
The Role of Patients and Patient Activism in the Development of Long COVID Policy

COMMUNICATION | EDITORIAL | INVITED CONTRIBUTION | PERSPECTIVE | REPORT | **REVIEW**

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ABSTRACT

The COVID-19 pandemic has focused on the acute respiratory phase of SARS-CoV-2 infection which has killed over three million people globally [1]. Attention is now increasing on the serious long-term, multi-organ illness occurring after COVID-19 infection: Long Covid. Long Covid symptoms include: extreme fatigue; insomnia; headaches; lung, kidney and cardiac damage; and muscle and joint pain. These debilitating symptoms affect individuals who have had both mild and severe acute COVID-19 and are estimated to affect five million people globally. Long Covid awareness originated from Long Covid patients, known as long haulers, finding each other on social media and support groups. Long hauler patient activism has been the driving force behind Long Covid recognition, research and health policy development. Two support groups have played key roles: The Body Politic COVID-19 Support Group and The Long Covid Patient Support Group. These bodies have raised awareness of Long Covid in the media, and in academic and medical communities. They have also provided support for long haulers. The Body Politic COVID-19 Support Group produced a patient-led research report which catalysed research policy for Long Covid. Peer-reviewed research has revealed a diverse array of severe, multi-organ symptoms of Long Covid and has recommended a multi-disciplinary healthcare approach to Long Covid. This recommendation has been adopted by various governments and medical institutions, which have opened Long Covid clinics. Population morbidity from Long Covid is a rising challenge, requiring research, a multi-disciplinary healthcare approach and socio-economic support.

SCIENCE \Rightarrow POLICY

Long Covid is a serious multi-organ long-term illness that occurs in individuals after severe and mild COVID-19 infection. Population morbidity from Long Covid is a rising challenge, requiring; research, multi-disciplinary healthcare approaches and socio-economic support. Long Covid recognition, research and health policy has been driven by patients and patient activism.

Keywords Long Covid · COVID-19 · Patient Activism · Research Policy

Introduction

Over three million people have died globally from the acute respiratory illness COVID-19 and many more are currently suffering serious, long-term symptoms following COVID-19 infection [2]. Long Covid, also known as post-Covid syndrome, has no widely accepted clinical definition. There is general consensus that Long Covid consists of the ‘signs and symptoms that develop during or after an infection consistent with COVID-19’ [3]. It is the duration of symptoms after initial infection that is debated. Some research studies use the definition of symptoms beyond three weeks post infection [4, 5], while the recent UK National Institute for Healthcare Excellence (NICE) guidelines use 12 weeks [3]. The lack of a precise, clinically accepted definition is indicative of our developing understanding of Long Covid. Long Covid research is still in its infancy and further investigation is necessary to reach a clinical definition. This article explores the development of Long Covid policy in two main areas: research and healthcare policy, with emphasis on the role of patients and patient activism.

Many viruses can cause long-term illness, such as the Epstein Barre virus which causes infectious mononucleosis (commonly known as glandular fever) and influenza which can cause post-viral fatigue. What makes COVID-19 unique is the ‘sheer number of infected people and the damaging effects of infection on multiple organ systems, including the lungs, liver, brain, kidneys and heart’ [6]. Long Covid ‘is the other side of COVID: the long haulers that could turn out to be a bigger public health problem than excess death from COVID-19’ [7]. With estimates of millions of long haulers globally dealing with debilitating symptoms and associated increasing population morbidity, it is important that we understand the scope and impact of Long Covid in order to develop good research and health and socio-economic policies. The driving force behind Long Covid policy and recognition has, so far, been patients and their collectivised support groups.

Long Covid was coined by Italian patient and doctor Elisa Perego on Twitter [8], and has since been adopted by patients and patient support groups to describe their long-term symptoms af-

ter an initial COVID-19 infection [9]. Patients who had previously suffered from a COVID-19 infection or COVID-19 like infection, and were experiencing long-term symptoms, found each other on social media. They collectivised in online support groups as long haulers and together characterised their illness, Long Covid. Long haulers have worked hard to raise awareness of Long Covid in the media, within academic and medical institutions, and within governmental and intergovernmental organisations. Long haulers and their support groups have been the dominant driving force behind Long Covid policy.

