

Research Briefing

31 October 2024

By Claire Duddy

Coronavirus: Long covid



Summary

- 1 Long covid: diagnosis and treatment
- 2 Research on long covid
- 3 Impact of long covid in the UK

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Summary

Some people who are infected by SARS-CoV-2, the virus that causes Covid-19, experience [symptoms after the acute stage of the illness has passed](#). Long covid is a term used to describe ongoing symptoms of Covid-19, or new symptoms that develop after a Covid-19 infection. People with long covid can experience a wide range of symptoms affecting different parts of the body. Research exploring the causes of the condition and potential treatment options is ongoing.

In March 2023, [an estimated 1.9 million people in the UK reported that they were experiencing long covid](#), representing 2.9% of the population. Of these, 1.3 million had symptoms that had lasted for more than a year and 762,000 had symptoms lasting for more than two years. Fatigue was the most common symptom (reported by 72% of those with long covid), followed by difficulty concentrating (51%), muscle ache (49%) and shortness of breath (48%).

Some groups of people are more affected than others. In this survey, the prevalence of long covid was higher for those with pre-existing health conditions than those without them. Long covid prevalence increased with age and level of socioeconomic deprivation and was slightly higher for women than men.

NHS guidance and services for long covid

The National Institute for Health and Care Excellence (NICE) published [guidance on managing the long-term effects of Covid-19](#) in 2020 and updated this guidance in November 2021. Its recommendations state that people presenting with symptoms of long covid should be offered guidance and support for managing their symptoms and may also be referred to a specialist.

In July 2022, NHS England published the [NHS plan for improving long covid services](#), which set out a strategy for establishing long covid services with access to specialist diagnosis, treatment and rehabilitation.

In March 2024 the government stated it had invested [£314 million to provide care for people with long covid](#) and has established over 100 specialised long covid services for adults, children and young people across England. Further information, including a list of NHS trusts providing specialist services, can be found on the [NHS England website](#).

Information about support available in Scotland can be found on the [NHS Inform website](#). The [Welsh Government website provides information on support available to people with long covid](#). Information on getting support for long covid in Northern Ireland is signposted on the [patient-facing NI Direct webpage on Covid-19](#).

Impact of long covid on healthcare, employment and education

Concerns about the impact of long covid on healthcare services centre on the cost of providing services for long covid patients and the impact of long covid on the NHS workforce. The British Medical Association, the trade union for doctors, has called for a range of measures, including [financial support and improved services for doctors and healthcare staff](#) affected by long covid.

The Society of Occupational Medicine has noted the [widespread impact that long covid has had on the workforce](#) (PDF) and called for organisations to review their absence management and flexible working practices to help support employees. The Advisory, Conciliation and Arbitration Service (Acas) has a guidance page [Whether long covid is a disability](#) that discusses this question in detail.

The Government has acknowledged that [long covid can affect children's school attendance](#) and that affected children may need additional support to access full-time education. Since the relaxation of restrictions on schools imposed during the height of the Covid-19 pandemic, there have been concerns about increased absence from school. The Library briefing [School attendance in England](#) provides more information on this topic.

Calls for greater recognition and support

Patients, charities and healthcare professionals have raised concerns about recognition and awareness of long covid, and difficulties in accessing appropriate medical assessments and support.

Patient-led support groups like [Long Covid SOS](#), [Long Covid Support](#), [Long Covid Kids](#) and [Long Covid Physio](#) have been established to provide information and help people affected by long covid. These groups work to highlight the impact of the condition and campaign for greater awareness of long covid, improved services and more research. These groups are also contributing evidence to the [UK Covid-19 Inquiry](#).

1 Long covid: diagnosis and treatment

Some people who are infected by SARS-CoV-2, the virus that causes Covid-19, experience [symptoms after the acute stage of the illness has passed](#).¹ The term long covid is used to describe symptoms that continue after 12 weeks, or new symptoms that develop after a Covid-19 infection. People affected by long covid can experience a wide range of symptoms affecting different body systems.

Long covid is a new condition that is still being studied. There is no consensus on the causes of long covid and why it affects some people and not others. There is currently no effective treatment for long covid. Recommended therapies usually focus on self-management and rehabilitation.

Multiple definitions and names for the condition have been used, including long covid, long-haul Covid, post-Covid-19 syndrome, post-Covid-19 condition, chronic Covid and post-acute sequelae of SARS-CoV-2 (PASC).² The terms 'long covid' and 'long-haul covid' were first used by patients who continued to experience symptoms after their initial infection.³

The Department of Health and Social Care (DHSC) has published [information on finding help and support if you have long covid](#).⁴

1.1 How is long covid diagnosed?

The National Institute for Health and Care Excellence (NICE) develops guidance for the health and social care sector in England and Wales. Working in collaboration with the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP) NICE has produced guidance covering the identification, assessment and management of the long-term effects of Covid-19.⁵ This guidance was last updated in November 2021.

In July 2022, NHS England published additional advice on long covid for healthcare professionals working in primary care settings, such as GP

¹ NHS, [Long-term effects of COVID-19 \(long COVID\)](#), 21 March 2023; NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

² National Institutes of Health (US), [Long COVID](#), 28 September 2023

³ Felicity Callard and Elisa Perego, [How and why patients made Long Covid](#), *Social Science and Medicine*, Vol 268, January 2021

⁴ Department of Health and Social Care, [Find help and support if you have long COVID](#), 29 March 2023

⁵ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

surgeries and pharmacies.⁶ This document summarises the NICE guidance and signposts professionals to resources for patients and educational materials.

This guidance applies in England, Wales and Scotland, and is signposted on the [patient-facing NI Direct webpage on Covid-19](#) in Northern Ireland.⁷

Defining long covid

The NICE guidance includes the following case definitions to help clinicians to identify and diagnose longer-term effects of Covid-19. It notes that the term 'long covid' is commonly used to describe both 'ongoing symptomatic Covid-19' and 'post-Covid-19 syndrome'.⁸

- Acute Covid-19: signs and symptoms of Covid-19 that last for up to four weeks
- Ongoing symptomatic Covid-19: signs and symptoms of Covid-19 that continue for between four and 12 weeks
- Post-Covid-19 syndrome: signs and symptoms that develop during or after an infection consistent with Covid-19, that continue for more than 12 weeks, and are not explained by an alternative diagnosis.⁹

The guidance outlines additional features of post-Covid-19 syndrome:

It usually involves clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.¹⁰

Other case definitions have been proposed. In October 2021, the World Health Organization (WHO) published [a clinical case definition of post-Covid-19 condition](#).¹¹ The definition proposed by WHO is similar to the definition adopted by NICE for post-Covid-19 syndrome:

Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on

⁶ NHS England, [Long COVID: Advice and resources for healthcare professionals in primary care](#), 28 July 2022

⁷ NI Direct, [Symptoms of respiratory infections including COVID-19](#), no date, accessed 21 December 2023

⁸ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

⁹ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

¹⁰ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

¹¹ WHO, [A clinical case definition of post COVID-19 condition by a Delphi consensus](#), 6 October 2021

everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.¹²

Symptoms

People with longer-term effects after a Covid-19 infection can experience a wide range of symptoms that can affect different parts of the body. These can include:

- Respiratory symptoms, such as breathlessness or a cough
- Cardiovascular symptoms, such as chest tightness or pain, or palpitations (a noticeable heartbeat, that may feel fast or irregular)
- Generalised symptoms, including fatigue, fever (a temperature over 38°C) or pain
- Neurological symptoms, including cognitive impairment (sometimes termed ‘brain fog’), headaches, disrupted sleep, peripheral neuropathy (pins and needles or numbness in the hands or feet), dizziness, delirium, mobility impairment or visual disturbances
- Gastrointestinal symptoms, including pain, nausea, vomiting, diarrhoea, weight loss and reduced appetite
- Musculoskeletal symptoms, such as joint or muscle pain
- Ear, nose and throat symptoms, such as tinnitus (hearing sounds that do not come from an outside source), earache, sore throat, the loss of taste and/or smell, nasal congestion (blocked nose)
- Dermatological symptoms, such as skin rashes or hair loss
- Psychological or psychiatric symptoms, such as depression, anxiety or symptoms of post-traumatic stress disorder (PTSD).¹³

The NICE guidance notes that clinicians should be aware that some symptoms are less common in children and young people. In particular, children may be less affected by respiratory symptoms (including shortness of breath and cough) and cardiovascular symptoms (including palpitations or pain).¹⁴

¹² WHO, [A clinical case definition of post COVID-19 condition by a Delphi consensus](#), 6 October 2021

¹³ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

¹⁴ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

Emerging research findings suggest that there may be several sub-types of long covid, based on common clusters of symptoms.¹⁵ For example, some patients primarily experience ongoing respiratory and cardiovascular symptoms, while others experience neurological symptoms.

Assessment and investigations

Before a diagnosis is made, NICE recommends that patients are assessed using a “holistic, person-centred approach”.¹⁶

This assessment should include taking a comprehensive clinical history (including the history of known or suspected Covid-19 infections and other health conditions) and examining the patient to assess their physical, cognitive, psychological and psychiatric symptoms, as well as their ability to carry out day-to-day tasks.¹⁷

The NICE guidance recommends that tests and investigations should be offered to patients based on their symptoms, with the aim of ruling out serious complications of Covid-19 infection and alternative diagnoses. These might include blood tests, exercise tolerance tests or chest x-rays (for continuing respiratory symptoms), or patients’ self-monitoring of heart rate, blood pressure, pulse oximetry, or ongoing symptoms.¹⁸

Referral to other services

When serious complications of Covid-19 and alternative diagnoses have been ruled out, the guidance recommends that clinicians should consider referring people to “an appropriate service, such as an integrated multidisciplinary assessment service”. A clinician could refer a patient to an assessment service at any time after four weeks have passed since the start of an acute Covid-19 infection.¹⁹

¹⁵ Trisha Greenhalgh and others, [Long COVID: a clinical update](#), The Lancet, Vol 404, No 10453, 17 August 2024; Trisha Greenhalgh and others, [Long covid – an update for primary care](#), British Medical Journal, Vol 378, 22 September 2022; Hao Zhang and others, [Data-driven identification of post-cute SARS-CoV-2 infection subphenotypes](#), Nature Medicine, Vol 29, 1 December 2022; Justin T Reese and others, [Generalisable long COVID subtypes: findings from the NIH N3C and RECOVER programmes](#), eBioMedicine, Vol 87, January 2023; Skyler Resendez and others, [Defining the Subtypes of Long COVID and Risk Factors for Prolonged Disease](#) [Pre-print], medRxiv, 21 May 2023; Felicity Liew and others, [Large scale phenotyping of long COVID inflammation reveals mechanistic subtypes of disease](#) [Pre-print], medRxiv, 12 June 2023; Liane S Canas and others, [Profiling post-COVID-19 condition across different variants of SARS-CoV-2](#), The Lancet Digital Health, Vol 5, No 7, July 2023.

¹⁶ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

¹⁷ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

¹⁸ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

¹⁹ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

The guidance is clear that a patient does not have to have had a positive Covid-19 test to be referred to another service or to receive specialist input or investigations.²⁰

In addition, the guidance recommends that patients should be urgently referred for psychiatric assessment if they have severe psychiatric symptoms or are at high risk of self-harm or suicide. For those with less severe psychiatric symptoms, anxiety or mood disorders, it recommends that clinicians consider referrals for psychological therapies or a liaison psychiatry service, depending on need.²¹

1.2 Management and rehabilitation

There are currently no known effective treatments that can cure long covid, although research on potential treatments is ongoing (see section 2). As a result, NICE guidance focuses on self-management and rehabilitation for people who are affected by the condition.

Advice and information about self-management should include advice about managing symptoms and information about relevant support services that patients may be able to access. The guidance also recommends that patients should be supported in discussions about returning to education or work.

Patients may also be offered:

- support from integrated and coordinated primary care, community, rehabilitation and mental health services
- referral to an integrated multidisciplinary assessment service
- referral to specialist care for specific complications.²²

Clinicians should discuss support and rehabilitation needs with patients, taking the impact of their symptoms and available local services into account. The guidance recommends that rehabilitation is delivered by a multidisciplinary team and that a personalised plan (including a discharge plan) is developed for each patient.

²⁰ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

²¹ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

²² NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

1.3

NHS services

The UK Government states it has invested £314 million to provide care for people with long covid, and has established over 100 specialised services for adults, children, and young people across England. These services assess people with long covid and direct them to appropriate support, treatment and rehabilitation services.²³

Further information, including a list of NHS trusts providing specialist long covid services, can be found on the [NHS England website](#).²⁴

The Department of Health and Social Care (DHSC) have also published [information on finding help and support if you have long covid](#).²⁵

NHS long covid services in England

In December 2021, the Health and Social Care Committee published its report [Clearing the backlog caused by the pandemic](#).²⁶ The committee considered evidence in relation to the number of people affected by long covid and availability of healthcare services. The report noted that some patients had been unable to access appropriate help and recommended that NHS England should publish a plan to deal with long covid:

We therefore recommend that NHS England publishes, before the end of this financial year, a long covid plan covering the period until 2023. The plan must be developed in consultation with a wide range of stakeholders, including patient groups. NHS England should integrate this into its wider health and care recovery plan, as long covid is likely to have implications for demand and workforce across a range of services.²⁷

In May 2022, the Government published its response, which stated:

NHS England will work with stakeholders, including patient groups, to develop and publish a new Long COVID Plan for 2022 to 2023 which considers the points raised by the HSC, and demonstrate how the plan relates to the overall NHS recovery plan.²⁸

In July 2022 NHS England published the [NHS plan for improving long covid services](#). This set out the NHS strategy for dealing with long covid, including

²³ Letter dated 18 December 2023 from Lord Markham to Baroness Merron regarding questions raised during the debate on Living in a COVID World: A Long-term Approach to Resilience and Wellbeing: those who are immuno- compromised, those suffering with long COVID ([Deposited Paper - DEP2023-1006 \(18 December 2023\)](#))

²⁴ NHS England, [Post-COVID syndrome \(long COVID\)](#)

²⁵ Department of Health and Social Care, [Find help and support if you have long COVID](#), 29 March 2023

²⁶ Health and Social Care Committee, [Clearing the backlog caused by the pandemic](#), 14 December 2021, HC 599

²⁷ Health and Social Care Committee, [Clearing the backlog caused by the pandemic](#), 14 December 2021, HC 599, p19

²⁸ DHSC, Government response to '[Clearing the backlog caused by the pandemic](#)' report from the [Health and Social Care Select Committee](#), 17 May 2022

the establishment of post-Covid services which provide access to specialist diagnosis, treatment, and rehabilitation. The plan also provided an update on progress made on the actions set out in the NHS long covid plan for 2021/22 and sets out the framework for deploying the funding committed by the NHS for long covid services during the 2022/23 financial year.

