



Addressing the health challenge of long COVID

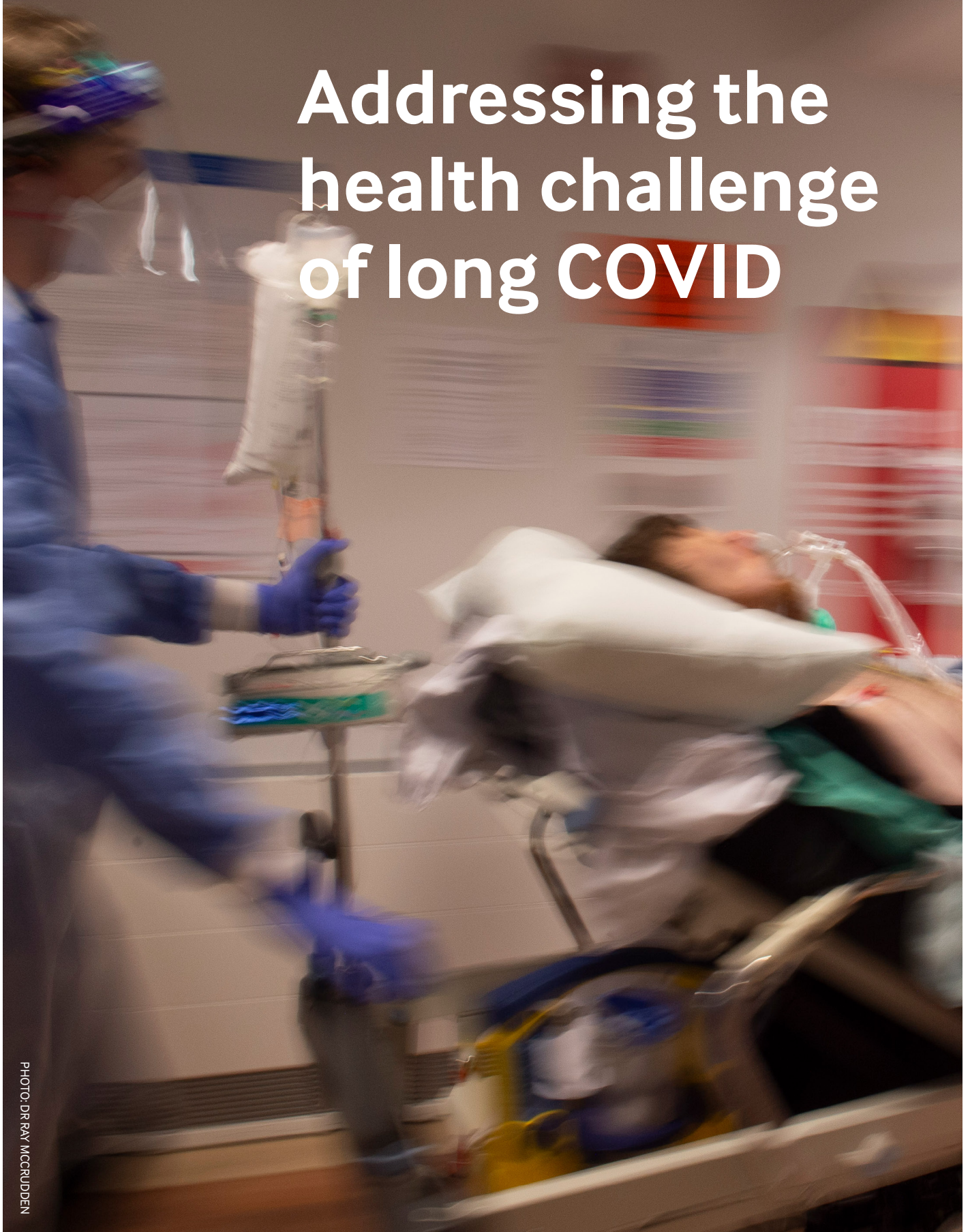


PHOTO: DR RAY MCCRUDDEN



Executive summary

Long COVID is placing a considerable burden on people's lives, health, the health service and the UK's nations. There are variations in the definition and prevalence of long COVID, and the lack of diagnostic criteria and dependence on self-reporting makes it difficult to establish the exact prevalence of the condition.

The vaccination programme has and will continue to reduce the risk of long COVID, but despite this, people are still at risk of developing long COVID – particularly during times of high transmission of COVID-19. Therefore, more needs to be done to meet the rising demand of people (including children) suffering with long COVID in the UK.

Research is key to increasing our understanding of the condition and developing more effective treatments; multidisciplinary teams are key to attending to the multi-system nature of the condition. In addition, better support, particularly financial support, is needed for those with long COVID.

To help improve the understanding, treatment, care and support of people with long COVID, the BMA is calling for action in the following areas:

- Detailed data collection on the prevalence and presentation of long COVID
- Increased funding for research and infrastructure
- Prevention of long COVID in children
- Support for health professionals to identify and treat long COVID
- Funding and resources to establish multidisciplinary services
- Improved financial and wider support for people unable to work due to long COVID
- Improved support and compensation scheme for doctors and health care workers who have long COVID



Introduction

Long COVID is a multi-system, debilitating condition for many sufferers. As of July 2022, 2.8% of the UK population were experiencing self-reported symptoms of long COVID, at least four weeks after having COVID-19.¹ This has become an important public health issue in the UK and represents a new, significant challenge for the health system – one that is likely to be a driver of ill-health for years to come.