Long Covid Support Groups and Patient Activism

Patients and patient activism have always contributed to disease recognition and policy development. Long Covid is unique because patients have defined, researched and raised awareness of Long Covid alone, gaining recognition, support and research into their illness in the process. They have achieved this through the actions of prominent individuals and collectivisation in online support groups. There are many COVID-19 support groups, but this article focuses on ‘The Body Politic COVID-19 Support Group’ [10] and the ‘Long Covid Support Group’ [11]. Other COVID-19 support groups include the respiratory focused ‘Coronalong Square Group’ in the Netherlands [12], and the ‘Survivor Corps’ in the United States [13]. The Body Politic COVID-19 Support Group and the Long Covid Support Group are two of the first and largest groups, having made the greatest impact in progressing Long Covid Policy. These groups have: produced compelling Long Covid testimonials in the media; generated a large, coordinated social media presence, reaching out to long haulers globally; engaged with medical and research institutions, and produced the first report on Long Covid.

The initial awareness of Long Covid within the mainstream media and academic and medical research communities came from patient activists. The Body Politic COVID-19 Support Group was founded by long haulers Fiona Lowenstein and Sabrina Bleich in March 2020 and has grown to include over 18,000 individuals [10]. The organ-

isation includes online support for all COVID-19 patients that have suffered from both acute and Long Covid, as well as carers and loved ones. The organisation started in New York and has grown to include members from all over the globe. Fiona Lowenstein was one of the first to publish a Long Covid testimonial in an opinion piece in the New York Times [14]. The Long Covid Support Group, with 33,200 members, was founded by Clare Hastie [11] and is most active in the UK. When these groups were set up, they were the only support available to long haulers. They gave long haulers the opportunity to share and learn from each other and receive validation that has mostly been unavailable from healthcare providers. 'Long Covid is the first illness to be made through patients finding one another on Twitter and other social media' [9]. These support groups have continued to grow as the number of long haulers increases rapidly during this pandemic.

The support groups and prominent individuals reached out to academia and mainstream media to raise awareness of the new phenomenon that is Long Covid. The individual testimonies from long haulers with prominence in the medical fields played a crucial role in raising Long Covid awareness in scientific and medical communities. Professor Paul Garner, professor of infectious diseases, published his personal account of Long Covid in the British Medical Journal [15]. It has been made clear that 'patient-made evidence in the form of one case study was important when no peer-reviewed articles had yet documented long-lasting symptoms. Non-hospitalised patients were at that point, literally beyond the gaze of biomedical research' [9]. Medical professional long haulers have been active in campaigning government and medical institutions [16]. 'Doctors as patients,' a group in the UK, published a manifesto calling for 'collaboration between politicians, healthcare services, public health professionals, scientists and society' to tackle Long Covid [17]. Doctors were particularly effective at reaching out to long haulers globally in their mainstream media appeals, giving long haulers a sense of community, and helping them to understand their symptoms [18]. Consequently, Long Covid started to be acknowledged on the healthcare, academic and media horizon.

Long haulers have shared their experiences and symptoms in social media based support groups, revealing Long Covid as an illness that extends beyond a short acute respiratory phase and includes serious multi organ symptoms, even in those who only had a mild acute phase. The serious, long-term symptoms and individual morbidity rates revealed in these support groups and consequently shared in the media have highlighted the need for further research to characterise Long Covid. In May 2020, the patient-led research team of the Body Politic COVID-19 Support Group published the first report on Long Covid titled 'What does COVID-19 recovery actually look like?' [19]. The report was based on data from a survey of 640 members of The Body Politic COVID-19 Support Group [19]. The survey was created and analysed by patient-researchers and is one of the most important examples of patient activism in the field of patient-led research. The report elucidated the most common symptoms Long Covid as being: fatigue, chills/sweats, body aches, headaches, brain fog-concentration challenges, gastrointestinal issues, trouble sleeping, dizziness and loss of appetite [19]. The report found over 50 symptoms in total and that neurological symptoms were more common than having a cough. At the time of the survey, 90.6% of respondents had not yet recovered, 89% said the symptoms fluctuated in intensity and frequency, and 70% saw fluctuation in the type of symptoms, suggesting that the recovery period may include relapses. Many respondents reported feeling unsupported by healthcare systems [19]. This report was effective in influencing and kick-starting Long Covid research policy globally. The quantitative data and analysis in the report provided convincing evidence of a potential new severe long-term illness caused by COVID-19 infection, leading to the acknowledgement of Long Covid within medical and academic institutions, and the expansion of COVID-19 research policy to include studies into this malady. The research community tested the reproducibility of this report, and conducted research to characterise Long Covid. Subsequently, this report has been cited and largely confirmed in scientific and medical literature [20]. The work was engaged with by academia and major medical institutions, such as the Centre for Disease Control (CDC), the World Health Organisation (WHO) and the National Institute for Health

(NIH). Patients have thus defined, researched and raised awareness of Long Covid alone. Having put Long Covid on the global agenda, long haulers have maintained their strong activist position to continue to steer policy development.

