Patient-made Long Covid changed COVID-19 (and the production of science, too): analysis of patients' epistemic contributions to a new illness

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ABSTRACT

Background: Significant knowledge about long-term symptoms following SARS-CoV-2 infection has been produced by patients, which made Long Covid.

Objective: To document and analyse such knowledge, outline how it changed understanding of COVID-19, and specify ethical and socio-political challenges associated with its development.

Methods: Analysis of publicly available materials on Long Covid by people with Long Covid, largely in English and Italian, and across media and genre.

Results: Those with Long Covid have made epistemic contributions across multiple media, including: oral, written and visual narratives, testimonies and arguments; quantitative and qualitative research; grey literature, essays, opinion pieces and commentaries; and advocacy and policy interventions.

Discussion: Patient knowledge contributed to shifting assumptions concerning COVID-19 symptoms and disease pathways; phasing and duration; classification and naming of illness; disease morbidity; and who is affected. Patients' use of a wide range of media challenged the conventional scientific production of epistemic claims. Many ethical and political challenges lie ahead, including exploitation of patients, their knowledge, and their data.

Conclusions: Long Covid patient activism and research have been instrumental to key epistemic shifts that have changed understandings of COVID-19. They have also changed – possibly permanently – how science and medical knowledge are produced. Patient expertise must be routinely integrated into medicine beyond the current pandemic. We also need to ensure the ethical use of patient-led expertise and patient-produced data in Long Covid.

Patient contribution: Both authors are patients and researchers with Long Covid, who have contributed to making 'Long Covid', and to advocacy around its definition and recognition.

Keywords

citizen science, COVID-19, epistemology, experiential knowledge, Long Covid, Long-haulers, patient expertise, patient knowledge, patient-led research, SARS-CoV-2, symptoms

Introduction

On 21 August 2020, the World Health Organization (WHO) met Long Covid advocates and experts at a landmark private meeting, which led to official recognition of long-term, debilitating COVID-19 symptoms.^{1,2} Closing the meeting, Tedros Adhanom Ghebreyesus, WHO Director General, re-quoted part of one patient group's presentation back to assembled advocates: 'with patient-led research and patient-led activism, it appears that patients are writing the first textbook on long covid'.¹ Nearly nine months after China reported the outbreak of a novel coronavirus to the WHO, the WHO acknowledged the central role of patient expertise in relation to COVID-19. We argue here – by qualitatively analysing shifts regarding conceptualisations and symptoms of COVID-19 – that patients' epistemic contributions have extended beyond writing the 'first textbook on long covid'. They have: (i) helped reshape assumptions about COVID-19; (ii) contributed new knowledge about COVID-19; and (iii) changed, possibly permanently, how knowledge is produced about a novel disease.

What is Long Covid?

'Long Covid' is the term collectively made by patients to describe long-term symptoms and sequelae following symptom onset clinically suggestive of SARS-CoV-2 infection.³ Patients, the vast majority of whom endured a new disease outside of in-patient hospital settings, set up support groups and initiated campaigns for care and recognition worldwide. 'Long-haulers' (a term introduced by patient Amy Watson)⁴ and 'long-haul Covid' circulated widely across patients and media reports and have also been used by clinician scientists.⁵ Cognate term 'Long Covid' was first used on Twitter, as a hashtag, in May 2020 by Elisa Perego from Lombardy.⁶ Perego used it as a contraction of long-term Covid illness, which engaged with her own experience of a cyclical, multiphasic, and multi-system condition. #longcovid became an increasingly prominent hashtag – initially used by patients and then by many others – and 'Long Covid' rapidly moved from social media into other domains. It subsequently appeared in scientific journal articles by conventional (non-patient) researchers: first, within the text's main body;^{7,8} later, directly in titles.⁹ Published studies increasingly recognize long-term COVID-19 symptoms and sequelae in a significant percentage of survivors.^{10,11} While the fine-grained mechanism(s) driving long-term symptoms need(s) further investigation, protracted immune responses and autoimmunity are suspected, multiple sequelae in many organs are now reported, and several secondary mechanisms might be involved.^{12,13}

The alacrity and extent of take-up of the term Long Covid – first by patients and, subsequently, by many others – demonstrates its effectiveness and ability to resonate with patients' experiences and to describe a new illness whose time course and mechanism(s) remain poorly understood. We document, in Section I, how patient knowledge surrounding 'Long Covid' was instrumental to epistemic shifts regarding COVID-19. Our phrase 'patient knowledge' encompasses multidimensional forms of such knowledge – which range from experiential knowledge (which can contribute to conceptual advances, hypothesis development, data interpretation, and ways of living), to full scale patient-led research projects.^{14–17} In Section II, we discuss the production and use of patient knowledge regarding Long Covid, highlighting ethical and socio-political risks ahead.