In December 2023, NHS England published [commissioning guidance for post-COVID services for adults, children and young people](#).²⁹ In March 2024, responsibility for commissioning long covid services was transferred from NHS England to local integrated care boards (ICBs). The commissioning guidance notes that these services should have a range of features, including multidisciplinary teams, symptom-based rehabilitation, referral to specialists, self-management plans and integrated peer support and social prescribing.³⁰

Services in Scotland, Wales and Northern Ireland

Information about support available in Scotland can be found on the [NHS Inform website](#).³¹ In September 2021 the Scottish Government published [Scotland's long covid service](#) setting out the key elements that underpin its approach to care and support for people with long covid.³²

The [Welsh Government website provides information on support available to people with long covid](#).³³

Information on getting support for long covid in Northern Ireland is signposted on the [patient-facing NI Direct webpage on Covid-19](#).³⁴

²⁹ NHS England, [Commissioning guidance for post-COVID services for adults, children and young people](#), 7 December 2023

³⁰ NHS England, [Commissioning guidance for post-COVID services for adults, children and young people](#), 7 December 2023

³¹ NHS Inform, [Long-term effects of COVID-19 – Your recovery](#)

³² Scottish Government, [Scotland's Long Covid service \(30 September 2021\)](#)

³³ Welsh Government, [Getting support for recovery from COVID-19 \(long COVID\)](#)

³⁴ NI Direct, [Symptoms of respiratory infections including COVID-19](#)

2

Research on long covid

Long covid is a new condition that is still being studied. There is no consensus on the causes of long covid or on the best treatments. Research on the causes and impact of long covid, and on potential treatment for the condition is ongoing in the UK and globally.

In October 2024, the Parliamentary Under-Secretary for Health and Social Care, Andrew Gwynne MP, drew attention to UK-funded research projects:

The Government has invested £58 million in research through two specific funding calls to better understand long COVID and how to treat it. The projects funded aim to improve our understanding of the diagnosis and underlying mechanisms of the disease and the effectiveness of both pharmacological and non-pharmacological therapies and interventions, as well as to evaluate clinical care. The NHS and scientific community are working at pace to progress long COVID research.³⁵

2.1

Major research studies

In the UK, the [National Institute for Health Research](#) (NIHR) and [UK Research and Innovation](#) (UKRI) have funded a range of studies to improve understanding of the condition.³⁶ Major studies include:

- [REACT Long COVID](#): this study is gathering data using surveys and interviews to help researchers understand experiences of long covid and why some people are affected by longer-term symptoms.³⁷ In October 2023, these researchers reported that persistent symptoms were associated with female sex, higher deprivation, pre-existing health conditions, more severe acute Covid-19 symptoms and being infected with the original “Wild-type” SARS-Cov-2 variant. The study also found that mental health and quality of life were worse among patients with ongoing symptoms.³⁸
- [The TLC Study](#): this research is using a digital app and tracking devices to collect information on patients’ symptoms and activity. The researchers aim to work with patients to develop effective support for

³⁵ PQ 9967 [on: [Long Covid: Medical Treatments](#)] 18 November 2024

³⁶ NIHR, [Researching long COVID: addressing a new global health challenge](#), 12 May 2022

³⁷ Imperial College London, [REACT Long COVID](#), no date, accessed 29 November 2023

³⁸ Christina J Atchison and others, [Long-term health impacts of COVID-19 among 242,712 adults in England](#), Nature Communications, Vol 14, 24 October 2023

particular groups of symptoms that can be delivered via an app or nurses.³⁹

- **Convalescence:** this study is using a variety of research methods to explore definitions of long covid, risk factors and consequences of the condition and how changes to GP patient records could improve diagnosis and management.⁴⁰ In 2022, the researchers reported that prolonged symptoms after Covid-19 were associated with female sex, white ethnicity, poor pre-pandemic health, obesity and asthma.⁴¹
- **STIMULATE-ICP:** this study is using a range of research methods to assess integrated care pathways for patients with long covid and to test common medicines to see if they are effective in treating long covid.⁴² In 2024, the researchers reported that long covid was associated with female sex, non-white ethnicity, obesity and pre-existing medical conditions, including anxiety and type 2 diabetes.⁴³ They have also proposed a model for integrated, multidisciplinary care for patients with long covid and similar conditions.⁴⁴
- **LOCOMOTION:** this study used a range of research methods to examine existing models of care for patients with long covid to develop a ‘gold standard’ for care in different settings. This will include developing and implementing guidelines and assessing the impact of long covid services.⁴⁵ In 2024, the researchers published their key findings, highlighting the importance of multidisciplinary care and involving people with lived experience in the design and evaluation of long covid services.⁴⁶

The NIHR have published an article providing more [details of ongoing and completed studies on long covid](#).⁴⁷ In addition, it has published two summaries of research evidence on long covid: [living with Covid19](#) and [living with Covid19 – Second review](#).⁴⁸

³⁹ University of Birmingham, [About the TLC Study](#), no date, accessed 19 September 2024

⁴⁰ University College London, [Convalescence long COVID study](#), no date, accessed 29 November 2023

⁴¹ Ellen J Thompson and others, [Long COVID burden and risk factors in 10 UK longitudinal studies and electronic health records](#), Nature Communications, Vol 13, 28 June 2022

⁴² STIMULATE-ICP, [About STIMULATE-ICP](#), no date, accessed 29 November 2023

⁴³ Han-I. Wang and others, [Prevalence, risk factors and characterisation of individuals with long COVID using Electronic Health Records in over 1.5 million COVID cases in England](#), Journal of Infection, Vol 89, No 4, 8 August 2024

⁴⁴ Christina M. van der Feltz-Cornelis and others, [Integrated care policy recommendations for complex multisystem long term conditions and long COVID](#), Nature Scientific Reports, Vol 14, 13 June 2024

⁴⁵ University of Leeds, [LOCOMOTION – Long COVID Study](#), no date, accessed 29 February 2024

⁴⁶ Julie Derbyshire and others, [Improving quality in adult long covid services: Findings from the LOCOMOTION quality improvement collaborative](#), Clinical Medicine, Vol 24, No 5, September 2024

⁴⁷ NIHR, [Researching long COVID](#), no date, accessed 29 February 2024

⁴⁸ NIHR, [Living with Covid19](#), 15 October 2020; NIHR [Living with Covid19 – Second review](#), 16 March 2021

Elsewhere, the European Commission (EC) has funded multiple research studies focused on long covid via the Horizon 2020 and Horizon Europe funding schemes.⁴⁹