Over the last two years, the BMA has expressed concern about many aspects of the COVID-19 pandemic, including the huge health toll and health burden it has created, the impact on the medical profession and on health care services, and the Government's handling of the pandemic. The UK is now in a better position to respond to the ongoing challenges COVID-19 poses, following the successful development and rollout of highly effective vaccines, which have significantly reduced the number of deaths from COVID-19 and the chances of getting severely ill from the disease. However, there remains a significant burden of long-term illness from COVID-19, which is likely to increase as more and more people contract COVID-19, putting them at risk of long COVID.

The large number of people being affected by long COVID is a significant concern and it is crucial UK Governments invest in the monitoring, research and treatment of long COVID, including a multidisciplinary approach to its management. While some progress towards developing treatments and improving support for people with long COVID has been made, far more needs to be done.

This briefing explores the prevalence of long COVID in the UK population and sets out what is needed to:

- prevent long COVID, including in children
- manage and treat long COVID effectively
- and support people who are unable to work due to long COVID.

It sets out a series of specific areas for action for government and others to build our understanding of long COVID, support people with long COVID and to minimise its ongoing health burden in the UK.

There are variations in the definition and prevalence of long COVID, but it is affecting many people in the UK

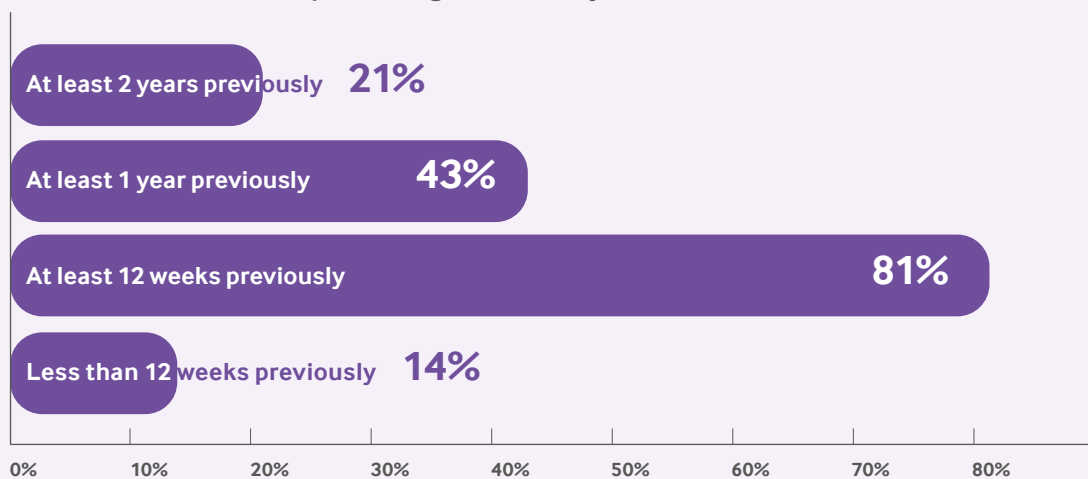
There is no internationally agreed clinical definition of 'long COVID' and the evidence base on what constitutes long COVID, in terms of range and length of symptoms, is still emerging. In October 2021, the WHO (World Health Organisation) defined 'post COVID-19 condition' as occurring *"in individuals with a history of probable or confirmed SARS CoV-2 infection, usually three months from the onset of COVID-19 with symptoms and that last for at least two months and cannot be explained by an alternative diagnosis."*² Common symptoms of long COVID include fatigue, shortness of breath, chest pain, problems with memory, heart palpitations, dizziness, and joint pain – but many more have been reported.

This briefing bases the definition of long COVID on the most recent clinical guidelines in the UK by NICE (National Institute for Health and Care Excellence). This guidance on managing the long-term effects of COVID-19 covers care for *"people who have signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than four weeks and are not explained by an alternative diagnosis."*³

According to this definition of long COVID, ONS data reports that as of 2 July 2022, there were an estimated 1.8 million people living in private households in the UK who were experiencing self-reported long COVID (not clinically diagnosed)^a. Of these people, 14% first had (or suspected they had) COVID-19 less than 12 weeks previously, 81% first had (or suspected they had) COVID-19 at least 12 weeks previously, and 43% first had (or suspected they had) COVID-19 at least one year previously.¹

Prevalence of self-reported long COVID symptoms among private households in the UK, by onset

■ Prevalence of self-reported long COVID % (July 2022)