Methods

Our analytic paper engages with extensive materials produced by those with Long Covid. We both have Long Covid, and have contributed to the making of this patient-made term, as well as advocacy around Long Covid's definition and recognition.^{3,18} The paper draws on our analysis of fast-moving debates and research across different media, research institutions, and policy spaces. In view of language constraints, we largely focus on English and Italian materials. Since falling ill with COVID-19 in early 2020, we have followed and contributed to discussions across various media, and conducted regular database searches in both journals and newspapers to locate material on Long Covid/long-haul Covid. We distilled our material into themes that orient our sub-sections below, which we combine with conceptual and ethical reflections. These reflections draw on what we have experienced in the course of the pandemic, as well on our expertise in health research, from Long Covid to patient-/service user-led research.^{19,20} Our selection of specific examples, below, is linked to our ethical commitment to ensuring that we were able to acquire explicit permission from any person from whom we reference published materials or knowledge that we consider sensitive (into this category we place publicly available social media posts and personal communications).

1. Patient knowledge

Patient contributions are individually, collectively, and anonymously authored; most have emerged through collective sharing with other patients experiencing long-term symptoms and sequelae. A non-exhaustive list of contributions across multiple media includes: oral, written and visual narratives, testimonies and arguments; quantitative and qualitative research; grey literature, essays, opinion pieces and commentaries; and advocacy and policy interventions.

1.1 *Multiple symptoms and disease pathways*

2020 witnessed, Sharrona Pearl has argued, the emergence of a 'new genre of writing...: the Covid-19 symptoms thread'.²¹ Through this new genre, those with COVID-19 provided early, rich 'self-generated symptomatology[ies]'²¹ of a new disease, which are themselves evidence of a distinctive kind of illness narrative.²² Threads – such as for example one by Dani Oliver²³ – elaborated COVID-19's multi-systemic nature ensuring that patients helped broaden the focus beyond the pulmonary system, which was dominant in public messaging early in the pandemic. Another widely circulated thread and newspaper column by Fern Riddell, from April, emphasized her 'purely gastric' rather than pulmonary symptoms;^{24,25} another thread and newspaper article by Hannah Davis in July described symptoms affecting multiple organs, including the brain.^{26,27} Patient-made films from Spain and the UK profiled patients holding placards that documented vast, variable arrays of symptoms affecting multiple organs from heart to skin.^{28,29} The films made visible an emergent cohort for whom care, investigation and research was urgently needed, while giving solidity to both shared and heterogeneous symptomatology.

A survey by an all-patient team from the Body Politic Support Group, published in May 2020, comprised the first research which addressed the complexity of long-term symptoms, and collected quantitative and qualitative data.³⁰ The same team subsequently established itself as a formal research unit (Patient Led Research for COVID-19) and produced findings in December from a large-scale research survey describing the development of 205 multi-system symptoms across seven months.³¹ The ontology of COVID-19 itself, is, we emphasise, currently multiple: its nature remains, in part, mysterious. While first characterized as a respiratory

disease, and named as such, by April 2020, COVID-19 was being conceived as a systemic or endothelial disease.³² As the persistent form(s) and/or sequela(e) of a still poorly understood disease, Long Covid, patients stressed from early pandemic months, is likely to incorporate multiple conditions precipitated by SARS-CoV-2.³³ Many patients offered speculations and hypotheses based on careful observation of their own symptoms,^{34,35} on comparisons with others and with materials emerging from scientific research,³⁶ and on the effects of self-administered medication, such as aspirin and antihistamines,³⁷ which are now objects of research by conventional scientists.^{38,39} Some, such as Angela Meriquez, argued for the potential role of mast cell activation, dysautonomia, autoimmunity, cytokine release and complex cardiovascular damage.^{40,41} Patients also stressed the importance of tackling persistent organ impairment and tissue inflammation.^{42,43} Many of these phenomena are now addressed in publications in scientific journals.⁴⁴⁻⁴⁷ Patients often cemented the plausibility of their hypotheses by pointing to emerging research indicating cardiovascular, respiratory, kidney, neurological, autoimmune, and endothelial sequelae.^{44,48} They shared results of their own medical tests on various platforms, asked medical providers for specific examinations, and made calls to conventional research communities.^{1,33} These have prompted subsequent research on Long Covid symptoms and sequelae, as well led to collaborations with conventional researchers.⁴⁹ These include issues – such as eye, menstruation and arthritis-like problems – which have been common amongst Long Covid patient communities, but were not visible in public discussions or peer-reviewed articles in the first pandemic months. The patient-making of Long Covid, then, not only provided early, complex symptomatology, but contributed to revisioning SARS-CoV-2's range of damage, emphasized the need to keep in sight all potential sequelae, and offered hypotheses and speculations as regards disease mechanism(s) and potential therapeutics.