Similar research is underway in the USA, via the Researching COVID to Enhance Recovery (RECOVER) Initiative, which is funded by the US National Institutes of Health (NIH).⁵⁰ In August 2023, as part of this initiative, the NIH launched a series of clinical trials, including a study to test the effectiveness of the anti-viral medication Paxlovid as treatment for long covid.⁵¹

The Evidence for Policy and Practice (EPPI) Centre regularly collate and publish summaries of research evidence on long covid to support the DHSC's work to develop policy and services.⁵²

2.2

Causes of long covid

Covid-19 and long covid are both relatively new conditions, and it is not yet known why some people experience long-term symptoms following an infection while others don't. A recent review of the published research evidence found that "[there are likely multiple, potentially overlapping, causes of long covid](#)".⁵³

Related emerging research findings suggest that there may be multiple subtypes of long covid associated with different symptoms and underlying causes.⁵⁴

Current theories about the biological mechanisms involved in long covid include:

- Persistent infection with the SARS-CoV-2 virus, which causes Covid-19

⁴⁹ European Commission, [Coronavirus research and innovation – Research on the post COVID-19 condition \(also known as “long COVID”\)](#), no date, accessed 29 November 2023

⁵⁰ NIH, [RECOVER: Researching COVID to Enhance Recovery](#), no date, accessed 29 November 2023

⁵¹ NIH, [NIH Launches Clinical Trials for Long COVID Treatments](#), 18 August 2023

⁵² EPPI Centre, [Quarterly scopes of the Long COVID literature: Systematic reviews on Long COVID and RCTs on Long COVID treatments](#), accessed 29 February 2024

⁵³ Hannah E Davis and others, [Long COVID: major findings, mechanisms and recommendations](#), Nature Reviews Microbiology, Vol 21, 13 January 2023

⁵⁴ Hao Zhang and others, [Data-driven identification of post-acute SARS-CoV-2 infection subphenotypes](#), Nature Medicine, Vol 29, 1 December 2022; Justin T Reese and others, [Generalisable long COVID subtypes: findings from the NIH N3C and RECOVER programmes](#), eBioMedicine, Vol 87, January 2023; Skyler Resendez and others, [Defining the Subtypes of Long COVID and Risk Factors for Prolonged Disease](#) [Pre-print], medRxiv, 21 May 2023; Felicity Liew and others, [Large scale phenotyping of long COVID inflammation reveals mechanistic subtypes of disease](#) [Pre-print], medRxiv, 12 June 2023; Liane S Canas and others, [Profiling post-COVID-19 condition across different variants of SARS-CoV-2](#), The Lancet Digital Health, Vol 5, No 7, July 2023

- Immune system problems, including the reactivation of other viruses that may be dormant in the body, or the development of an autoimmune response, where the body attacks its own systems
- Changes to the microbiota, the microorganisms that live on and in the human body
- Problems with blood clotting and changes to endothelial cells, which are found inside blood vessels
- Problems with the nervous system, including in the brainstem or vagus nerve, which carries signals between the brain, heart and digestive system.⁵⁵

2.3

Research into managing long covid

Research investigating potential treatment for long covid is diverse, reflecting the wide range of symptoms that long covid patients experience, and ongoing uncertainty about what causes the condition.⁵⁶ Research studies often focus on treatments for specific symptoms, such as breathlessness, ongoing loss of taste or smell, or fatigue.⁵⁷ Proposed treatments are based on pilot studies or on what has worked to treat similar symptoms in other diseases.

The NICE guidance on long covid includes specific recommendations for future research on management of the condition. These include research on:

- interventions like social prescribing and structured community support, and whether these are more or less effective for different groups of patients
- specific symptoms that should prompt a referral to a specialist
- different ways of delivering rehabilitation services to help improve patients' quality of life
- the effectiveness of exercise interventions and whether these are more or less effective for different groups of patients.⁵⁸

⁵⁵ Hannah E Davis and others, [Long COVID: major findings, mechanisms and recommendations](#), Nature Reviews Microbiology, Vol 21, 13 January 2023; Rubeshan Perumal and others, [Biological mechanisms underpinning the development of long COVID](#), iScience, Vol 26, No 6, 18 May 2023; Trisha Greenhalgh and others, [Long COVID: a clinical update](#), The Lancet, Vol 404, No 10453, 17 August 2024

⁵⁶ Hannah E Davis and others, [Long COVID: major findings, mechanisms and recommendations](#), Nature Reviews Microbiology, Vol 21, 13 January 2023

⁵⁷ Hannah E Davis and others, [Long COVID: major findings, mechanisms and recommendations](#), Nature Reviews Microbiology, Vol 21, 13 January 2023

⁵⁸ NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), NICE guideline [NG188], 25 January 2024

3 Impact of long covid in the UK

3.1 How many people are affected by long covid?

The Office for National Statistics (ONS) previously produced [estimates of the prevalence of self-reported long covid](#) in the UK, using data from the Covid-19 Infection Survey. Data collection for the survey ended in March 2023.⁵⁹

In March 2023, an estimated 1.9 million people in the UK were experiencing self-reported long covid, representing 2.9% of the population.⁶⁰ Of these, 1.3 million (69%) first had (or suspected they had) covid-19 least one year previously and 762,000 (41%) at least two years previously.

Of all people with self-reported long covid, 1.5 million (79%), experienced at least some limitation to their day-to-day activities as a result, and 381,000 (20%) reported that their day-to-day activities had been limited a lot.

Fatigue was the most common symptom (reported by 72% of those with long covid), followed by difficulty concentrating (51%), muscle ache (49%) and shortness of breath (48%).

More recently, a [Winter Coronavirus \(COVID-19\) Infection Study](#) was carried out in England and Scotland between November 2023 to March 2024. The participants in this study were a subset of those who had participated in the UK-wide study.

Findings from the winter 2023/24 study suggest that 2.0 million people in England and Scotland were experiencing long covid at the end of the study period, representing 3.3% of the population. Of these, it is estimated that 71% had symptoms lasting at least one year, 51% at least two years, and 31% at least three years. The ONS cautions that, due to methodological differences, these figures should not be directly compared with those from the UK-wide study.⁶¹

⁵⁹ A new Winter Covid-19 Infection Study is currently underway. UK Health Security Agency, [UKHSA and ONS launch new Winter COVID-19 Infection Study](#) [Press release], 2 October 2023

⁶⁰ ONS, [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK](#), 30 March 2023

⁶¹ ONS, [Self-reported coronavirus \(COVID-19\) infections and associated symptoms, England and Scotland: November 2023 to March 2024](#), 25 April 2024

Self-reported long covid

These survey-based estimates relate to self-reported long covid, as experienced by study participants, rather than clinically diagnosed cases in the full population. Self-reported long covid was defined as symptoms persisting for more than four weeks after the first (suspected) covid-19 infection that were not explained by something else.

The self-reported nature of long covid status means that misclassification is possible. For example, some survey participants may be experiencing symptoms because of another health condition unrelated to covid-19 infection. Others who do have symptoms caused by covid-19 may not describe themselves as experiencing long covid (for example, because of lack of awareness of the term or not knowing they were initially infected with covid-19).