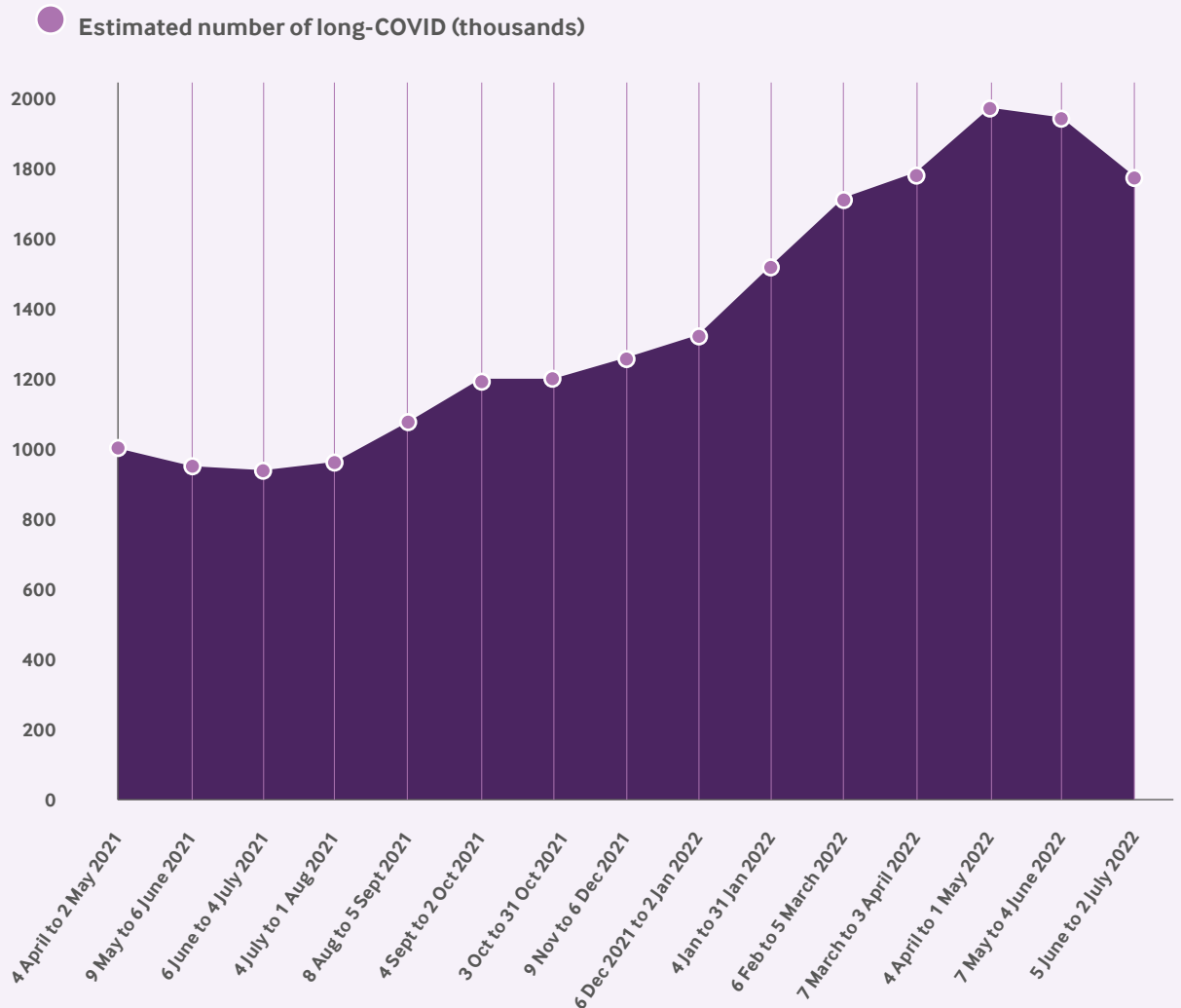
Source: Office for National Statistics: Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 4 August 2022

* Please note – as the categorisations are overlapping (non-discrete), overall % figures do not sum to 100%. Those with an unknown date of first (suspected) COVID-19 infection are not included in duration specific estimates.

a Those who describe themselves as having 'long COVID', that is, still experiencing symptoms more than 4 weeks after they first had COVID-19, that are not explained by something else.

In terms of the *proportion* of people affected by COVID-19 who go on to have symptoms for longer than 12 weeks, the ONS data from April 2020 – August 2021 shows that between 3% and 12% of people infected with coronavirus have symptoms 12 weeks after the initial infection.⁴ In terms of the nature of symptoms people experience, a 2022 systematic review of Post-COVID-19 syndrome found that approximately one in three individuals experienced fatigue 12 or more weeks following COVID-19 diagnosis, and one in five exhibited cognitive impairment 12 or more weeks following COVID-19 diagnosis.⁵

Time-series of estimated number of people living in private households with self-reported long-COVID



Source: Office for National Statistics: Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 4 August 2022

ONS figures on prevalence have generally been increasing since 2021, despite a recent drop. As of April 2021 (when data was first collected), just over 1 million people in the UK were experiencing self-reported long COVID compared to approximately 1.8 million in July 2022. This might reflect the increasing numbers of people contracting COVID-19 during this time, many of whom then went on to develop long COVID. Between January 2022 and June 2022, there was a very sharp crease in long COVID prevalence in the UK, from 1.5 to 2 million people.

The recent ONS data also shows that the prevalence of self-reported long COVID was greatest in females, people living in more deprived areas, those working in social care and those with another activity-limiting health condition or disability.¹ ONS data has also shown consistent higher prevalence amongst those working in teaching and education and health care, likely reflecting increased exposure in these sectors.⁶

In order to advance our understanding of long COVID, it is crucial that prevalence data is collected. Government commitments have been made – for example, in June 2021, NHS England committed to setting up a long COVID registry to collect long COVID activity data.⁷ However, to date, data is not collected accurately and consistently across the UK, meaning the UK Government is still relying on ONS self-reported data.⁸

There should be a focus on preventing long COVID in the population

Vaccination is an important mitigation against long COVID

Vaccination reduces the likelihood of developing long COVID and the severity of the symptoms. A 2022 rapid evidence review by the UKHSA (UK Health Security Agency) investigated the relationship between vaccination and long COVID in 15 UK and international studies.⁹ Eight of the studies looked at the impact of vaccination administered before infection with COVID-19 and found that people who had received two doses of the Pfizer, AstraZeneca or Moderna vaccines, or one dose of the Janssen vaccine, were about half as likely as people who received one dose or were unvaccinated to develop long COVID symptoms lasting more than 28 days.^b This is likely due to a combination of the vaccination reducing the probability of getting COVID-19 as well as long COVID.