1.2 *Phasing, tempo, duration*

Perego's use of #longcovid intended to complicate the bi-phasic disease model that characterized some early accounts. In late March 2020, for example, Lescure et al. described a milder prodromal stage followed by interstitial pneumonia in the second week from onset, with a peak in severity between the tenth to twelfth day.⁵⁰ Patient interventions rendered this timeline more complex^{51,52} – underlining the possibility of temporal patterns in disease cycles and progression, an intensification of symptoms in weeks 4-5, the movement of symptoms to different organs over time, delayed peaks from onset, multiple relapses across several months, and symptom intensification in relation to triggers such as activity or periods.^{37,53-55} These hypotheses are now being increasingly substantiated by research publications.^{46,56,57} Patient Led's first survey showed already in May that ~90% of respondents had symptoms fluctuating in intensity and frequency, and pointed to certain symptoms returning in cyclical ways.³⁰ These findings were expanded in Patient Led's larger research survey from December 2020.³¹ Individual patients frequently made visible the day (or month) of their symptom report – e.g. Day 129, month 10.5 – on social or other media. This further underlined the persistence, heterogeneity, and complex time course of symptoms. In broadening the temporal scope particularly of 'mild' COVID-19, patients indicated the urgent need for careful natural histories that focused beyond the first few weeks from onset. That multiple patients have persisted in documenting publicly symptoms many months after onset brought attention to the significant absence of monitoring – particularly for early cohorts – and the urgent need for improvements.

The term 'Long Covid' further allowed patients to foreground that the point at which COVID-19 moves from an acute to a post-acute phase remains *unclear*, as do duration and final outcomes.³³ Patients

insisted that the duration of viral persistence is not yet fully understood. Evidence of viral persistence extending in some cases beyond the first few days from onset has subsequently been published in peer-reviewed articles.⁵⁸ Patients also underlined that more research is required on the complex interaction between SARS-CoV-2 and the host immune system – with particular regard to phenomena such as potential autoimmunity, immune misfiring and/or persistent immune activation taking place after 30-40 days from onset and/or hospital discharge. Such phenomena remain poorly documented because of lack of long-term patient monitoring, but are now gaining increasing consideration thanks to the first longitudinal immunological studies.⁴⁶ Prior to formal publications, those with Long Covid also undertook citizen science projects on immune response to SARS-CoV-2: Gez Medinger, for example, gathered and analysed antibody test results from long-hauler Facebook groups to explore hypotheses regarding potential differences in immune reactions.⁵⁹ Open interactions between patients and scientists have been instrumental in fostering new Long Covid research – such as immunological research by Akiko Iwasaki, which required blood samples from those with Long Covid.⁶⁰

1.3   *Disease classification*

In outlining the complex time-course of Long Covid, patients challenged dominant public assumptions, built on early formal reports from Wuhan, which proposed recovery for ‘mild disease’ within two weeks.⁶¹ Early classifications of COVID-19 were made along the single axis of disease severity (dividing into mild, severe, and critical). COVID-19 was assumed to be a respiratory disease: classification was largely based around pneumonia severity and the potential to develop respiratory and/or multi-organ failure within the first month.^{61,62} Long Covid made clear how this categorisation does not do justice to heterogeneous disease trajectories and the gravity of on-going reduction in functioning and quality of life. Patients took apart the ‘mild’ – emphasizing how difficult it is to adjudicate severity when many serious sequelae can occur at different stages of illness – and raised the likelihood that ‘mild’ COVID-19 might be too capacious as a category to be helpful for clinical decision-making (given that 80% of patients were said to fall into this category in early reports).^{63,64} Mild, patients emphasised, is a term that downplays the often profound consequences of infection, and therefore is unlikely to have ‘face validity’ for many. It is also unhelpful for public health messaging – given mild’s bland connotations.

Such arguments also made clear that hospitalization is an imperfect indicator of severity, even if it was commonly used both as a standard for access to many post-Covid clinics and as a threshold criterion in many studies. Criteria for hospital admission has varied from country to country, and within countries: in some hard-hit countries not all patients in need of urgent medical attention have been hospitalized or treated.^{65–67} Hospitalized patients had access to treatments, such as oxygen, antibiotics or steroids, which might have prevented some damage from COVID-19. Medication might have, in addition, altered the natural progression of the disease – or at least its symptomatology – thereby making hospitalized patients different from those who have been recovering at home with limited access to medication and care. Patients noted – for example during a forum on Long Covid in December 2020 – that some hospitalized patients with more serious early symptoms appeared to have fared better than others with ‘mild’ illness, potentially because of early access to care or differences in disease trajectory; this issue is increasingly addressed by medical professionals.⁶⁸

Patient-made Long Covid, therefore, made clear that key issues such as symptom duration, daily life disruptions and functional impairment had not yet adequately been addressed when adjudicating severity. Any

revisions to current COVID-19 classifications, and/or any formal classification of ‘Long Covid’ and potential future subdivisions require, we argue, the involvement of multiple patients in conceptualizing severity and suffering, as well as analysis of diverse disease pathways and divergent access to care and medical intervention across disease course.