Characteristics of people with long covid

Analysis of prevalence rates by various socio-demographic characteristics, using [data from the UK Covid-19 Infection Survey](#), suggests that some groups are more likely to experience long covid than others (see chart below).

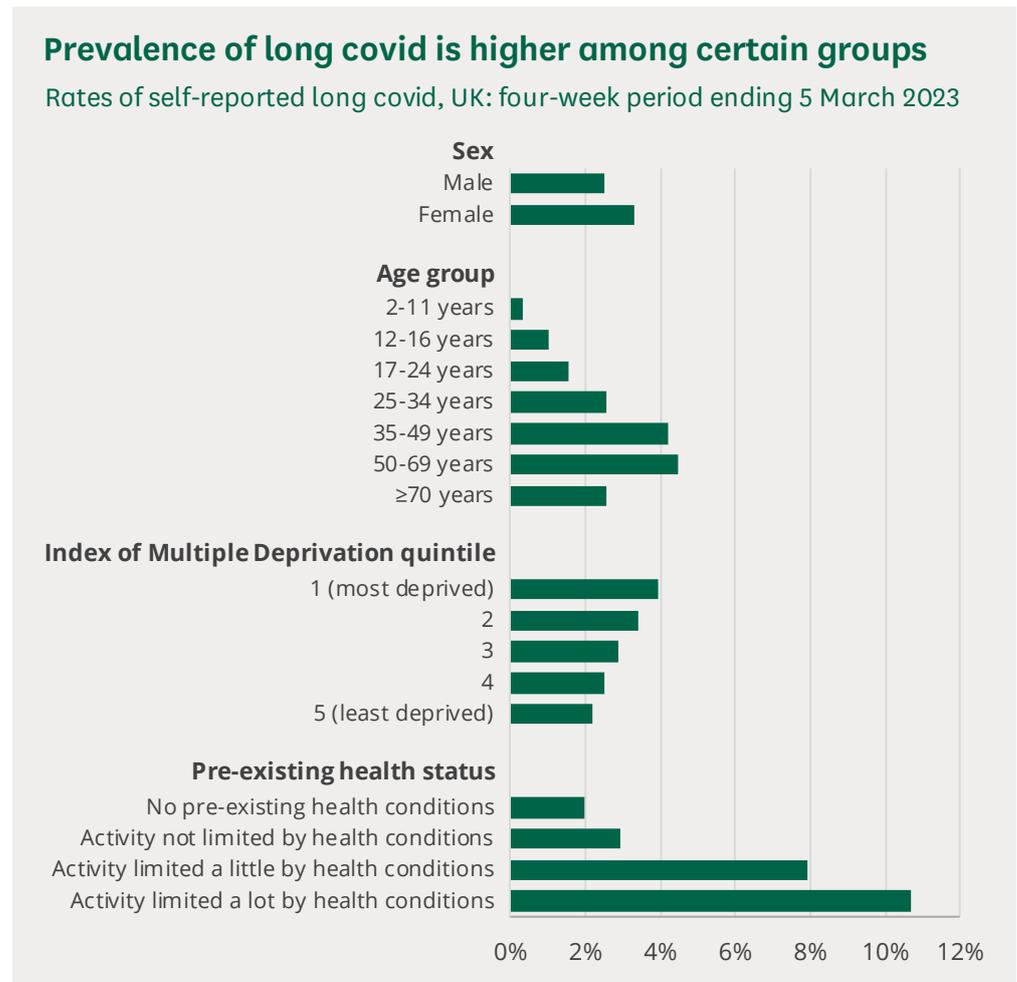
As a proportion of the UK population, the prevalence of self-reported long covid was greater among female respondents (3.3%) than male respondents (2.5%).

Prevalence rates were higher among people aged 35 to 49 (4.2%) and 50 to 69 (4.5%) than the general population (2.9%). Children and young people were least at risk, with rates in those under the age of 25 lower than in all other age groups.

The starkest difference was between people who had a self-reported, pre-existing health condition that affects their ability to carry out day-to-day activities, who were considerably more likely to experience long covid than those with a non-limiting health condition or no pre-existing conditions. Those whose activity was limited a lot by their pre-existing condition were most likely to experience long covid (10.7%).

Prevalence of self-reported long covid was higher among those living in the most deprived areas (3.9%), as measured by the Index of Multiple Deprivation, while those in the least deprived areas experienced the lowest rates (2.2%).⁶²

⁶² The Index of Multiple Deprivation is a measure of relative deprivation across small geographical areas that is created by combining measures that relate to different dimensions of deprivation (such as income, employment, health, education, crime, housing, and the living environment).



Source: ONS, [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK dataset](#), 30 March 2023, Table 4

A higher proportion of people in the White ethnic group reported experiencing long covid (3.0%) than people in the Black (1.7%) or Asian (2.4%) ethnic groups. It is not possible to make reliable comparisons with the Mixed or Other ethnic groups due to statistical uncertainty.

Prevalence rates were also higher among people working in social care (5.3%) and health care (4.4%) than in other employment sectors.

When comparing rates in the different regions and parts of the UK, prevalence was highest among those living in the North East of England (3.7%) and in Scotland (3.3%).

It is not possible to say whether these patterns are because of differences in the risk of getting covid-19 in the first place, or in susceptibility to experiencing long covid following a covid-19 infection.

Trends in the characteristics of those reporting long covid in the more recent [Winter Coronavirus Infection Study](#) in England and Scotland were similar to the trends seen towards the end of the UK-wide study.

3.2

How has long covid affected healthcare services?

Concerns about the impact of long covid on healthcare services centre on the cost of providing services for long covid patients and the impact of long covid on the NHS workforce.

Little evidence about the cost and burden of long covid for healthcare services has been published.

In January 2023, a BBC Panorama programme reported analysis that estimated that [between 5,000 and 10,000 NHS staff could be off sick with long covid](#) at that time.⁶³

In November 2023, researchers at the University of Birmingham published a modelling study that estimated that [primary care consultations in relation to long covid could cost over £23 million each year](#).⁶⁴

Long covid and healthcare workers

Organisations that represent healthcare professionals have also raised concerns about recognition of the condition and its impact, and support for those affected.⁶⁵

In July 2023, the British Medical Association (BMA), the doctors' trade union, published a report [Over-exposed and under-protected: the long-term impact of COVID-19 on doctors](#).⁶⁶ The report's findings were based on the results of a survey of 600 doctors experiencing longer-term effects of Covid-19. It highlighted the significant personal and professional impact of long covid. Notably, 18% of survey respondents reported that they were left unable to work, and others have reduced their working and/or training hours.⁶⁷

The BMA has called for a range of measures, including financial support and improved services for doctors and healthcare staff affected by long covid.⁶⁸ The BMA has also called for the condition to be recognised as an occupational disease for healthcare workers, for improvements in protection

⁶³ BBC News, [Thousands of NHS staff with long Covid risk losing their pay](#), 30 January 2023

⁶⁴ Jake Tufts and others, [The cost of primary care consultations associated with long COVID in non-hospitalised adults: a retrospective cohort study using UK primary care data](#), BMC Primary Care, Vol 24, No 245, 20 November 2023

⁶⁵ Adele Waters, [Long covid: the doctors' lives destroyed by an illness they caught while doing their jobs](#), British Medical Journal, Vol 382, 20 September 2023

⁶⁶ BMA, [Over-exposed and under-protected: the long-term impact of COVID-19 on doctors](#), 4 July 2023

⁶⁷ BMA, [Over-exposed and under-protected: the long-term impact of COVID-19 on doctors](#), 4 July 2023, p5-6

⁶⁸ BMA, [Long COVID: support for doctors](#), 16 January 2023

for healthcare staff and for support for those affected by long covid to safely return to work.⁶⁹

The Royal College of Nursing (RCN), a nurses union, has established a peer support group for nurses who developed the condition and provide advice for nursing staff in relation to sickness absence, returning to work and financial support.⁷⁰

NHS England have published guidelines for NHS managers and leaders to support NHS staff affected by long covid.⁷¹ The guidelines set out a range of support available for NHS staff who are experiencing symptoms of long covid. This includes training and guidance for teams and leaders as well as access to occupational health and local Employee Assistance Programmes.