There is also some evidence that vaccination helps reduce the severity of long COVID. The remaining studies looked at the effects of vaccination among people who already had long COVID symptoms, three of which suggested that more people with long COVID reported an improvement than a worsening in symptoms after vaccination, either immediately or over several weeks. For example, in one study, 57.9% of participants with long COVID reported an improvement in their symptoms after vaccination compared to 17.9% who reported a deterioration.¹⁰

Take-up of first dose vaccination across the UK overall is high, at approximately 93% of the population aged 12 and over.^c However, there remains a small proportion of the population across the UK who have still not been vaccinated. Wide inequalities in take-up of the COVID-19 vaccine are also apparent. For example, it has been found that Black African, Black Caribbean and Pakistani and Bangladeshi groups are less likely to be vaccinated compared to White groups.¹² Issues such as age, clinical vulnerability and income deprivation can also impact the likelihood of vaccine take-up.¹³ There needs to be a sustained focus on the vaccination rollout in the UK, including on booster vaccines and addressing vaccine hesitancy, as a principal mitigation measure for the development of long COVID.

The vaccination programme is crucial for prevention, but additional measures are also needed

The mitigating impact of vaccination on long COVID is a positive step in addressing the public health challenge of long COVID. However, there will still be many individuals who experience long-term symptoms of COVID-19 despite being vaccinated, and many others who are still suffering from symptoms of long COVID which they contracted prior to being vaccinated.

Vaccination and pharmaceutical interventions form the main approach of the 'Living with COVID-19' strategy taken by Governments across the UK. Reducing transmission through non-pharmaceutical interventions (for example, mask wearing and social distancing) is becoming less likely in the current context, as these interventions are no longer mandatory. This lifting of

^b An important caveat is that the vaccination program coincided with the move from a predominant Alpha to a predominant Delta variant, and although it is believed to be a benefit of the vaccine, we cannot be certain that this is not due to the differential impact of the variant.

^c NI – 89.4%, Wales – 98.6%, England – 93.4%, Scotland – 95% as of August 2022.

COVID-19 restrictions and the end to the legal duty to self-isolate across the UK means that many more people are at risk of contracting COVID-19, and in turn of developing symptoms of long COVID. This risk is particularly significant during times of high case numbers of COVID-19 in the population. There may also be some variants of COVID-19 that carry a greater risk of long COVID, even if they do not lead to more hospitalisations and deaths.¹⁴ Furthermore, it is unclear if multiple exposures to COVID-19 have an impact on the likelihood of contracting long-COVID or the severity of long-COVID symptoms. As such, the risks of long COVID are still not fully understood.

Overall, it is noteworthy that there is very little promotion of public health messages on how people can reduce the likelihood of contracting COVID-19 or developing long COVID, if they are infected. This, in turn, places significant reliance on individuals making decisions about their own health and care, which is difficult without accurate information and guidance. For example, emerging evidence shows that it is crucial that people with long COVID are encouraged to rest and are provided with sufficient recuperation time, with a positive correlation between inadequate initial rest and long COVID and indications that physical activity can exacerbate symptoms of long COVID.¹⁵ Disseminating such information widely would likely reduce the number of long COVID cases, improve lives and reduce pressure on already stretched healthcare services.

There should be more effort to prevent long COVID in children

COVID-19 continues to spread in children – a population group that was among the last to be offered the vaccine. There have been challenges around the prevention of long COVID in children, and arguably, not enough has been done to understand and prevent this issue.

For much of the pandemic, children have had higher exposure to COVID-19 from being in school or pre-school settings, often with minimal measures in place to protect them. In a 2022 report on long COVID, the APPG (All Party Parliamentary Group) on Coronavirus found that the UK Government's COVID-19 policy applicable to schools and educational settings failed to adequately protect pupils from contracting COVID-19 and therefore developing long COVID.¹⁶

Data shows that long COVID is now becoming increasingly common in children, with the most recent ONS data on prevalence showing that 98,000 children^d living in private households in the UK have self-reported long COVID of any duration, with 90,000 reporting symptoms lasting beyond 12 weeks.¹ These numbers have increased from 38,000 and 29,000 respectively since September 2021.¹⁷

In terms of the proportion of children with COVID-19 who go on to develop long COVID symptoms, the world's largest study on long COVID in children and young people, published in September 2021, found that one in seven children and young people in England who had COVID-19 still had three or more symptoms 15 weeks after their test.¹⁸

There may also be challenges in identifying and managing long COVID in children and young people. Limited communication skills in children, particularly younger children, can make it difficult to diagnose long COVID and to distinguish it from other infections such as flu and glandular fever, which present in a similar way. Furthermore, long COVID symptoms such as fatigue, headaches and difficulties concentrating could be caused by other pandemic-related phenomena, such as the trauma of seeing family members sick or dying from COVID-19, or isolation and school closures.¹⁹

Vaccination is now available in the UK for all children aged five to 15 years old: it was approved for children aged 11 to 15 years old in September 2021, and for those aged five to 11 years old in February 2022.²⁰ Like with adults, this should reduce the risk of children developing long COVID.

d Those aged 2-16.