1.4 *Naming a new illness*

The patient-made name ‘Long Covid’ is itself a significant epistemological contribution.⁶⁹ Long Covid centred patient knowledge about COVID-19 while attempting to navigate the discriminatory or reductionist valence that may become attached to terms such as ‘chronic’ or ‘syndrome’.¹⁸ ‘Long’ is intentionally different from the more familiar medical adjective ‘chronic’: with its simple assertion of a ‘long’ temporal trajectory, Long Covid carries its history of having disrupted early assumptions about the ‘shortness’ of ‘mild’ COVID-19. By focusing on tempo and uncertain timeline, Long Covid also draws attention to the dynamic nature of the disease, as well as to developments and progressions in disease course, which are now evidenced in at least some subsets of COVID-19 patients in the short and long term, and widely addressed in patient fora and on social media.

Chronic, on the other hand, remains anchored to the dyad acute–chronic, which may serve to make suffering invisible by occluding the structural forces that are often of far greater importance than biomedical reasons for the production and maintenance of illness and suffering.⁷⁰ Long Covid, therefore, is proactive in asking for investigation and appropriate care. When aetiology is not understood for lack of investigation, or symptoms not widely recognized or reported, ‘chronic’ and ‘syndrome’, particularly when attached to illnesses that have become gendered in particular ways, can make it more difficult to receive care.⁷¹ Many patients’ agnosticism regarding the point at which a ‘post-viral’, convalescent or post-COVID phase begins,¹⁸ has intensified their disagreement with the emerging terminology of ‘post-Covid syndrome’, preferred in certain formal medical channels.⁷² While some phenomena linked to COVID-19, such as pneumonia, may peak early and fully resolve, significant events, including hospitalization and death, are now reported later in the disease course.⁷³ Long Covid, therefore acknowledges the complex interaction and development of multiple symptoms and timelines across disease development.

That ‘Long Covid’ was created *collectively* also intervenes in relation to a wider history of naming diseases. That history involves the gradual dissolution, in the twentieth century, of eponymous naming whereby a singular – usually white male – scientist and/or medical professional came to be honoured. The history of naming diseases also includes terms that have been argued by those living under them to be stigmatizing, discriminatory and unhelpful both therapeutically and in relation to public health (e.g. borderline personality disorder, chronic fatigue syndrome, ‘swine flu’).^{74,75} The WHO, in its document outlining best practices for naming new infectious diseases, presents as key principles the use of generic (e.g. respiratory disease), plain and specific (e.g. juvenile, severe), and short terms.⁷⁶ Long Covid satisfies many of these principles. It does, however, specifically depart from the suggested terms for time course: the WHO suggests using ‘[a]cute, sub-acute, chronic, progressive, transient’. ‘Long’ does not impose an end (‘post’) nor implies chronicity; it does not divide the illness into COVID-19 and what comes after. It draws attention to the need to understand early disease mechanisms, and the importance of early intervention, and timely care. The history of medicine shows

that how diseases are named and classified, and the models used to investigate them, significantly shape how patients are supported, and the gravity with which suffering is acknowledged and treated. As a patient-made term that gained consistency in just a few weeks against all odds, Long Covid asks for patient expertise and lived experience to be at the forefront of disease research and definition.

1.5   *Morbidity*

In the early pandemic months, mortality dominated COVID-19 discourse. Discussions amongst ‘long-haulers’ insisted, in contrast, that morbidity is just as crucial – both for those already suffering, and to re-orient policy-making that, through ignoring morbidity, carries the risk of massive social and healthcare burden in the future. Those with Long Covid used various tactics to emphasise the significant personal, economic and social costs of long-term symptoms and sequelae. Public health doctor, Nisreen Alwan, who has Long Covid, initiated the social media campaign #CountLongCovid to emphasize the urgent need for proper case definitions of recovery; standardized methods of collecting data; and large, population-based samples, preferably gathered through surveillance.^{64,77–79} Many patients amplified the #CountLongCovid campaign by testifying to their changed lives. For example, in September 2020, a Tweet by Talya Varga, which developed into a long thread, combined the hashtag #CountLongCovid with the phrase ‘Six months ago’ and photographs from people’s pre-Covid (and sometimes post-Covid) life to mark the debilitating effects of infection half a year on, which left many confined to their bed and/or requiring a wheelchair.⁸⁰ Those with Long Covid wrote with great sensitivity about the complex experience of, and challenges surrounding, becoming (potentially) disabled.⁸¹

