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A Long-Term Plan for Long Covid

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Foreword

It is now clear that over 400,000 people in the UK suffer from the debilitating effects of Long Covid or, as it is now called officially, Post-Covid-19 Syndrome, and a proportion of these will have symptoms persisting for some years. We know more about the problem than we did back in October when we launched the first report. We now have a working definition, but many aspects of its cause and mechanisms remain unclear. Unfortunately, although it is now well recognised, we have not progressed much in the treatment of the condition. The risk factors for the condition are now clearer and, although it can affect anyone of any age, we know that long-duration symptoms are more common with increasing age and in females. Studies from the ZOE Covid Symptom Study app show that having more than five different symptoms in the first week of the illness is a predictor of much increased risk.

We urgently need to focus on treatment and trials of intervention, especially at three months to see if the immune cycle that prolongs symptoms can be broken. The government has invested some targeted funds for Long Covid, but these funds don't match the scale of the problem. There are now some specialist clinical facilities around the country, but these are still patchy and too few in number and, importantly, patients and GPs lack a clear pathway to seek information and help via dedicated websites or apps. This report highlights many of the key remaining issues and how they might be addressed.

Tim Spector

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Overview

We last wrote about Long Covid when we published [Long Covid: Reviewing the Science and Assessing the Risk](#) in October which was followed up by [a blog](#) from members of Long Covid support groups. Since then, various studies and research have confirmed what many suspected in October: that Long Covid will have a significant impact on the lives and livelihoods of thousands of people, regardless of the severity of their initial Covid-19 infection.

According to estimates published by the ONS in December, the prevalence of Long Covid is as follows: ¹

- Around one in five respondents testing positive for Covid-19 exhibit symptoms for a period of five weeks or longer.
- Around one in ten respondents testing positive for Covid-19 exhibit symptoms for a period of 12 weeks or longer.

Over 4 million people in the UK have tested positive for Covid-19 as of 9 March 2021. ² This could mean that 800,000 people (one in five) suffer from Long Covid for five weeks or longer, and 400,000 (one in ten) people suffer for 12 weeks or longer. These estimates only include those who have taken a test and tested positive, not those who may have received a false negative result, were asymptomatic or did not take a test despite having symptoms of the virus.

Long Covid is interfering with people's health and their ability to work, indicating larger ramifications for not only the NHS but the economy as well. An online survey of 3,762 respondents from 56 countries found that 45.2 per cent of respondents reported requiring a reduced work schedule compared to pre-illness and that 22.3 per cent were not working at the time of the survey due to their health conditions. ³

What Is Long Covid: A Reminder

Colloquially, the ongoing and recurring symptoms following a confirmed or suspected Covid-19 infection experienced by thousands is known as "Long Covid". Clinically, the National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP) use the following clinical definitions for Long Covid: ⁴

- Acute Covid-19: signs and symptoms of Covid-19 for up to four weeks
- Ongoing symptomatic Covid-19: signs and symptoms of Covid-19 from four to 12 weeks
- Post-Covid-19 Syndrome: signs and symptoms that develop during or after an infection consistent

with Covid-19, continue for more than 12 weeks and are not explained by an alternative diagnosis

The most commonly reported long-term symptoms include:⁵

- Fatigue
- Shortness of breath
- Cough
- Joint pain
- Chest pain

Other reported long-term symptoms include:

- Difficulty with thinking and concentration (sometimes referred to as “brain fog”)
- Depression
- Muscle pain
- Headache
- Intermittent fever
- Fast-beating or pounding heart

More serious long-term complications appear to be less common but have been reported. These have been noted to affect different organ systems in the body. These include:

- Cardiovascular: inflammation of the heart muscle
- Respiratory: lung function abnormalities
- Renal: acute kidney injury
- Dermatologic: rash, hair loss
- Neurological: smell and taste problems, sleep issues, difficulty with concentration, memory problems
- Psychiatric: depression, anxiety, changes in mood

What Has Happened Since Our Report

Since October there have been many developments relating to Long Covid, in terms of what we know about the condition, more accurate estimates of how many people are suffering from Long Covid and actions that the government has taken to address this issue.