However, the rollout of these vaccines has been slow compared to that of adults, only beginning several months after the JCVI (Joint Committee on Vaccination and Immunisation) had approved them for these age groups. Patchy uptake to date has been blamed partly on mixed messaging from the Government about the benefits of vaccination in children.^{21,22} By 31 July 2022, 52.7% of children aged 12 to 15 in England had received their first dose, and 10.5% of children aged five to 11 had received their first dose.²³ Scotland has seen a slightly higher uptake with 66.8% of 12 to 15 year olds having received their first dose by 31 July 2022, and 22.5% of children aged 5-11.^{24,e} Furthermore, the UK has been much slower than other EU member states in offering vaccination to this age group,²⁵ which means that many children who could have benefitted from the vaccine will have already contracted COVID-19 and may have, or be at risk of, long COVID.

There needs to be a sustained effort to increase the proportion of children who are vaccinated across the UK, in order to protect them from the risk of long COVID. An education campaign should be developed by UK government to inform children and, importantly, parents who may be concerned about vaccinating their children, of the potential impacts of long COVID and provide guidance on prevention.

There needs to be better treatment and care for people with long COVID

There needs to be increased investment into long COVID research

Currently, there are a lot of unknowns when it comes to treating long COVID. Despite recent investment, more research is needed to increase understanding of the condition, including any psychological aspects, and develop more effective treatments.

In October 2020, NHS England and NHS Improvement set out a '5-point plan for long COVID support' which included a commitment of £50 million to fund research into long COVID.²⁶ In July 2021, the Government said that £20 million of the £50 million previously committed to research would go to 15 UK-based research studies, through the NIHR (National Institute for Health Research) to better understand the condition, improve diagnosis and find new treatments.²⁷ As part of this investment, various studies are investigating whether there might be potential pharmaceutical treatments that would be effective in treating long COVID.^{28,29,30}

Long COVID is also a focus for researchers globally, with the European Commission announcing it would accelerate research into long COVID and seek to develop treatments,³¹ while the US is also running clinical trials.³² Similarly, several major pharmaceutical companies have demonstrated an interest in developing targeted new treatments or repurposing existing ones.

Although researchers have been surveying the broad spectrum of symptoms associated with long COVID, they have not found one biological explanation. It is likely that there are various mechanisms involved. Similarities between long COVID and other post-infection syndromes have been considered. For example, patients with chronic fatigue syndrome/myalgic encephalomyelitis (which is often post-viral) become exhausted after even mild activity, alongside experiencing other symptoms such as headaches. It isn't uncommon for an infection to trigger long-lasting symptoms.³³

Despite the investment into research for treatments for long COVID, much of the research is in the early stages, resulting in a lack of evidence on effective treatments. This has often left people with long COVID feeling isolated and frustrated in their search for treatment.³⁴

While initial commitments are positive, there needs to be further funding for long COVID research, to bring us closer to finding suitable treatments for long COVID, so that people can be relieved of symptoms and have an improved quality of life. Alongside this, it needs to be made easier to both conduct and implement research, including through streamlining

e Equivalent data for Wales and Northern Ireland is not available.

approvals to facilitate research pathways, and through developing pathways to support more rapid implementation of promising findings in relation to the diagnosis, assessment and treatment of long COVID. For example, the MHRA (Medicines and Healthcare products Regulatory Agency) offers streamlined approvals via closer working practices with the UK research ethics services and the HRA (Health Research Authority), via a combined review service. This process includes a single application route, a coordinated review to set timeframes, and a combined UK decision on a trial. Through the Innovative Licensing and Access Pathway, the MHRA also aims to accelerate the time it takes to get treatments to the market by supporting innovative approaches to the safe, timely and efficient development of medicines to improve patient access. However, ambitions like these need changes to clinical trials research legislation to enable them to be carried out.³⁵

There needs to be better management of and care for people with long COVID

Care for people with long COVID can vary. People with long COVID have reported mixed experiences accessing the treatment and support they need due to the level of understanding of the condition by health professionals. Primary care is often the first step in the patient pathway, so it is crucial that GPs are fully supported to understand the variable symptoms of long COVID, what support is available (including mental health support), and how to refer people to it.

Despite the unknowns around the biological mechanisms of long COVID, it is clear that people have symptoms affecting multiple organs, suggesting that it is a 'multisystem disorder'. This means that symptoms of long COVID may have a number of different diagnoses, spread across multiple specialties.

This presents a challenge for secondary care in the NHS which is, largely, organised around single specialties designed to address individual problems. People suffering with long COVID require holistic treatment, that addresses the multisystem symptoms of this condition.³⁶ Pathways for long COVID should focus on addressing patients' multisystem symptoms and rehabilitation needs and provide individualised care plans accordingly. In developing new pathways of care for long COVID, it will be important to learn from successful examples of healthcare delivery (see case study 1), that have designed approaches to improve the coordination and care of people with multimorbidity. For example, research has found that multi-professional collaboration including, for example, primary care physicians, hospital specialists, nurses and social workers needs to be at the heart of integrated care for people with multimorbidity.³⁷ It is also crucial that patients get access to multi-disciplinary teams as early as possible as this will reduce the chances of them needing to access more costly and specialised care further down the line.