Current Research

Academic and clinical research into Long Covid has focused on characterising symptoms, their duration and how many people suffer from Long Covid. An Italian study of hospitalised patients found that 87% of the sample surveyed had at least one symptom 60 days after infection [21]. Long-term symptoms in hospitalised and non-hospitalised patients have been recorded up to 4 months after infection [22]. In addition, 2-3 weeks after testing positive, 1 in 5 patients between the ages of 18-34 with no chronic medical conditions had yet to return to their previous health status [5]. This confirmed the personal accounts in the support groups and the data in the surveys: long-term symptoms from COVID-19 infection were prevalent even in healthy, young, non-hospitalised COVID-19 patients. Some studies have indicated that women may be up to 50% more likely to experience Long Covid than men [23, 24]. Women are also more likely to be diagnosed with other fatigue illnesses, the reasons behind this are yet to be fully elucidated [25]. The most common symptoms from peer reviewed studies are: fatigue, shortness of breath, cough, joint pain and chest pain. Less common symptoms include: cognitive impairment, depression, muscle pain, headaches and migraines, fever and palpitations [5, 21, 26, 27]. These symptoms are the same as those found in the patient-led survey, but the peer-reviewed research produced more detailed information on the more serious symptoms indicative of organ damage. Significant cardiac symptoms that could lead to long haulers with cardiac issues for years afterwards have also been documented [28–30]. Severely impaired lung function [31, 32], acute kidney injury [33], neurodegenerative symptoms [26, 27, 34, 35], and psychiatric issues such as depression and anxiety [26] have also been observed and reported. For long haulers, this research has validated their concerns and paved the way for recognition and treatment from medical institutions. It has also underscored

the wide range of serious symptoms associated with Long Covid and the urgency of updated healthcare policy.

A unique research method has emerged utilising modern technology and citizen science: the ‘COVID Symptom Study’ at King’s College London [36]. The study recruits members of the public as citizen scientists, recording their symptoms over time on the study’s app [4]. This study showed that 10% of COVID-19 patients still have symptoms three weeks after infection and may continue to have them for many months [4]. The method of the ‘COVID Symptom Study’ has since been validated in a peer reviewed study [37], making the study ‘an impressive demonstration of the power of citizen science’ [38]. Importantly, this study illustrates the power of technologically enabled citizen science for future pandemics [37]. The COVID Symptom Study can monitor the health of a large population during a pandemic when health resources are stretched, creating a great tool for population health management during pandemics, whilst increasing our understanding of Long Covid. Citizen science has emerged as a new and powerful tool to understand Long Covid, the COVID-19 pandemic and future pandemics.

Recognising the importance of patient-led research and patient activism, a second patient-led research survey supported by researchers at University College London has been launched [39, 40]. Recruiting mainly from the Body Politic COVID-19 Support Group, the second survey ‘will be examining antibody testing results, wider and more detailed symptoms, including neurological, cardiovascular, systemic and beyond, as well as the impact on mental health’ [40]. Following on from the success of the first report, a similar symptom survey was conducted by the Indiana School of Medicine and Survivor Corps (another COVID-19 support network) [41]. The patient support groups have been a significant source of participants for research studies [42].

Research thus far has revealed that a minority of COVID-19 patients have multi-organ symptoms that relapse and remit over many months, leaving individuals with a worsened quality of life. Most studies have concluded that more research and a multidisciplinary approach including immunology, cardiology, vascular biology, nephrology, respira-

tory medicine, hepatology, neurology, endocrinology, rheumatology and gastroenterology, is necessary for clinical research and treatment of long haulers [26, 43]. The precise prevalence of Long Covid patients continues to be researched globally, with differing estimates of the rate of Long Covid amongst those who have been infected.

Future Research

Though research on characterising Long Covid and long haulers is progressing, research into the pathophysiology of Long Covid is limited and in its very early stages. There is a scientific consensus that Long Covid is most likely explained by a combination of direct damage by SARS-CoV-2 and other effects mediated by the immune system [44]. These immune mediated effects are hypothesised to be the result of an aberrant immune response or latent virus in immune privileged sites; such as the central nervous system. An aberrant immune response is when the body's immune system reacts in an uncoordinated and dysregulated manner to infection or autoimmunity. Cytokines are small proteins which coordinate the immune response and inflammation, when there are excessive levels of cytokines hyper-inflammation (cytokine storm) occurs which can cause serious damage to the patient. Funded research policy focusing on understanding the immunological basis of Long Covid is required to develop effective therapeutics, clinical strategies and management strategies.