The flurry of studies that have been published on the subject over the last several months have indicated that Long Covid usually presents with clusters of symptoms that may change over time and can affect any system within the body. Many individuals report relapses.

Based on ONS data, we estimated that 800,000 people experience symptoms for five weeks or more, and 400,000 experience symptoms for 12 weeks or more,⁶ an increase from initial estimates that predicted 300,000 people had Covid-19 symptoms for a month and 60,000 for three months or more.

The government announced plans to launch an initial 40 Long Covid clinics in November, set out official guidance for the diagnosis and treatment for Long Covid, and published an awareness-campaign video at the end of October 2020. On 18 February, the DHSC announced an additional £18.5 million for Long Covid research.

What We Called for in Our Last Report

In our previous report we set out a series of recommendations on how the government could make progress in responding to Long Covid. These recommendations covered:

- Addressing the need for further research on Long Covid.
- Launching an awareness campaign.
- Improving diagnosis of Long Covid.
- Putting in place specialist support for sufferers.
- Using the Covid Symptom Study data to screen for those likely to develop Long Covid.

Below we include:

1. More detail on the recommendations we made.
2. An update on what has happened in each area.
3. Where appropriate, what more could be done.

Our Original Recommendations

Further Research

What we called for:

We recommended further studies be carried out, particularly ones drawing on international data to give the best possible evidence for the scale of the problem. The data aim to build as full a picture as possible on the extent of Long Covid, particularly among asymptomatic carriers and those who, based on the current list of three symptoms (high temperature; new, continuous cough; loss of sense of taste or smell), did not seek a Covid-19 test. This should be compiled into a publicly available, global database, requiring global coordination.

Progress update:

We welcomed the announcement that the Office for National Statistics (ONS) had begun publishing statistics related to Long Covid at the end of 2020. This research seeks to quantify Long Covid in terms of its prevalence, risk factors, and symptoms following a confirmed or suspected infection, as well as characterise the nature of complications.⁷

On 18 February the Department of Health and Social Care (DHSC) announced an additional £18.5 million to fund research projects to better understand the causes, symptoms and treatment of Long Covid. The funding is set to be given to four studies to identify effective therapies to treat people who experience ongoing symptoms of the virus and understand why some people suffer from Long Covid while others do not.⁸

How is the government doing?

The ONS data on Long Covid is an important foundation for building our understanding of the symptoms, prevalence and impact of Long Covid. The ONS has also stated plans to further refine their Long Covid surveys in order to capture the most accurate data.

We also called for a publicly available, global database centred around Long Covid. The Covid-19 pandemic has exposed just how important global health security and coordination is, and any conversations on harmonising Covid-19 data and databases should also include Long Covid data.

What more should the government do?

The announcement of £18.5 million for Long Covid was welcome news as more research is needed to explore the underlying mechanisms of Long Covid in order to improve understanding and discover treatments for existing patients. From a preventative perspective, some of the funds allocated to Long Covid research could be used to fund early-intervention trials that explore new treatments that are aimed at shortening the duration of symptoms and reducing relapses.

One key question that remains unanswered regarding Long Covid is if the damage caused to organs, such as the heart and lungs, is permanent. More research is needed to determine if all patients will make a full recovery and if so, how long it will take to do so. The only way we will know for sure is to track this carefully on an ongoing basis. Post-pandemic, the NHS could face a waiting list of millions of people who are suffering from Long Covid, so it is essential that these questions are answered and that we are armed with the fullest possible picture on the scope and scale of the illness.

Research is also lacking on how, and if at all, vaccines will affect the likelihood of developing Long Covid and if those vaccinated will see a reduction in persistent Long Covid symptoms. Or, if those with Long Covid would benefit from the Covid-19 jab and could therefore be prioritised. As the UK's vaccine rollout continues, these considerations should be included in vaccination research and analysis.