Case study 1: Multimorbidity and Polypharmacy in the Silkeborg Hospital, Denmark³⁸

Multidisciplinary collaboration in this clinic in Denmark has been achieved through meetings of medical specialists from different disciplines along with nurses, pharmacists, physiotherapists and occupational therapists. Meetings to discuss the needs and care plan of a specific (multimorbidity or polypharmacy) patient are arranged during lunch breaks^f and the participation of the care professionals is on the basis of equality and focused on the specific needs of the patient. This approach helped reduce obstacles such as a lack of time or bureaucracy. The clinic also cooperates closely with primary care, to facilitate referrals of patients with complex care needs to the clinic for a comprehensive needs assessment. Primary Care clinicians are then supported by the clinic afterwards to provide the necessary care in their practice.

^f This is an example from Denmark. If such a service was to be rolled out in the UK it would need to be properly staffed, funded and resourced to ensure all staff were able to take appropriate breaks/ lunch breaks.

Existing treatment pathways for long COVID differ across the UK. In Scotland and Wales, long COVID treatment pathways are delivered by health boards offering services according to local population need,^{39,40} whereas specialist clinics have been developed in England and Northern Ireland.^{41,42}

There are criticisms of the differing long COVID treatment pathways across the UK. For example, the localised services in Wales have been criticised for being fragmented and the lack of specialised COVID clinics has reportedly resulted in patients seeking private health care.⁴³ In England there are early indications that the 'long COVID assessment clinics' lack true specialist medical supervision or specialist multidisciplinary teams,⁴⁴ despite purportedly being designed to "bring together doctors, nurses, physiotherapists and occupational therapists to offer both physical and psychological assessments."⁴⁵ Data from NHSE also shows that there have been a small number of referrals to these clinics, suggesting a need to increase awareness of them amongst healthcare professionals and patients.^{46,47}

There is emerging evidence that timely access to long COVID clinics in England has been a postcode lottery,¹⁵ and there can be very long waiting times after being referred to a clinic. A survey conducted by the campaign group Long COVID Support suggests that patients who responded to the survey were typically waiting five to six months for a first appointment after being referred by their GP,⁴⁶ with extreme geographic variation from three weeks in some regions to more than nine months in others. At the time of writing, the most recent NHS data on waiting times for the Post COVID Assessment Service in England showed 36% of referred patients are waiting 0-6 weeks, but the same percentage are waiting more than 15 weeks.⁴⁶ The proportion of those waiting more than 15 weeks has increased since data was first collected in August 2021, from 19% to 36%. Similarly, in Northern Ireland some patients have reported waiting up to 36 weeks for an appointment at a long COVID clinic.⁴⁸ In addition, of more than 1,900 people referred to the clinics in Northern Ireland, just over 600 had had an appointment by June 2022.⁴⁹

There needs to be more consistent provision of long COVID care, so that people do not have to wait unacceptably long times to access care. In July 2022, NHS England announced an updated long COVID action plan for England, although at the time of writing this plan has not been published in full. The plan is said to include ambitions for all patients to have an initial assessment within six weeks, ensuring timely diagnosis and treatment.⁵⁰ While this ambition is welcome, it can only be achieved if there is sufficient resource and staffing, which is not a given as the announcement includes no new funding, beyond what has previously been announced.

In addition, an increased focus on providing proper multidisciplinary care for long COVID across the UK's health services is needed. This will be difficult given the overall staffing shortages they face. In England, the updated Long COVID Action Plan includes plans for patients to be referred to 'local one stop shops and mobile clinics' for tests.⁵⁰ Provided they are implemented well, such referrals have the potential to improve multi-disciplinary care provision, as well as take some pressure off GP practices. However, one stop shops and mobile clinics should both be truly multidisciplinary and properly resourced. Future workforce planning needs to take into account patient need and workforce trends and should be backed by independent assessments of need, including the emergence of new drivers of ill health such as long COVID.

In June 2021, the NHS announced it was establishing 15 specialist paediatric hubs in England for children suffering with long COVID to provide post-COVID care,⁵¹ but there are currently no specific long COVID services for children in Scotland, Wales or Northern Ireland.⁵² It is important that the NHS remains focused on how to improve long COVID treatment for children and to ensure appropriate services and support across the UK.

Despite the criticisms, there are some COVID-19 clinics that have been operating very successfully (see case study 2 below).

Case Study 2: A long COVID clinic in Southwest England

This clinic has been operational from January 2021, with approximately 500 referrals to the service to date. All long COVID patients are contacted rapidly, have a single point of contact and get a full multidisciplinary evaluation within six weeks of referral, and in most cases within a month.

The success of this service is dependent on pre-existing services that were able to flex and adapt to the change in service demand. For example, this region had already established community rehabilitation services and had an integrated (ME/CFS) Myalgic Encephalomyelitis/Chronic Fatigue syndrome multidisciplinary team in place, which was rapidly expanded and adapted to provide multidisciplinary input to people with long COVID.