Long-term funded research studies are an important component of research policy for Long Covid. In the respiratory diseases SARS (Severe Acute Respiratory Syndrome) and MERS (Middle East Respiratory Syndrome), a long tail of symptoms were noted [45], but there was a lack of adequately funded, long-term, follow-up studies. In one study, it was noted that within a SARS survivor cohort, 40% of patients had fatigue and 40% had psychiatric symptoms over 3 years after initial infection [46]. The lack of long-term studies has denied the scientific community important understanding into the long-term symptoms of viral infections and the immunological mechanisms involved [26]; information that would have been very useful during this pandemic. Long-term studies are incredibly important, not just

for current and future long haulers, but to ensure an understanding of the biological mechanisms behind these conditions and how to manage them for future respiratory illnesses and pandemics. Some long and medium term studies have been set up, including The Post-hospitalisation COVID-19 Study (PHOSP-COVID) in the UK which will follow 10,000 hospitalised COVID-19 patients over the course of a year [47]. The ADAPT study at the Kirby Institute in Australia also follows individuals with COVID-19 (hospitalised and non-hospitalised) over at least a year [48]. The NIH and University of California, San Francisco, also have ongoing longitudinal studies on Long Covid [49, 50]. Currently there are approximately 45 Long Covid research projects globally, out of over 5,000 COVID-19 related projects [51], illustrating the need for more research into Long Covid.

There is a recurring theme in both long-term and cohort studies of over-representation of hospitalised patients, despite it being established that both hospitalised and non-hospitalised COVID-19 patients can get Long Covid [17]. Research policy needs to include the non-hospitalised group, in addition to those who were infected with SARS-CoV-2 particularly during the first wave, but were never tested and are now experiencing Long Covid. This latter group, in particular, makes up a lot of the online support groups, but is highly underrepresented in research. Support groups have continued their advocacy to ensure that all long haulers are included in the emergent research policies [17, 18]. When patient demographics are not included or are underrepresented in research, studies may misrepresent the nature of Long Covid and long haulers. Policy made from this research may not meet the needs of all those affected.

As academic and clinical research into Long Covid continues, support groups have maintained their role of guiding research policy. The Long Covid Support Group collaborated with two international pandemic-focused organisations to hold a Long Covid joint research forum in December 2020 [52]. The first of these organisations, the Global Research Collaboration for Infectious Disease Preparedness (GloPID-R), is an international network of major research funding organisations set up to facilitate rapid and effective responses to pandemics [53]. The second organisation, the Inter-

national Severe Acute Respiratory and emerging Infection Consortium (ISARIC), is a global network of clinical researchers, created to deal with respiratory pandemics [54]. This collaboration is indicative of the global importance currently being placed on Long Covid. The forum objectives were ‘to gain a better understanding of Long Covid; the science and the personal impact’ and ‘to define research gaps for funders and researchers to take forward’ [52]. The forum brought together clinicians, researchers, patient support groups, international networks and organisations such as the WHO, as well as government representatives to create a coordinated strategic research policy agenda [52]. As the numbers of long haulers continue to rise, defining and pushing this research agenda is of increasing importance.

Healthcare Policy

As research and our understanding of Long Covid has developed, it has enabled governments and medical institutions to begin developing and enacting Long Covid health policy. ‘Only with an understanding of the prevalence of Long Covid and the chronic health consequences of SARS-CoV-2 infection, will it be possible to determine the true impact of the pandemic and to adapt healthcare to effectively diagnose, monitor and treat patients over the long term’ [6]. Many governments and medical institutions have taken on board the recommendations from Long Covid research, including the creation of multi-disciplinary Long Covid Clinics [5, 26, 27]. In the UK, the National Health Service (NHS) has launched a network of more than 60 Long Covid specialist clinics to help long haulers manage their persistent symptoms [55]. The NHS has also ‘launched a new taskforce with patients, charities, researchers and clinicians, to help manage the NHS approach to ‘Long Covid’ and produce information and support materials for patients and healthcare professionals to develop a wider understanding of the condition’ [56]. The inclusion of patients in this taskforce demonstrates the recognition of the important role they play in Long Covid awareness and policy. Post-Covid-19 care centres are opening at academic medical centres in the United States, bringing together multidisciplinary teams to provide a comprehensive and

coordinated treatment to COVID-19 aftercare [57]. There are currently Long Covid clinics in 30 out of the 50 states in the US [58], including the Centre for Post-COVID care at Mount Sinai hospital [59] and the Post-COVID assessment and Recovery Clinic at Penn Medicine [60]. Clinics are also opening in Canada [61] and Europe [62]. Long Covid clinics in the UK, Europe and Canada are the result of healthcare policy implementation, based on the recommendations of research.