1.6   *Making children visible*

Adults and children with Long Covid worked hard to bring to visibility the existence of children with long-term symptoms and sequelae. In so doing, they epistemologically intervened by disrupting common assumptions of how pediatric experiences of COVID-19 were different from those of adults. From the early pandemic months, we noted how many adults in patient support groups were describing their children’s distressing experience of persistent symptoms – while this was initially invisible in public commentary. Since then, both adults and children profiled the complex and multi-systemic character of paediatric Long Covid, and the hashtag #LongCovidKids has circulated widely.^{82,83} Frances Simpson presented testimonies from both parents and children at the August WHO meeting, and conducted an informal patient-led survey across support groups: her survey demonstrated multiple symptoms, including widespread gastrointestinal difficulties.^{1,84} As soon as the Multi-Inflammatory Systemic Disorder (MIS-C) in children was first identified in April 2020,⁸⁵ patients speculated that there may be connections between MIS-C and some Long Covid symptoms in adults.⁸⁶ Evidence in journals has mounted since April 2020 that both young people and children have symptoms beyond two weeks; Long Covid in pediatric patients has now been reported by conventional scientists.⁸⁷ An analogous disease to MIS-C in adults has also been proposed (MIS-A),⁸⁸ and increasing scientific attention is now being devoted to potential relationships between MIS-C and some aspects of Long Covid.⁸⁹ The epistemic significance of adults’ and children’s testimonies regarding childhood Long Covid was given further weight in January 2021 when the All-Party Parliamentary Group on Coronavirus in the UK held a public hearing on Long Covid in children.⁹⁰

1.7   *Combatting discrimination*

Long Covid was born out of collective suffering that, often, was precipitated as much by political and medical neglect as by SARS-CoV-2 infection. Those with Long Covid have used various tactics and media – see, for example, Monique Jackson’s illustrated diary ‘Still Ill’⁹¹ – to emphasize the centrality of social and political factors,⁹² particularly of discrimination (including racism and able-ism), and of inequitable access to times for rest and recuperation.⁹³ They have articulated how those with Long Covid might best learn from and work in solidarity with disabled people and those in other patient movements.⁸¹ Advocates with Long Covid have worked collaboratively, for example, with those with Myalgic Encephalomyelitis (ME) – co-signing Solve ME’s letter to Congress, which constituted part of the pressure that resulted in the releasing of \$1.15bn in funds for research on Long Covid and post-viral illnesses.⁹⁴

Many with Long Covid have challenged the dominant, able-ist framing through which COVID-19 has often been discussed. Much reporting of COVID-19 mortality singled out those considered ‘healthy’ from those with ‘underlying conditions’, which strengthens eugenicist logics.⁹⁵ Many of those who made Long Covid – including us – have experiences of disability and chronic illness predating COVID-19, experienced discriminatory practices in relation to accessing care and treatment, and draw on research and models developed by disability and patient/service user activists and researchers.³³ Our own experiences, as well as our participation in discussion with others with Long Covid, leads us to argue that:

- disabled people, who are already at higher risk of marginalization, are particularly likely to experience further abuse and discrimination in relation to access to SARS-CoV-2 testing, treatment, screening, care and economic support.
- people who have previously received psychiatric diagnoses are at risk of ‘diagnostic overshadowing’, whereby their Long Covid symptoms are at greater risk of being interpreted through mental health lenses, thereby resulting in potential under-recognition of physical symptoms.⁹⁶
- many who experience COVID-19 and/or Long Covid – whether or not they were disabled prior to infection – have found the experience of COVID-19 and lack of care traumatic, and often disabling in ways that it risks to make damage from SARS-CoV-2 more acute and long lasting.

2   Knowledge production during a pandemic

2.1   *Patient contributions and social media*

As patients created, at speed, a new illness, they disrupted conventional scientific modes of doing research, creating knowledge, gathering and disseminating evidence, and building clinical archives/datasets. Tweets, Facebook posts, contributions to Slack and WhatsApp groups, patient-led reports and surveys, blogs, opinion pieces, and conversations between patients preceded the formal generation and dissemination of data about long-term symptoms and sequelae by conventional researchers, particularly for those not hospitalized. Some of the largest archives concerning Long Covid symptoms are currently found under hashtags (e.g. #longcovid, #apresj20), and within private/semi-private patient support groups (e.g. Body Politic COVID-19 Support Group <https://www.wearebodypolitic.com/covid19>; Long Covid Support Group <https://www.facebook.com/groups/longcovid/>). There have been other instances in which patient collectivities

and illness entities have formed through people finding one another through various media.⁹⁷ However, the making of Long Covid, because of the sheer pace of its consolidation, the use of particular media platforms like Twitter, and the novelty of COVID-19, is, we argue, distinctive in certain ways. Different media platforms offer distinctive affordances in terms of how they encourage the formation of collectivities, consolidate discursive framings, facilitate particular kinds of affective dynamics, and translate and disseminate text and images. Both Twitter and other online digital media (e.g. Facebook, Slack) have been important in allowing patients to find and communicate with one another at times of significant physical restrictions in the form of lockdowns. The ‘self-generated symptomatology’ in the form of Twitter threads, for example, have genre characteristics that are likely specific to Twitter: this would merit further analysis. Twitter was also key in facilitating the rapid transmission of #LongCovid to non-patient constituencies with a speed that would have been less likely in less ‘public’ media (e.g. Facebook support groups which predominantly contain patients): the large number of conversations between those with Long Covid and others (particularly conventional scientists) not only helped cement the name Long Covid,³ but is likely to have shaped the manner in which patient knowledge of COVID-19 has travelled more widely.