There should be better ‘wider’ support for people with long COVID

Workers with long COVID who are unable to work need greater financial support

Many workers whose ability to work has been impacted by long COVID need better financial support. The most common symptom of long COVID, extreme tiredness, has left many people unable to carry out their jobs, with many having to go on sick leave.^{53,54}

In the ONS analysis of the impact of long COVID on adults in Great Britain, published in July 2021, 40% of those who said they were experiencing long COVID reported that it was negatively affecting their work.⁵⁵ Key workers are a group that have been disproportionately affected by this, due to greater exposure risks. The latest ONS data shows that, of the people living in private households with self-reported long COVID, who first had (or suspected they had) COVID-19 at least 12 weeks previously, 3.19% were health workers, 3.39% were teachers and 4.22% worked in social care; this compares to 2.24% of all people surveyed (from all other sectors).¹ (Issues regarding doctors with long COVID are discussed in the following section.)

SSP (Statutory Sick Pay) of £96.35 a week is available for up to 28 weeks for eligible people unable to work due to long COVID. The UK pays much less statutory sick pay compared to other countries. For example, in the majority of EU countries, the proportion of an individual's wages that are covered by sickness benefits varies between 70% and 100%, with countries such as Germany paying 100% of wages. The UK, in contrast, stands out for its low replacement rate of just 20% for the average worker. In addition, since the pandemic started, many countries (such as Germany, Portugal, and Sweden) have changed their regulations to increase mandatory sick pay for employees on sick leave due to COVID-19.^{56,57} Although many employers in the UK offer non-mandatory occupational sick pay above the statutory minimum, this is not the case for around a quarter (26%) of workers who receive only the minimum.⁵⁸ A higher proportion of these workers are in customer-facing occupations such as caring, leisure and service occupations.⁵⁹

The eligibility criteria for SSP also excludes the two million lowest paid workers in the UK, as workers need to be earning over £120 per week to be eligible;⁶⁰ and the 4.3 million self-employed workers in the UK (who are also not entitled to SSP).⁶⁰

As a recent employment tribunal found,⁶¹ long COVID may be classified as a workforce disability in line with the Equality Act 2010 if certain conditions are met. This could mean that, if symptoms are having a substantial adverse impact on an employee's ability to carry out day-to-day activities,

and the impairment has lasted or is likely to last 12 months, then employers would have a legal responsibility to make workplace adjustments, and occupational health physicians should advise on what reasonable adjustments can be made.⁶²

In order to ensure appropriate support for people unable to work due to long COVID, the UK Government should review the current support provided to workers whose ability to work has been impacted by long COVID. In addition, they should produce clear consistent information for employers on what support they are required to provide to employees with long COVID and guidance on how to implement support procedures.

Doctors and other health care professionals with long COVID need greater support and financial compensation

Many doctors and other health care professionals have been impacted by long COVID and need better support, including when they are unable to work due to their condition. As noted above, healthcare workers report higher levels of long COVID than the general population. In a study of health care workers, approximately a third (32%) of those who contracted COVID-19 during the first wave were still struggling to cope with persistent symptoms 3 – 4 months following the peak of the wave.⁶³ The BMA's February 2022 viewpoint survey of doctors, which surveys a sample of BMA members from all settings and specialties in England, Wales and Northern Ireland, found that (of those responding) 7.2% of doctors were currently experiencing symptoms of COVID-19 that had lasted longer than 12 weeks, with another 5.3% saying they had experienced this previously, but had since recovered.

Because of the debilitating effects of long COVID, many doctors were previously left, or remain, unable to work. Of the BMA survey respondents who currently or previously had long COVID, 20% had to take sick leave due to long COVID and 10% had worked reduced hours or had to reduce their responsibilities. Although NHSE publishes data on staff absences in the UK, including the reason (i.e. cold, cough, flu) and also data on absences related to COVID-19, this does not include staff who are absent due to long COVID specifically. However, based on FOI data from 70 NHS trusts in England, MPs on the APPG on Coronavirus found that the average trust had more than 100 staff absent with long COVID and lost more than 8,000 days in absences between March 2020 and September 2021.⁶⁴ While this data is for England only, it is likely that these staff absences due to long COVID are adding to the significant pressure on health services across the UK, which were already understaffed before the pandemic.

During the pandemic, the NHS introduced COVID-19 sickness pay provisions across the UK to ensure that when staff are absent with COVID-19 they received full pay.^{65,66,67,68} However, the implementation of COVID-19 and long COVID sick pay provisions has been inconsistent and the guidance for employers on providing sick pay for those impacted by long COVID is unclear.

This is particularly the case for primary care in England. During the pandemic, NHS England and NHS Improvement made additional funding available to GP practices, such as the General Practice COVID Capacity Expansion Fund. However, the guidance from NHSE/I on how this fund could be used to cover the cost of long COVID related sick pay in primary care was not clear, and provision of this fund (from CCGs, now replaced by ICS (Integrated Care Systems)) to practices to cover the costs of COVID-19 related sick pay has varied. This COVID-19 funding was not recurrent and has now ended, which limits how sick pay is provided in primary care. For example, GPs could apply for funding from their CCG for locum reimbursement, however this was only provided for a maximum of six months – thereafter, it was at the discretion of the CCG. In addition, as self-employed doctors, locums are not entitled to SSP (unless agreed with the provider) and sick pay provisions for partners can be dependent on individual partnership agreements.