Awareness Campaigns

What we called for:

We advocated for campaigns to increase awareness of Long Covid as well as to help drive compliance with containment measures such as the use of masks. Initially, discussions of severe Covid-19 infections were centred around the elderly or those with underlying conditions. One study found that in a young, low-risk population with ongoing symptoms, almost 70 per cent of individuals had impairment in one or more organs four months after initial symptoms of Covid-19. Although this study had a small sample size, there are implications for both the burden of Long Covid and also the public-health approaches that have assumed low risk for young people with no comorbidities.⁹

Since evidence indicates that Long Covid does not appear to discriminate based on age, we felt it was important the government's public messaging highlight the fact that these symptoms have affected younger people and those who are otherwise fit.

Progress update:

Alongside the announcement that the government was going to fund Long Covid clinics back in October, the [DHSC published a video](#) on their YouTube channel underscoring the fact that young and healthy people are not exempt from Long Covid and its persistent symptoms. Aside from this initial video, Long Covid has not been prominent in the various Covid-19 campaigns that the government has put out.

How is the government doing?

Although the government has not done as much for Long Covid awareness as many would have liked, Long Covid support groups have taken it upon themselves to raise the issue of Long Covid to the government and spread awareness among the general public. The [LongCovidSOS](#) campaign group's open letter to the prime minister has so far accrued more than 1,000 signatures. There is also a [live petition](#) for government to create an awareness campaign detailing effects of Covid-19 on children.

In addition to LongCovidSOS and the groups "[Message in a Bottle](#)" campaign, there are several other groups, both UK-based and international, that are campaigning for the recognition, rehabilitation and research needed for Long Covid. Some other groups include Long Covid Support, Long Covid Kids, Long Covid Scotland, Long Covid Wales, Covid-19 Research Involvement Group and Long Covid Physio.

What more should the government do?

The government needs to put out updated awareness campaigns that accurately set out the risk and prevalence of Long Covid and that stress the fact that Long Covid does not only affect the elderly. Mass vaccination is taking place at speed in the UK, but it is important that those who are months away from receiving their jabs are aware of the risks of getting Covid-19, even if their initial infection is mild. We're also advocating for Long Covid updates to be included in Downing Street briefings.

There is also the option for the government to publicly support or respond to the existing Long Covid campaigns put forth by various support groups.

Voices of Long Covid

The Long Covid alarm was first sounded on social media in March 2020 by a group of patients – including Dr Elisa Perego from Italy, who named the condition – who documented their continued Covid-19 symptoms.

With the threshold for hospital admission set so high, these patients were instructed to stay home, rest, drink water and take paracetamol. They were told this was just like the flu and they would bounce back after two weeks, but almost a year on, some still haven't recovered.

I lived with new symptoms of Covid-19 from April 2020 until October 2020, they included: tachycardia, headaches, chest pain, pleurisy, breathing issues, muscle aches, mobility issues, sore throats, fevers and fatigue. I am one of the lucky ones who would now consider themselves firmly on the road to recovery. It took a team of private doctors, paid for by the private health insurance provided by my employer to help me, including a cardiologist, neurologist, respiratory specialist and specialist physios. My recovery was boosted because of access to specialist drugs including ivabradine, which is now being trialled in Long Covid patients, specialist care, a supportive employer and patient-led support groups online.

Patient-led groups on social media have been a key resource throughout the pandemic for so many as thousands joined online global communities to try to figure out why they still weren't better. Groups including Long Covid Support, Long Covid SOS, the Body Politic group on Slack and many more continue to inform policymakers and health-care professionals as the numbers of chronically sick people grow. Many people were too sick to be treated by their GP but not sick enough to be admitted to hospital and have been lost in the system. They have lost jobs, relationships and homes.

After months of feeling invisible, these patient-led groups welcome steps to support the hundreds of thousands of people affected by Long Covid. However, the majority of our members are struggling to access the medical and other help they desperately need. It is vital that patient groups are included in the development of services as they understand the needs of people living with this poorly understood condition, can identify gaps in provision and utilise their lived experience to drive service improvement. "Nothing about us without us."