Equally important has been the wider pandemic media landscape: publishers’ decisions to make many COVID-19 papers freely available, as well as the frequent use of pre-prints,⁹⁸ has meant that a wide range of patients – though this is highly differentiated in terms of class and geographical location – have been able to access, share, and discuss scientific materials on multiple platforms ‘in real time’. While the grassroots movement that made Long Covid has included clinicians and scientists,⁹⁹ patients without medical credentials – though with other forms of expertise – have made significant epistemic contributions across multiple fora. The symptomatology of COVID-19 itself has also been a salient factor: Long Covid was mostly made by those patients who endured significant, but – crucially – often fluctuating, illness at home. We note that many of those who were hospitalized, particularly older people, and those who were intubated, might have been too ill, and without easy access to media platforms, to fully contribute to the epistemic debates. This relative invisibility of some with Long Covid risks some aspects of Long Covid (e.g. the possibility of lifelong lung and cardiovascular damage) being downplayed in public perceptions of Long Covid and in clinical fora.

2.2 *Ethics and justice*

The pandemic has provoked both a political-economic and a public health crisis. Many with Long Covid have reported difficulties in accessing sick pay and disability benefits, or have lost their jobs while still unwell.¹⁰⁰ That many minoritized/marginalized groups have been exposed to SARS-CoV-2 infection at higher rates means that they are likely to be disproportionately affected by Long Covid. There arise multiple pressing issues of ethics and social justice. In Table 1, we itemize some likely long-term consequences of Long Covid, and urge more systematic documentation and addressing of these and comparable issues.

** INSERT TABLE 1 **

** INSERT TABLE 2 **

We are concerned – given our knowledge of social, medical and political responses to previous epidemics and crisis situations, as well as the ethical issues we have seen arise in the course of our own participation in many

discussions amongst those living with Long Covid – about various risks that face those with Long Covid. We outline some of these risks and their potential effects in Table 2.

In Table 3, we focus on issues that bear specifically on the ability of those living with Long Covid to make on-going epistemic contributions to COVID-19. These we thematize under three categories: (i) exclusion, (ii) exploitation and (iii) the consolidation of particular conceptualizations of long-term symptoms. We urge conventional researchers to give attention to help address and where necessary remedy these problems. We address three particularly pressing issues in a more detail below:

***INSERT TABLE 3 ***

a) **Data and archives:** Many with Long Covid are participants in, and owners of, archives now containing immense quantities of material. These are enormously clinically, sociologically, and politically valuable – as well as sensitive. Any use of these materials outside of the specific, patient-determined purposes for which they were founded (largely mutual aid) poses enormous ethical issues. We have participated in conversations from which we infer that there is a real danger of what we believe would be unjust, unethical and exploitative use of patient-created data and archives.¹⁰¹ The use of publicly available social media data for research is not exempt from potential charges of exploitation – especially given that much social data on Long Covid arises from patients who have been posting while ill and experiencing a life-threatening disease (not all of whom have survived). There are already indications that some scientists might not be aware of the ethical stakes attached to the use of patient data. For example, studies of COVID-19 symptomatology, based on social media data, have already been published with no mention of the ethical stakes of using such data.^{102,103}

b) **Acknowledgement of epistemic contributions:** As we emphasised, multiple patients have offered hypotheses, speculations, and observations concerning symptoms, potential mechanisms, potential aetiologies, potential diagnoses for sequelae, and potential therapeutic agents. These contributions have often been made, using social media platforms, weeks if not months before their appearance in peer-reviewed articles. Like the use of 'Long Covid' itself, it is, we believe, very likely that some contributed to conventional scientists' hypothesis-building, given the extensive discussions regarding Long Covid across patient and scientific communities online. We urge the scientific community to find ways of acknowledging and giving epistemic weight to these contributions.

c) **Power relations and patient knowledge:** While there is increasing evidence of patients' involvement in creating knowledge about Long Covid, we know from existing research how difficult it can be for conventional researchers to acknowledge and epistemically authorise patient contributions.^{104,105} At the time of writing, efforts have been made to consolidate long-term COVID-19 symptoms and sequelae as 'Post Covid syndrome'⁷² (a name many patients have contested),⁶⁹ as well as to commission services and allocate significant funds for research.¹⁰⁶ How epistemic power relations will play out in forthcoming research on Long Covid remains to be seen – particularly whether the epistemic contributions of patients without clinical credentials, and those subject to greater levels of societal discrimination, are given weight by conventional actors.