Governments across the UK have now ended enhanced sick pay for secondary care NHS staff with COVID-19, meaning staff will revert to normal contractual sick pay arrangements. Staff currently away from work with a COVID-19 related illness will be subject to a transition period from July 7 to August 31. Staff that contracted COVID-19 after 7 July will not be eligible for any enhanced sick pay arrangements. This is a decision that the BMA has condemned.⁶⁹ It will prevent health care professionals from accessing appropriate and necessary remuneration and could result in staff being pressured into returning to work before they are fully recovered – causing significant risks to themselves and patients.

There is no consensus on the best approach for compensating doctors and health care professionals who are unable to work due to long COVID over the longer term, although a number of potential options have been proposed by different organisations. These include classifying long COVID as an occupational disease, which would mean doctors being able to claim Industry Injuries Benefit^g (a move which the BMA supports for the UK and which has recently been agreed by the European Union);⁷⁰ and including long COVID in the NHS injury allowance.^h

It has also been recommended by the APPG on Coronavirus that a separate long COVID compensation scheme should be established for key workers – a view that is supported by the BMA.⁷¹ The scheme must go beyond existing sick pay schemes and must be specific to those living with long COVID.⁷²

Regardless of which approach, or combination of approaches, is agreed, there is clearly a need for a better system for ensuring doctors – and other healthcare professionals – with long COVID receive appropriate financial support and compensation and that this must apply fairly to all areas of practice, including primary care.

While financial compensation is important, there should also be other measures in place to support doctors whose ability to work has been affected by long COVID. This could include mechanisms for doctors to be supported by occupational health physicians to find more flexible working arrangements so they can continue working in the NHS. There have been reports that some NHS staff, who have been off with long COVID, have struggled to secure the adjustments they need to make a successful return to work. Failures to provide appropriate support can lead to staff being lost to the NHS entirely.⁷³

Specific areas for action on long COVID

Long COVID is placing a considerable burden on people's lives, health and health services across the UK's nations. Although there are variations in the definition and prevalence of long COVID, it is affecting a considerable number of people in the UK and can be debilitating for sufferers. The vaccination programme has and will continue to reduce the risk of long COVID, but despite this, people are still at risk of developing long COVID (particularly during times of high transmission of COVID-19) and the risks and long-term impact of long Covid are not fully understood.

There needs to be more action on long COVID, to meet the rising demand of people suffering with long COVID in the UK. In particular, action is needed in the following areas:

- **Detailed data collection** – greater detail on the prevalence and presentation of long COVID needs to be collected to help accurately measure, report and monitor the number of people living with the condition. For example, a UK wide NHS data set which includes labelling of subtypes of long COVID, in order to plan service provision – specifically fatigue (ME type), cardiac/autonomic dysfunctionⁱ and post Intensive Care Unit syndrome. Currently the ONS data that is collected on long COVID is reliant on self-reporting of long COVID which does not include these factors.
- **Increased funding for research and infrastructure** – although there has been some investment into research for long COVID, the UK Government should increase this further to meet the scale of the challenge that long COVID presents in the UK. Research processes such as approvals pathways and implementing findings need to be streamlined.

g Payment from Department of Work and Pensions to support people who are ill or disabled from an accident or disease caused by work.

h A payment made by NHS employers to eligible staff that tops up sick pay, or earnings when on a phased return to work, to 85% of pay. Compensation can be 0%-100% salary.

i Autonomic dysfunction develops when the nerves of the automatic nervous system are damaged. Typical signs and symptoms include fast heart rate, low blood pressure, digestive system problems, disturbed bladder function and sweating regulation.

- **Preventing long COVID in children** – Governments should develop a campaign with more consistent messaging about long COVID, and clear information and guidance for parents regarding the benefits of vaccination for children and how this can protect children from long COVID.
- **Support for health professionals to identify and treat long COVID** – all health professionals should be supported and equipped with up-to-date information to ensure they understand the variable symptoms of long COVID and are aware of the available support and how to refer people to it.
- **Funding and resources to establish multidisciplinary services** – pathways for long COVID should focus on addressing patients' multisystem symptoms and rehabilitation needs and provide individualised care plans accordingly. There also needs to be more consistent provision of long COVID clinics, including for children, so that there is less variation in waiting times for treatment. Increased funding and independent workforce planning is key to the success of these services.
- **Improved financial and wider support for people unable to work due to long COVID**
The UK Government should provide employers with better guidance on how to support employees with long COVID. The UK Government should set up a taskforce to review the UK's statutory sick pay allowance and whether this should be increased so that it is in line with other OECD countries. It should also review its eligibility criteria for statutory sick pay, which currently exclude the self-employed and the lowest paid workers in the UK.
- **Improved support and compensation scheme for doctors and health care workers who have long COVID** – after being exposed to increased risk working on the frontline during the COVID-19 pandemic, there are now doctors and healthcare workers across the country living with the long-term, debilitating impacts of having caught the virus. The decision to end Special Covid Leave for NHS staff with Covid across the UK is completely unacceptable and will put patients and healthcare workers at significant risk. It is crucial that UK Governments reinstate this scheme until a longer-term compensation scheme is in place to support healthcare staff, who have risked their lives to look after others, and their families who are now living with long COVID.

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