The opening of clinics has resulted in The Long Covid Support Group evolving to take on an independent oversight role. The Long Covid Support Group are currently running surveys on patient experiences of the new Long Covid clinics in England [63]. Anecdotal evidence so far suggests that the dismissal of patients and their symptoms, as seen in the beginning of 2020, still remains a problem in Long Covid healthcare [63] and remains a core challenge of healthcare policy globally. This highlights the continuing need to raise awareness and understanding of Long Covid symptoms in the medical community.

Future Challenges and Policy Needs

Research studies have illuminated the symptoms, extent and nature of Long Covid and research policy is transitioning into long-term studies and more detailed analysis of the exact physiology, pathophysiology and biological mechanisms behind Long Covid. This will lead to new clinical management strategies and therapeutics (a clinical treatment or drug); for long haulers. For the first and second wave of long haulers, the outcomes of this research are unlikely to benefit them as the research is far from findings that will improve their quality of life. Research has helped inform and guide healthcare policy with the creation of Long Covid clinics. Long Covid clinics are not present in all countries where long haulers may reside, and they have limited capacity. The clinics do offer some support and benefit to current long haulers, including coordinated treatment of a patient’s individual symptoms. While not curing or treating the immunological root of Long Covid, these coordinated symptomatic

treatments may improve a long hauler's quality of life. The other main way that policy can support long haulers is through government based socio-economic policy.

Long haulers are suffering from serious symptoms that are directly worsening their quality of life and ability to participate in society. 'Doctors are now concerned that the pandemic will lead to a significant surge of people battling lasting illnesses and disabilities' [64]. The current morbidity of Long Covid is such that most long haulers are unable to contribute to society and their communities as they did previously [65]. For most, this means they are unable to work at their previous productivity rates or are completely incapable of working, with basic everyday tasks becoming a challenge. The stress of being unable to work or perform basic tasks can exacerbate symptoms. Governments need socio-economic policies such as expanded disability support systems to support these individuals in their lives and to facilitate their convalescence and recovery and stop widening health inequalities [52]. Immunologist Dr Danny Altmann estimates 'we probably have way more than five million people on the planet with Long Covid' [51]. These are individuals who currently and will in the future place increasing burden on health and socio-economic systems. Substantial population morbidity is likely in the near and long future [65]. Population morbidity stems from individuals' decreased capacity for action and increased care requirements. Serious organ symptoms and damage are likely to lead to much higher levels of cardiac, respiratory, kidney and neurological issues in populations, including potentially increased early onset Parkinson's disease [66]. The onset of these increased healthcare requirements will, for developed nations, coincide with an ageing population, thus the necessity to increase the capacity of healthcare services is pivotal. Screening long haulers and acute COVID-19 survivors for cardiac, lung, kidney and neurological damage and markers now, will allow preventative medical treatment, delaying and deterring future serious illness. Increasing research funding for conditions such as Parkinson's disease will enable healthcare systems to better manage the oncoming ageing and long hauler populations. It is important to set up and expand existing health, disability and socio-economic support systems as

soon as possible to minimise the population-wide effects of Long Covid.

Conclusion

Long Covid was characterised by long haulers through online forums. Long Covid research policy and healthcare policy has and continues to be strongly influenced by patients and their support groups. The adoption and use of the patient term 'Long Covid' in research and healthcare indicates the patient roots of the illness, as well as how research has built on the foundations of patient action. Long Covid has also seen the emergence of new styles of research policy, where patients play a more active role as participants, citizen scientists and researchers. Integrated research shows great promise for dealing with the health problems of the future, emerging global diseases and future pandemics. Policy for Long Covid needs to continue to be developed and enacted to meet the challenges of current and increasing population morbidity. We need research to improve clinical strategies, healthcare, and socio-economic policies for the future and to support the needs of both current and future long haulers.

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Conflict of interest The Author declares no conflict of interest.