In April 2024 NHS Employers published a [blog on supporting NHS staff with long covid](#), written by the co-chairs of the NHS Staff Council's Health, Safety and Wellbeing Group (HSWG). This looked at the resources and practical measures available to support healthcare workers experiencing long covid.⁷²

In January 2023, the British Medical Journal reported that the campaign group Long Covid Doctors for Action were preparing to take legal action to seek compensation for physical injuries and financial losses related to long covid.⁷³

3.3 Long covid and employment

A 2022 paper from the Society of Occupational Medicine noted the widespread impact that long covid was having on the workforce:

Long COVID symptoms that seem to have the greatest impact on work and return to work are fatigue, cognitive dysfunction (such as difficulty concentrating and memory loss), and changes in taste and smell.

[...]

Nearly half of employers have employees with Long COVID in the past 12 months and one in four employers now include Long COVID among their main causes of long-term sickness absence.⁷⁴

⁶⁹ BMA, [Long COVID: support for doctors](#), 16 January 2023

⁷⁰ RCN, [Long COVID](#), 4 October 2023

⁷¹ NHS England, [Guidelines for supporting our NHS people affected by Long COVID](#), 7 July 2022

⁷² NHS Employers, [Supporting NHS staff with long COVID](#), 26 April 2024

⁷³ Adele Waters, [Covid-19: Doctors instruct law firm in bid for compensation after developing long covid](#), 25 January 2024

⁷⁴ Society of Occupational Medicine, [Long COVID and Return to Work – What Works?](#) [PDF], August 2022, pp6&10

The paper concluded noting the challenges for employees with long covid returning to work, calling for organisations to review their absence management and flexible working practices to help support this:

Return to work (RTW) after prolonged sickness absence with Long COVID needs a tailored, long-term and flexible approach. A key difference between Long COVID and other conditions is the multifactorial nature of the condition and it is important to distinguish the specific health problems in each case.⁷⁵

ONS data from self-reported long covid outcomes shows that “working-age people are less likely to participate in the labour market after developing long COVID symptoms than they were before being infected with coronavirus (COVID-19).”⁷⁶

The House of Lords Economic Affairs Committee looked at the potential impact of long covid on the labour market in their December 2022 report [Where have all the workers gone?](#) The committee heard evidence on the employment impacts of long covid from a range of sources:

- John Burn-Murdoch, Chief Data Reporter at the Financial Times, noted that the ONS Labour Force Survey does not have a long covid category for people to report the type of health condition that has caused them to be economically inactive, requiring the condition to be listed under the “other” category.
- A July 2022 report from the Institute for Fiscal Studies think tank said the impact of Long covid was equivalent to 110,000 workers being off sick on any given day.
- A November 2022 report from think tank Demos and the Physiological Society concluded long covid was unlikely to be driving the increase in economic inactivity as they said it would be observed in other countries with high rates of infection during the pandemic.⁷⁷

The report concluded that further research on how long covid affects the workforce was required, saying:

The impact of long COVID-19 and NHS waiting lists on economic inactivity is unclear. We recommend that further work be carried out, as part of the Department for Work and Pension’s review into workforce participation, to understand the potential effect of NHS waiting lists and long COVID-19 on the labour supply.⁷⁸

⁷⁵ Society of Occupational Medicine, [Long COVID and Return to Work – What Works?](#) [PDF], August 2022, p19

⁷⁶ ONS, [Self-reported long COVID and labour market outcomes, UK: 2022](#), 5 December 2022

⁷⁷ House of Lords Economic Affairs Committee: [Where have all the workers gone?](#) 2nd Report of Session 2022-23, 20 December 2022 HL Paper 115, paras 43-45

⁷⁸ House of Lords Economic Affairs Committee: [Where have all the workers gone?](#) 2nd Report of Session 2022-23, 20 December 2022 HL Paper 115, para 59

Employment law protections

Under the Equality Act 2010, employers are prohibited from discriminating against any employees on the basis of protected characteristics, including disability.⁷⁹ Whether or not long covid counts in law as a disability has been a matter of discussion and legal challenge in recent years.

The Advisory, Conciliation and Arbitration Service (Acas) has a guidance page [Whether long covid is a disability](#) that discusses this question in more detail.⁸⁰ This notes that the legal definition of a disability, given in [section 6 of the Equality Act 2010](#), is an impairment that has a “substantial” and “long-term” adverse effect on someone’s “ability to carry out normal day-to-day activities”. “Long-term” in this case is generally taken to mean conditions which are likely to last at least 12 months or for the rest of the person’s life.⁸¹

In cases where long covid has a substantial effect on someone’s ability to carry out day-to-day activities and where it lasts or seems likely to last at least 12 months, it will be considered a disability in law. Whether or not it meets these definitions will vary from case to case. There have been some cases where employment tribunals have ruled that cases of long covid do meet the legal test for a disability and so should have been protected under the Equality Act.⁸²

Reasonable adjustments at work

Under the Equality Act 2010, employers are also obliged to make ‘reasonable adjustments’ in the workplace, to remove or reduce any disadvantage caused by a worker’s disability.⁸³

This can include physical changes to the workplace, changes to working arrangements, changes to policies or procedures or the provision of additional equipment, services or support.

More information about what might constitute reasonable adjustments is provided by Acas on their guidance page [What reasonable adjustments are](#). What counts as ‘reasonable’ must always be judged on a case-by-case basis, taking into account all the circumstances of the employer and the needs of the worker. In the case of long covid, Acas notes that:

Employers should focus on the reasonable adjustments they can make rather than trying to work out if an employee's condition is a disability.⁸⁴

⁷⁹ [Section 39, Equality Act 2010](#)

⁸⁰ Acas, [Whether long covid is a disability](#), 12 January 2024

⁸¹ Acas, [What disability means by law: Definition of disability](#), 8 January 2024

⁸² See for example [Mr T Burke v Turning Point Scotland: 4112457/2021](#)

⁸³ [Section 20, Equality Act 2010](#)

⁸⁴ Acas, [Whether long covid is a disability](#), 12 January 2024

Parliamentary debate on support for employees with long covid

Support for employees with long covid has been raised repeatedly in parliamentary questions since the pandemic. Two major themes have been what extra flexibility can be offered to workers with long covid, and what financial support is available to people unable to work due to long covid, particularly former key workers.