Talya Varga, had new Covid-19 symptoms from April 2020 to October 2020

Guidance for Diagnosis

What we called for:

Our recommendation for improved diagnosis emphasised the importance of correctly identifying Long Covid cases. This will require mass testing as well as information on symptom duration, with the information collected centrally. The right case definition is needed alongside this, with certain symptoms, like loss of smell or taste, being highly indicative of an acute Covid-19 infection.

Progress update:

NICE, RCGP and SIGN published guidance for Long Covid in December 2020.¹⁰ [The guidelines](#) cover identifying, assessing and managing the long-term effects of Covid-19 and make recommendations about care in all health-care settings for adults, children and young people who have new or ongoing symptoms four weeks or more after the start of acute Covid-19. It also includes advice on organising services for Long Covid.

How is the government doing?

The publication of treatment and diagnosis guidelines was a welcome announcement. However, anecdotal evidence from individuals with Long Covid suggests that some patients are still struggling to access treatment and to have their condition taken seriously.

What more should the government do?

The current guidance for referral pathways for patients varies depending on if patients were admitted to hospital or not. The guidance indicates that individuals who tested positive for Covid-19 and were hospitalised with severe infections should have a clinical review after six weeks of ongoing symptoms. However, those who were not admitted to hospital, regardless of whether or not they took a Covid-19 test, “... should be offered referral if they have been experiencing post-Covid syndrome symptoms for 12 weeks or longer.”¹¹

We understand that Long Covid is a complex condition that presents itself in different ways in different individuals. This complexity requires GPs to take time eliminating other potential causes for symptoms before referring a patient to a Long Covid clinic. However, all patients, regardless of whether they were hospitalised or not, should have the option to be referred to a Long Covid clinic after six weeks, as opposed to making those who were not hospitalised with Covid-19 wait 12 weeks.

In addition, some members of the Long Covid community believe that the guidelines do not sufficiently address the relapsing nature of the condition, which puts patients at risk of being discharged from clinics during a time of remittance of symptoms but before resolution of the condition.¹²

Specialist Support

What we called for:

Based on our conversations with experts at the time of publication of our first report, back in October 2020, we believed that specialist support was needed to treat Long Covid, including more research into the non-medication approaches that were being trialled at the time and exploring the potential role of therapeutics. We hoped this information would be captured using the global database we recommended, ensuring that all approaches were recorded and their effectiveness monitored.

Progress update:

In October 2020 the NHS announced £10 million to fund Long Covid clinics in every area across England where respiratory consultants, physiotherapists, other specialists and GPs would assess, diagnose and treat individuals who have reported symptoms ranging from breathing difficulties, chest pain, fatigue, tachycardia, headaches, neurological issues and cognitive impairment. ¹³

How is the government doing?

The initial £10 million investment in Long Covid clinics was a step in the right direction for Long Covid care. However, with the number of people suffering from Long Covid growing, this investment needs to be sustained and monitored. With an estimated 800,000 people suffering for more than five weeks, the £10 million investment breaks down into just £12.50 per patient. Our understanding, based on discussions with experts, is that it costs far more than this to set up and maintain interdisciplinary clinics.

Given that little follow-up data has been published regarding the status of these clinics and how they are operating, evaluating the government's performance for this recommendation was difficult. It is also unclear what constitutes a "clinic".

What more should the government do?

The Long Covid clinic announcement was updated in December when it was revealed that over 60 Long Covid clinics were operating across the country with hundreds of patients already attending. However, as mentioned above, there has been little follow up on how these clinics are actually performing and how many individuals have been able to access treatment. It is unclear if most clinics are post-hospitalisation clinics led by chest physicians, or if the clinics are truly multidisciplinary in nature and are open to all sufferers of Long Covid, regardless of the severity of their initial infection.