Conclusion

Long Covid was collectively created by an international, grassroots movement of people who experienced a new, frightening and life-threatening disease. Many have undergone traumatic experiences in dramatic circumstances, which included political abandonment, significant mortality, lockdowns and other forms of restriction. Many have been denied medical care; many have experienced the fear of dying, untreated, at home; many have been poorly understood, even by close associates; many have had their symptoms disregarded or misdiagnosed as anxiety or other medical conditions; many have lost loved ones and are caring for others who are also ill.^{107,108} Many have lost – or live with the threat of losing – jobs, livelihoods, healthcare access, or residency status. Yet, those with long-term symptoms and sequelae have undertaken research, documented symptoms, built hypotheses, proposed therapeutic interventions, developed ways of living with illness, and articulated potential clinical and socio-political dangers ahead – in addition to engaging in enormous collective support, advocacy and activism. These epistemic contributions have helped change COVID-19 – as well as the trajectory of the pandemic.

The term ‘Long Covid’ moved from a single, rather unremarkable tweet which introduced a new hashtag (and was initially ‘liked’ only once), to use by the WHO in only three months. Long Covid was created via the collective circulation on social media of the hashtag #LongCovid: this is far from incidental to how, for patients, the term has become a means of holding together profound heterogeneity at the same time as insisting on phenomenological complexity and the need for whole-system approaches. Some of the most vibrant and detailed documentation and elaboration of long-term symptoms and sequelae – often taking place prior to their collection and dissemination via conventional scientific studies – have taken place on social and digital media. Many of these patient contributions would undoubtedly be considered ‘informal’ or ‘anecdotal’ according to formalized hierarchies of scientific evidence,^{109,110} since many have used media, channels, genres, and methods of observation that fall outside those through which epistemic authority in science and policy making tend to be built (e.g. blogs, surveys or polls that fall outside of research institutions’ specified frameworks, illustrated diaries, first-person accounts, patient-made films). They, therefore, risk being ignored, disregarded, or not known about. We also note the enormous number of epistemic contributions that have been made in private fora that are known only to patients in those fora.

We brought greater epistemic solidity to these contributions, so as to open out more broadly the different kinds of evidence that patients contribute in the face of wholly new phenomena. They form a new and notable chapter in the long-history of patient-made knowledge about health and illness.^{111,112} Patient knowledge made a new illness – caused by an entirely new infectious pathogen. Patients have offered multiple characterizations of its symptomatology, speculations concerning its pathways and mechanisms, and ways of dealing with its difficulties – many of which occurred prior to the publication of peer-reviewed research. We note the short temporal span within which patient knowledge, combined with patient advocacy, has been able to influence the epistemic horizons of stakeholders, including researchers, clinicians, and governments, at a moment in which epistemic frameworks governing COVID-19 are still in formation. This poses complex questions – both conceptual and empirical – concerning how patients individually and collectively contribute knowledge, how patients’ epistemic work in relation to Long Covid differ from patients’ epistemic contributions to other illnesses, as well as the routes through which patient knowledge is taken up into conventional scientific research.^{113,114}

How, and by whom, evidence is collected, authorised, and interpreted, will be central to what happens to Long Covid, and to those with Long Covid, in the coming months and years. It is notable that some conventional researchers and actors writing about persistent symptoms and sequelae have acknowledged and cited some of these patient-made contributions.^{8,13} This, we hope, will become a more frequent occurrence. If textbooks are commonly understood as conduits for disseminating established knowledge, then patients are doing significantly more than ‘writing the first textbook on long covid’. Since the early months of the pandemic, patients have been generators and analysers of observations, theories, conceptualizations and terms. They are epistemic originators, in other words – rather than latter-day compilers of established facts. This has implications that go beyond the current COVID-19 pandemic in terms of the renewed necessity of involving patients – substantially, and justly – in the building of medical knowledge.

Note: We have gained approval from every author whose social media post and/or personal communication we have cited here.

Acknowledgements: There are many whom we wish to thank. [Redacted for peer review and while awaiting confirmation that all we wish to acknowledge are happy to be named.]

Table 1 Potential effects and costs of Long Covid

Potential effects and costs of Long Covid	Examples (indicative, not exhaustive)
Personal–social	• Trauma arising from various causes – the experience of acute illness, impairment, (potential) disability, lack of access to care, disbelieving of symptoms, medical abandonment and abuse • On-going ill health • New accessibility issues: for example if a patient is suddenly in need of a wheelchair, or other disability aids • Fractured personal relationships, in view, for example, of one's new health/disability status and/or loss of income • Stigma, discrimination, and social exclusion or isolation, for example as a consequence of a still poorly understood persistent illness; people refusing to be near someone who has been infected and/or fearing they are still infectious; patients believing themselves to be still infectious • Impacts on carers and family members • Loss of educational opportunities (especially for those who had not completed education prior to falling ill) • Potential additional disability burden for those already disabled before SARS-CoV-2 infection
Medical	• Extensive need for appropriate screenings and investigations (including sophisticated tools for best diagnostic practices) • Training of medical professionals with specific knowledge of COVID-19 and its sequelae • Training of medical, rehabilitative and social care for large cohorts of patients, such as the creation of specialized clinics • Challenges for the clinical workforce – as many clinicians have developed Long Covid¹¹ • Healthcare systems are deeply damaged by the emergency and the long-term consequences of the pandemic (economic etc.)
Socio-economic	• Increased numbers of people with long-term illness/disabilities • Increase in mental health difficulties arising from a variety of causes – including discrimination, abandonment, and epistemic injustice¹¹⁵ • Need for appropriate and just legal and administrative frameworks for sick leave and