For example, on 8 March 2023, Fleur Anderson MP (Lab) asked whether the Government “has held discussions with employers on offering flexibility and part-time work to people with long Covid-19”.

The response from the Minister for Enterprise, Markets and Small Business Kevin Hollinrake was that the department had discussed a range of issues including managing employees with long covid, and noted plans to expand the right to request flexible working, some of which were being delivered by the [Employment Relations \(Flexible Working\) Act 2023](#).⁸⁵

On 24 February 2023, Deidre Brock MP (SNP) asked whether the Government would “make an assessment of the potential merits of establishing a hardship fund for keyworkers with long covid.”

In response, Department for Work and Pensions (DWP) minister Tom Pursglove noted the range of financial support already available to people who are unable to work for medical reasons, but said that the Government had no plans to introduce additional special support for key workers with long covid:

The DWP already offers financial support through Universal Credit and New Style Employment and Support Allowance for people who are unable to work due to long-Covid, subject to them satisfying the eligibility criteria and contribution conditions. In addition, people with Long-Covid may be eligible for Personal Independence Payment. This support is available regardless of keyworker status. The department is not currently planning to establish a hardship fund for keyworkers with Long-Covid.⁸⁶

Industrial Injuries Disablement Benefit

[Industrial Injuries Disablement Benefit \(IIDB\)](#) is a non-means-tested, tax-free, non-contributory benefit payable to people who have become disabled following an accident at work, or because of one of over 70 prescribed diseases known to be a risk from certain jobs.

Long covid is not currently prescribed as an occupational disease for the purposes of Industrial Injuries Disablement Benefit in the United Kingdom.

The [Industrial Injuries Advisory Council \(IIAC\)](#) is an independent statutory body that reviews the list of prescribed diseases and occupations and makes

⁸⁵ PQ 161437 (on [Employment: Long Covid](#)), 8 March 2023

⁸⁶ PQ 152239 (on [Key Workers: Long Covid](#)), 24 February 2023

recommendations to the Secretary of State for Work and Pensions on additions/changes to the list.

On 16 November 2022 IIAC published a report, [COVID-19 and Occupational Impacts](#). IIAC found "convincing and consistent evidence" of five serious pathological complications for health and social workers with long covid. These complications had been shown to cause persistent impairment and loss of function in some workers. Accordingly, IIAC recommended the following be added to the list of prescribed diseases allowing entitlement to IIDB:

- persisting pneumonitis or lung fibrosis (lung inflammation or scarring) following acute Covid-19 pneumonitis
- persisting pulmonary hypertension (high blood pressure in the lungs) caused by a pulmonary embolism developing between three days before and 90 days after a diagnosis of Covid-19
- ischaemic stroke developing within 28 days of a Covid-19 diagnosis
- myocardial infarction (heart attack) developing within 28 days of a Covid-19 diagnosis
- symptoms of Post Intensive Care Syndrome following ventilatory support treatment for Covid-19

These IIAC recommendations were limited to:

- workers in hospitals and other healthcare settings
- workers in care homes and care workers in patients' or clients' own homes working close to them in the two weeks prior to infection
- social workers visiting health facilities, hospitals, care homes and client homes⁸⁷

Ministers must now decide whether to accept IIAC's recommendations. A written answer on 6 March 2023 said that the [Department for Work and Pensions \(DWP\) was carrying out a detailed assessment of the report's recommendations](#) and that, once this work was complete, the department would provide a formal response.⁸⁸ It has not yet provided this formal response.

In the January 2024 minutes of the IIAC, a committee member asked DWP officials for an update on the Department's response to the November 2022 report. The minutes described the official's explanation that "a number of factors has had an effect on the work assessing the impact of the COVID

⁸⁷ Industrial Injuries Advisory Council, [COVID-19 and Occupational Impacts](#), CP 740, 16 November 2022

⁸⁸ PQ 152243 [on [Key Workers: Long Covid](#)], 6 March 2023

command paper, including having to lay additional regulations”, and went on to note that work would resume “sometime in the Spring”.⁸⁹

Debate about including long covid as a prescribed disease

IIAC’s 2022 report also noted there is an increasing scientific literature reporting a wide range of persisting symptoms following Covid-19 (‘long covid’ or ‘post-Covid syndrome’), which may affect daily activities including a person’s ability to work. It adds that “current understanding of the underlying pathophysiology, temporal course, and predictable effects of the key symptoms of Post-COVID syndrome is limited, as is the ability to diagnose the condition objectively.”

IIAC therefore considered there was not sufficient evidence at that time to recommend general prescription for long covid/post-Covid syndrome.

IIAC has continued to monitor the emerging evidence on long covid, and has been conducting further work examining further if it should be added as a prescribed condition for IIDB. This has yet to be published. The April 2024 minutes of the IIAC notes that a draft report includes the conclusion that “the Council is unable to recommend prescription for this condition at this time”.⁹⁰

3.4 Long covid and schools

There are two key pieces of guidance for schools in England on supporting children with medical conditions, including long covid:

- [Supporting pupils with medical conditions at school](#)
- [Education for children with health needs who cannot attend school](#)

Depending on the severity of a pupil’s condition, these are the key pieces of guidance schools should refer to when supporting their needs.

The Department for Education’s statutory guidance on [Working together to improve school attendance](#) provides more general information to support school attendance. The guidance emphasises that pupils who have medical conditions should be supported to access full-time education:

Some pupils face more complex barriers to attendance. This can include pupils who have long term physical or mental health conditions or who have special educational needs and disabilities (SEND). Their right to an education is the same as any other pupil and therefore the attendance ambition for these pupils should be the same as it is for any other pupil but additional support may need to be provided.⁹¹

⁸⁹ Industrial Injuries Advisory Council, [January 2024: IIAC Minutes](#), 11 January 2024, para 2.12

⁹⁰ Industrial Injuries Advisory Council, [April 2024: IIAC Minutes](#), 11 January 2024, section 3

⁹¹ Department for Education, [Working together to improve school attendance](#), August 2024, p23

In response to a question on long covid in December 2023, the then schools minister, Damien Hinds, emphasised the importance of regular attendance at school and acknowledged that pupils with long term medical conditions may require additional support to access full-time education. He stated:

The department recognises that some children may face barriers to attendance due to diagnosed medical conditions, such as long COVID. [...]

The department's new [attendance guidance](#) makes it clear that children with long term medical conditions may require additional support and that schools should provide this support where necessary to help them access their full-time education. This should include having sensitive conversations with pupils and parents, making reasonable adjustments where necessary, and considering additional support from external partners (including the local authority or health services). The department expects schools to work with families to develop specific support approaches for attendance and ensuring effective pastoral support is in place.

In some circumstances, pupils' symptoms may be so severe that they are unable to attend mainstream education. The guidance entitled 'Ensuring a Good Education for Children who cannot attend school because of health needs' sets out that a local authority must arrange suitable full-time education (or as much education as the child's health condition allows) for children of compulsory school age who, because of illness, would otherwise not receive suitable education.

Since the relaxation of restrictions on schools imposed during the height of the Covid-19 pandemic, there have been concerns about increased absence from school. The Library briefing [School attendance in England](#) provides more information on this topic.