It is also unclear how, if at all, data from these clinics is being stored or used for research purposes. Data can be useful in two ways in this case: One, data enables government to publish figures on the number of patients accessing Long Covid clinics, how sufficiently they are staffed, the treatments being used, and how accessible these clinics are to the general public in all areas, given there are less than 70 operating across England. Two, data can inform treatment plans in the future. Keeping track of what symptoms are being reported, which symptoms each type of patient is suffering from, and which treatment options are most effective will help inform and progress how well we treat and understand Long Covid. Data from these clinics can help provide a better understanding of the prevalence and nature of Long Covid throughout the UK.

Given the scope and scale of Long Covid, additional funding in the future will be necessary in order to maintain each clinic and high standards of care and treatment.

Screening

Our final recommendation had to do with screening, specifically using the data collected by the Covid Symptom Study to inform who is at risk from Long Covid. This data should be properly analysed and maintained before being used to understand how likely a person is – based on age and profile – to suffer from Long Covid symptoms. This insight could inform enhanced shielding measures and underpin individual risk profiles.

Progress update:

According to a publication in October, Covid Symptom Study researchers were able to build a model to predict the likelihood of developing Long Covid based on age, gender, BMI and the number and combination of symptoms experienced in the first week of illness. [14](#)

How is the government doing?

Progress has been made in this area as we now have a much better understanding, albeit not a complete understanding, of Long Covid. The data from the Covid Symptom Study has helped provide a model for predicting Long Covid cases, but it is unclear if this data is being reviewed on an ongoing basis. Although our understanding of Covid-19 and its suspected wide range of symptoms has evolved, the official government guidance does not reflect our improved understanding of the virus.

What more should the government do?

Researchers have urged the government to add fatigue, headache, sore throat and diarrhoea to the current list of three symptoms (high temperature; new, continuous cough; loss of sense of smell or taste) which entitle someone to book an NHS PCR Covid-19 test. King's College London and the ZOE Symptom Study app have suggested that testing based on these additional symptoms could pick up 30 per cent more cases.

Similarly, an open letter to Chief Medical Officer Chris Whitty and Dr Susan Hopkins published in the *British Medical Journal* (BMJ), penned by 140 GPs, asks the government to change the UK Covid-19 case definition and test criteria to include coryza and cold, making them consistent with the World Health Organisation. The national publicity campaign focuses on cough, high temperature and loss of smell or taste as symptoms to be aware of, yet evidence from communities and non-hospitalised patients has made it clear that Covid-19 infections present differently and can exist without any of the three symptoms required to get a test. GPs have had to advise patients to be dishonest to get a Covid-19 test if their symptoms are not one of the three listed. ¹⁵

Expanding the list of accepted symptoms of acute Covid-19 infections will also help identify Long Covid cases. It could reduce the number of individuals who do not have a positive test or did not experience any of the three symptoms but still believe they had Covid-19. ¹⁶

Since the start of the pandemic – when the initial three symptoms were listed – the UK has sufficiently increased its PCR capacity and can now absorb the uptick in testing that would occur if the official symptom list were expanded.

Further Recommendations

In addition to the recommendations set out above, we make the following recommendations to the government regarding Long Covid:

Surveillance

Some public-health experts have begun calling for illness caused by Covid-19 to be measured in the same way as deaths and for national and international surveillance systems to monitor recovery from the virus. Professor Nisreen Alwan from the University of Southampton has advocated for the use of Long Covid patient registers, making the argument that we cannot address what we are not measuring. She argues that, by measuring recovery and taking into account the relapsing nature of the illness, we can find out how many individuals have not fully recovered and come up with ways to better support people living with Long Covid.¹⁷

Clearer Guidance for Patients and GPs

Continued work is needed to improve communication for both GPs and patients. According to conversations with experts in the field, connecting suspected Long Covid patients to local support and clinics is still not straightforward. There is still a lack of information for GPs, and patients often don't know where to go, especially if they are not presenting with the three "tell-tale" symptoms of Covid-19. Anecdotal evidence also suggests that patients and even medical professionals find that the NHS webpages regarding Long Covid are not as helpful or straightforward as they could be. Our understanding of Long Covid is constantly evolving, and we must make sure that the way we treat and refer patients with Long Covid evolves alongside these new developments.