	disability allowance in a pandemic and post-pandemic world.

Table 2   **Potential risks in relation to Long Covid**

Potential risks* (indicative, not exhaustive)	Potential effects (indicative not exhaustive)
Pandemic policy choices	• Effects of SARS-CoV-2 infection – especially as a generator of long-term effects, and in relation to the young – as well as potential for re-infection are downplayed, increasing prevalence of Long Covid • Health and social care systems are left unprotected and underfunded • Focus and attention on vaccines and on post-pandemic planning results in lack of attention to those with Long Covid
Clinical approaches	• Use of inappropriate therapies and rehabilitative tools • Over-hasty diagnosis, diagnostic lumping, under-diagnosis – particularly when in-depth investigation of biological markers is not available, or when such investigations do not explain symptoms. (Potential trauma in both clinicians and patients might exacerbate these effects) • Diagnostic over-shadowing
Determinations of access to care, treatment, rehabilitation	• Differential access – which demonstrates discrimination and exacerbates inequalities (particularly grave dangers for disabled people and those with a shorter life expectancy) • Lack of access to appropriate testing and diagnostic tools, which might leave significant numbers undiagnosed and untreated • Lack of access to COVID-free spaces in the framework of potential reinfection: for example, where Long Covid clinics are missing, patients might be forced to go to general hospitals for care and be at risk of being put in Covid wards with infectious patients

	● Diminishment of the significance of Long Covid, resulting in inadequate or no care, which results in the exacerbation of persistent symptoms, and/or permanent damage and/or chronic illness and disability (children are particularly at risk of having symptoms disregarded) ● Problems in accessing SARS-CoV-2 vaccination (safety, priority in view of established vulnerability to SARS-CoV-2 infection)

*All risks are heightened for marginalised and ethnically minoritised communities; those living with pre-existing, and often multiple, conditions; those living in poverty; migrants, refugees, and asylum seekers; those who are LGBT+; those in prisons and detention centres; those who are homeless.

Table 3 Ethical issues affecting the ability of those with Long Covid to make epistemic contributions

Ethical issues	Examples (indicative, not comprehensive)
Exclusion	• Rapid gathering of epistemic authority around certain conventional researchers or research groups, which marginalises patient-led expertise and knowledge • Gate-keeping in relation to the publication of patients' contributions in journals • Those with Long Covid unable to access funding for research and advocacy • Silencing of voices – <i>including</i> in patient-led communities – from those from marginalised and minoritized groups, from those unable to access tools such as social media, and from those in the Global South • Definitions of expertise marginalize or ignore patients' heterogeneous forms of expertise • Privileging of patients with clinical expertise – at the expense of patients with other kinds of expertise • Exclusion of those with more severe illness and/or disabilities, who might be unable to engage because of societal barriers to participation • Exclusion of those with Long Covid from conventional scientific channels where policies, services, research priorities, and clinical classifications are determined
Exploitation	• The labour of those living with Long Covid goes unpaid or is inadequately remunerated • Pressure from journalists to narrate particular stories, revisit traumatic episodes, or disclose too much • Journalists and researchers/collaborators etc. fail to acknowledge effects of patients' symptoms and demand too much • The entry of ethically insensitive, non-patient researchers into patient-led spaces • Infiltration of imposters in support groups to gather health data • Privacy breaches • Exploitation, abuse, or inappropriate use of patients' records and testimonies – which were shared by patients on and through various media to raise awareness, and to help others suffering • Inadequate ethical oversight of acquiring data from support groups/patient organizations⁵⁰
Consolidation of a particular model for/definition of long-term symptoms	• De-prioritisation of epistemic and other contributions from those with Long Covid • Favouring of certain medical specializations, research groups, conceptual framings, and institutions • Medical and/or legal definitions impose thresholds which leave certain patients out • Allocation of funds for research and treatment favours certain approaches over others – which excludes certain patients, or goes against patients' priorities • Use and consolidation of 'representative' or 'exemplary' Long Covid cases which disregard other experiences of Long Covid

	• Over-emphasis of the role mental ill health can play in Long Covid • Under-emphasis of the role mental ill health can play in Long Covid

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