3.5 Calls for greater recognition and support for long covid

Patients, charities and health care professionals have raised concerns about recognition and awareness of long covid, and difficulties in accessing appropriate medical assessments and support.

[Healthwatch](#) is a statutory body that aims to ensure that the views of people who use health and social care services are represented and shared with the Care Quality Commission, Department of Health and Social Care, NHS England and English local authorities. In 2022, Healthwatch published [a report on experiences of treatment for long covid](#).⁹² The report highlighted a lack of awareness and knowledge of the condition and support services amongst GPs, mixed experience of long Covid clinics and a lack of holistic support.⁹³

⁹² Healthwatch, [What people told us about Long Covid](#), 30 May 2022

⁹³ Healthwatch, [What people told us about Long Covid](#), 30 May 2022

Patient-led support groups have been established to provide information and help people affected by long covid. These groups work to highlight the impact of the condition and campaign for greater awareness of long covid, improved services and more research on the condition.

- [Long Covid SOS](#) is a charity that campaigns for greater recognition of long covid amongst health care professionals, employers and the wider public, and the UK Government.⁹⁴ The charity focuses on three aims: recognition, research and rehabilitation.
- [Long Covid Support](#) is a charity that provides peer support for people affected by long covid and their carers and advocates for the voice of patients in policy and research on the condition.⁹⁵
- [Long Covid Kids](#) is a charity that aims to represent and support children and young people with long covid and related illnesses, and their parents and caregivers.⁹⁶

Concerns have also been expressed about the NICE guidance on long covid. A number of healthcare workers with experience of long covid responded to the first iteration of the guidance (published in December 2020) in a comment piece for The Lancet. They expressed concern that the guidance did not adequately describe the condition or its causes. They stated:

The guideline is overly focused on self-management, psychological support, and rehabilitation, resulting in the potential for ‘watered-down’ versions of NHS long COVID clinics that do not provide thorough physical assessment of patients.⁹⁷

The UK Covid-19 Inquiry

The UK Covid-19 Inquiry is the independent public inquiry that is examining the UK’s response to and impact of the Covid-19 pandemic.⁹⁸

Groups representing patients affected by long covid, including the charities Long Covid SOS, Long Covid Support and Long Covid Kids have contributed evidence to the inquiry.

In September 2023, the three charities submitted a joint opening statement to module 2 of the inquiry. This module is focused on [UK decision-making and political governance](#).⁹⁹ The statement highlighted concerns about delayed

⁹⁴ Long Covid SOS, [Our Story](#), no date, accessed 17 November 2023

⁹⁵ Long Covid Support, [Our Charity](#), no date, accessed 17 November 2023

⁹⁶ Long Covid Kids, [Home](#), no date, accessed 17 November 2023

⁹⁷ Robin Gorna and others, [Long COVID guidelines need to reflect lived experience](#) [Comment], The Lancet, Vol 397, No 10273, 6 February 2021

⁹⁸ UK Covid-19 Inquiry, [About](#), no date, accessed 17 November 2023

⁹⁹ UK Covid-19 Inquiry, [Opening Statement on behalf of Long Covid Kids, Long Covid SOS and Long Covid Support](#), 26 September 2023

recognition of the longer-term effects of Covid-19 and raised six key questions about long covid:

1. What decision-makers' understanding of long-term sequelae and Long Covid was;
2. What was the role of patient advocacy in the recognition and response to Long Covid;
3. Was there data collection and modelling of Long Covid
4. Was the prevalence and the risk of Long Covid taken into account when decisions, like the imposition and then easing of non-pharmaceutical interventions, were adopted;
5. How - and to what extent - did decision makers warn the public about the risk of developing Long Covid and take the disease into account in public health communications; and
6. Whether nearly 2 million people suffering from Long Covid today was avoidable?¹⁰⁰

Module 3 of the inquiry is focused on the impact of Covid-19 on UK healthcare systems. The written evidence submitted to module 3 includes an expert report on the treatment of long covid.¹⁰¹ It also received a further statement from the Long Covid Core Participant Group, prepared by representatives of Long Covid Kids, Long Covid SOS, Long Covid Support and another charity, Long COVID Physio.¹⁰² This statement focused on the impact of long covid on patients and healthcare staff and invited the inquiry to make recommendations to increase the focus on the potential long term effects of any future pandemic, increase support for children and workers who contracted Covid-19 at work and improve research into long covid.¹⁰³

In a witness statement dated 4 October 2023, the former Health and Social Care Secretary, Matt Hancock, noted that he had received advice from the Chief Medical Officer about the potential longer-term effects of Covid-19 infection.¹⁰⁴ The statement goes on to describe a number of actions taken in

¹⁰⁰ UK Covid-19 Inquiry, [Opening Statement on behalf of Long Covid Kids, Long Covid SOS and Long Covid Support](#), 26 September 2023

¹⁰¹ UK Covid-19 Inquiry, [INQ000421758 – Expert report prepared for Module 3 of the Covid-19 Inquiry by Professor Chris F Brightling and Dr Rachael A Evans, titled ‘An expert report on the treatment of Long Covid’, dated 09/04/2024](#), 29 October 2024

¹⁰² UK Covid-19 Inquiry, [INQ000370954 – Witness Statement provided by Sammie McFarland, Dr Mark Faghy, Ondine Sherwood and Natalie Rogers on behalf of The Long Covid Core Participant Group, dated 28/11/2023](#), 30 October 2024

¹⁰³ UK Covid-19 Inquiry, [INQ000370954 – Witness Statement provided by Sammie McFarland, Dr Mark Faghy, Ondine Sherwood and Natalie Rogers on behalf of The Long Covid Core Participant Group, dated 28/11/2023](#), 30 October 2024

¹⁰⁴ UK Covid-19 Inquiry, [Witness Statement of Matt Hancock, Member of Parliament for West Suffolk, dated 04/10/2023](#), 1 December 2023, p1-5

relation to long covid, including internal discussions and investments in research and NHS services for long covid.¹⁰⁵

While giving evidence on 7 December 2023, the former Prime Minister Boris Johnson was asked what advice he had received about long covid during the pandemic and why he was sceptical of the seriousness of the condition. He said that he had asked for reports and information on long covid to help him to understand the condition and apologised for describing long covid as “bollocks” in a handwritten note in October 2020.¹⁰⁶

Boris Johnson denied that his “prolonged disbelief” in long covid contributed to a delay in its recognition. Asked if he accepted that the public were unable to protect themselves from long covid, he said:

No, I think that people were given plenty of advice to protect themselves from Covid, and as soon as we began to understand what Long Covid was and its risks, we also publicised the risks of Long Covid as well.¹⁰⁷

¹⁰⁵ UK Covid-19 Inquiry, [Witness Statement of Matt Hancock, Member of Parliament for West Suffolk, dated 04/10/2023](#), 1 December 2023, p1-5

¹⁰⁶ UK Covid-19 Inquiry, [Transcript of Module 2 Public Hearing on 07 December 2023](#), 7 December 2023, p41

¹⁰⁷ UK Covid-19 Inquiry, [Transcript of Module 2 Public Hearing on 07 December 2023](#), 7 December 2023, p42

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