Create a Long Covid Taskforce

The UK's Vaccine Taskforce has been successful in the acquisition and distribution of Covid-19 vaccines, and many people attribute this success to the fact that the taskforce was run by a small, tight-knit group of people with a clear, common goal.¹⁸ The UK also has a Therapeutics Taskforce that oversees the identification, development and deployment of safe and effective treatments for Covid-19. Long Covid is an issue that will persist long after lockdown ends and it needs to be sufficiently addressed, starting now. A taskforce charged with both improving Long Covid care and addressing the wider societal issues of

Long Covid in addition to health care – such as its impact on employment, education and welfare – could help achieve this goal.

Appoint a Long Covid Minister

Appointing ministers for specific tasks can be effective, and clear roles and responsibilities help each person know what they need to focus on. ¹⁹ Patient Safety Learning and Long Covid Support have called for an urgent and significant increase in the scale and pace of the government’s Long Covid response, and suggested the efforts be set up and led by a minister with specific responsibility for Long Covid.

Recognise Long Covid as an Occupational Disease

A proposal to recognise Long Covid as an occupational disease has been put forward by the All Party Parliamentary Group on Coronavirus, as well as the British Medical Association (BMA). One goal of the proposal is to compensate frontline health and other key workers living with Long Covid’s ²⁰

According to the group, Belgium, Denmark, France, Germany and Spain have already recognised Covid-19 as an occupational disease, entitling employees and their dependants to protection and compensation if they contracted the virus while working. ²¹

The group also suggested that any proposed compensation scheme could mirror the Armed Forces Compensation Scheme that is in place for military veterans and that provides monthly payments based on circumstances and level of need. ²²

An occupational disease is any disease caused by or made worse by an individual’s job, and we support the proposal for Long Covid to be considered an occupational disease and for workers to be compensated when necessary, as suggested.

Conclusion

It is almost six months since we last wrote on Long Covid. In one sense, a number of things have changed, with progress having been made in certain areas.

We now have a recognised diagnosis for Long Covid. Specific funding has been provided by the government, and specialist clinics have been set up. Through the work of Professor Spector, King's College London and ZOE, we also have a clearer picture of the scope and scale of the problem.

In another sense though, few things have changed. Long Covid is a significant challenge and we remain in a position where we are not meeting the scale of the challenge with the requisite resources.

Long Covid sufferers are still struggling to access the right resources. While specialist clinics have been set up, they are too few in number. Our conversations with key groups indicate that many people are struggling to get referrals to these clinics, with geographic proximity to a clinic a further barrier. Funding has been given by government but not on the scale needed to match the growing need. Further and deeper research is also needed, particularly the effects of vaccination on those with Long Covid.

This report sets out how government can put in place the long-term plan we need to respond to the challenge of Long Covid.

Recommendations

- **Conduct further research** on the causes of Long Covid, the best practices for treatment and the potential impact of Covid-19 vaccines on Long Covid symptoms.
- **Release additional Long Covid awareness campaigns** or publicly support existing campaigns put forward by Long Covid support groups that target young people who may not be aware they can suffer from Long Covid regardless of their initial infection.
- **Provide additional funding** for Long Covid clinics.
- **Expand the list of symptoms that warrant a Covid-19 test** beyond a fever, new or continuous cough, and loss/change of taste or smell.
- **Monitor the prevalence of Long Covid** by creating Long Covid patient registers and implementing Long Covid surveillance.
- **Continue to develop and refine Long Covid guidance** for both patients and GPs.
- **Create a Long Covid taskforce** charged with improving Long Covid care and the wider societal issues of Long Covid, such as its impact on employment, education and welfare.

- **Appoint a Long Covid minister** to lead the government's Long Covid response.
- **Recognise Long Covid as an occupational disease** and compensate workers where necessary.

Footnotes

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