start-time “2020-05-20" –end-time “2020-08-22" "(#longcovid OR #longhauler) -is:retweet” filename.jsonl
twarc2 csv filename.jsonl filename.csv
```

### *Appendix II*

*Sample collection method*

```
“setwd("insert as appropriate")
set.seed(20210615).
data1<-data.frame(read.csv("tweets.csv"))
head(data1).
dim(data1).
random_row_numbers < -sample(nrow(data1), 1000, replace = F).
data2<-data1[random_row_numbers,]
write.csv(data2, file = "filename.csv")Results”
```

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