



Department  
of Health &  
Social Care

# **Long COVID: emerging data and implications for health and care**

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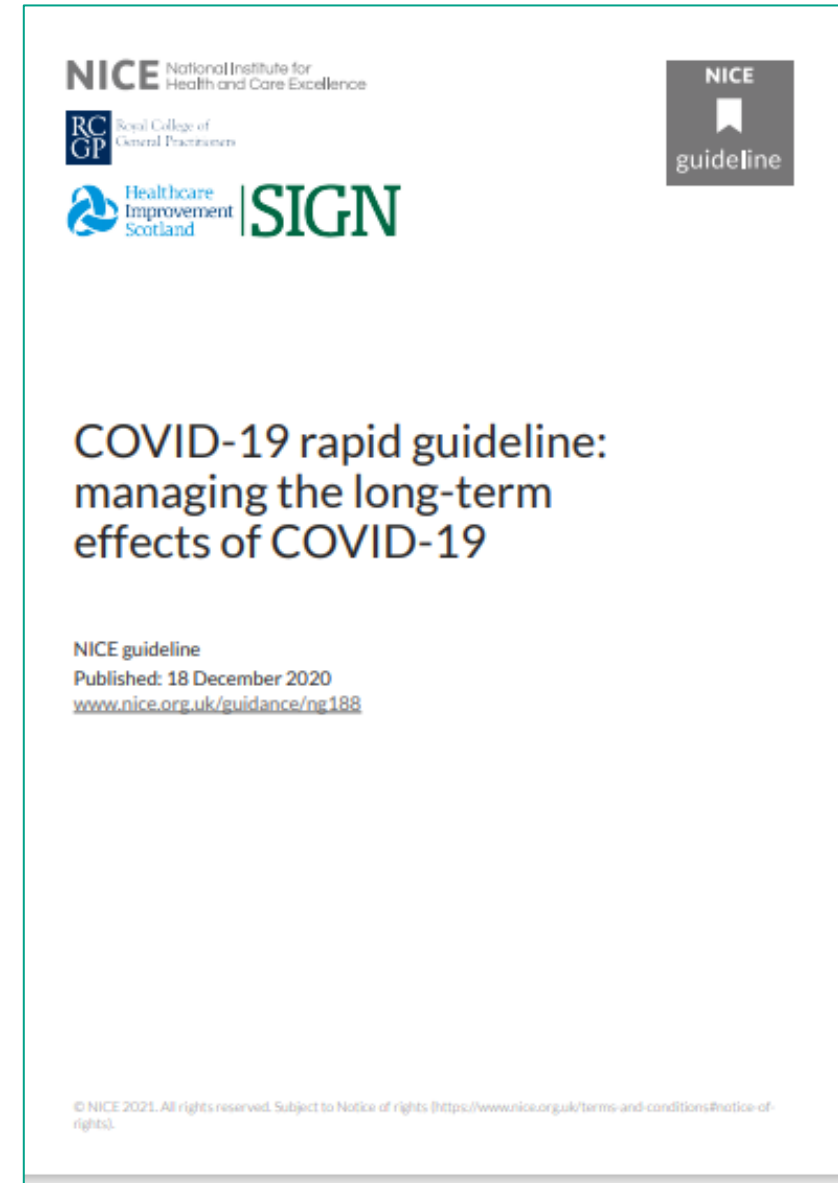
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# What is long COVID?

In its 2021 rapid guideline, NICE identified three phases post COVID-19 infection, the latter two of which are commonly used to describe long COVID:

- Acute COVID-19: signs and symptoms of COVID-19 for up to four weeks
- Ongoing symptomatic COVID-19 (signs and symptoms of COVID-19 for between 4 and 12 weeks)
- Post COVID-19 syndrome: signs and symptoms of COVID-19 that continue for more than 12 weeks and are not explained by an alternative diagnosis.

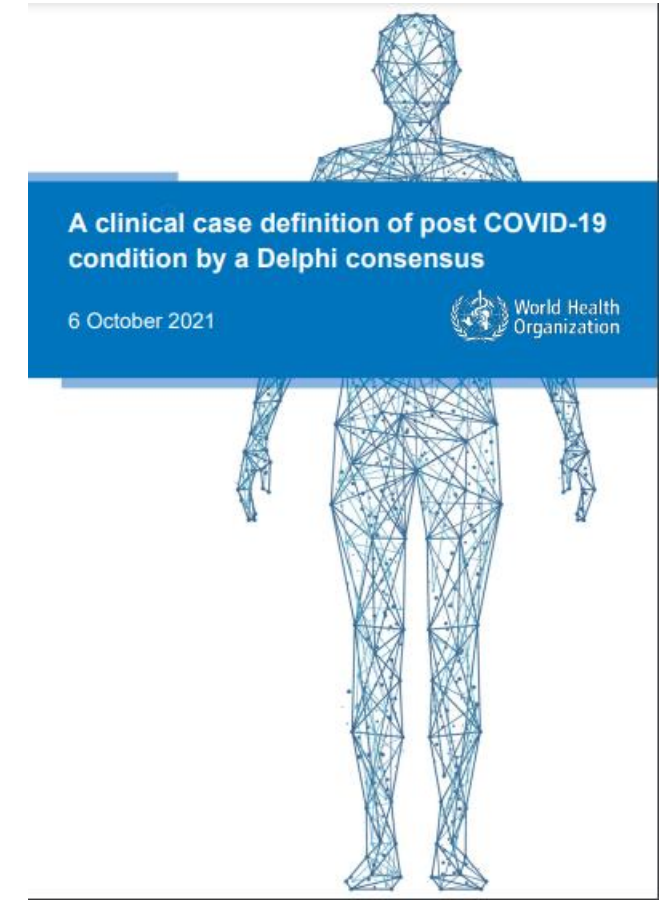
An update in November 2021 included new and amended recommendations on identification; planning care; multidisciplinary rehabilitation; follow up, monitoring and discharge; and service organisation. The list of common symptoms was updated, emphasising that these may be different for children.



# What is long COVID?

**On 6 October the WHO published its clinical definition of Post-COVID-19 condition**

*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 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 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. A separate definition may be applicable for children.*



# What is long COVID?

NIHR has suggested there may be multiple syndromes

- Post intensive care syndrome
- Post-viral fatigue syndrome
- Long-term COVID syndrome
- Permanent organ damage to heart and lungs

A Cochrane review into rehabilitation categorised the different stages of COVID-19 into sub categories of

- Acute
- Post-acute (continuing from the acute phase and its treatment)
- Permanent: unresolved or not solvable and causing a new health condition
- Late onset: appeared as a consequence of COVID-19 but after the end of the acute phase
- Impact of COVID-19 on people with a pre-existing health condition

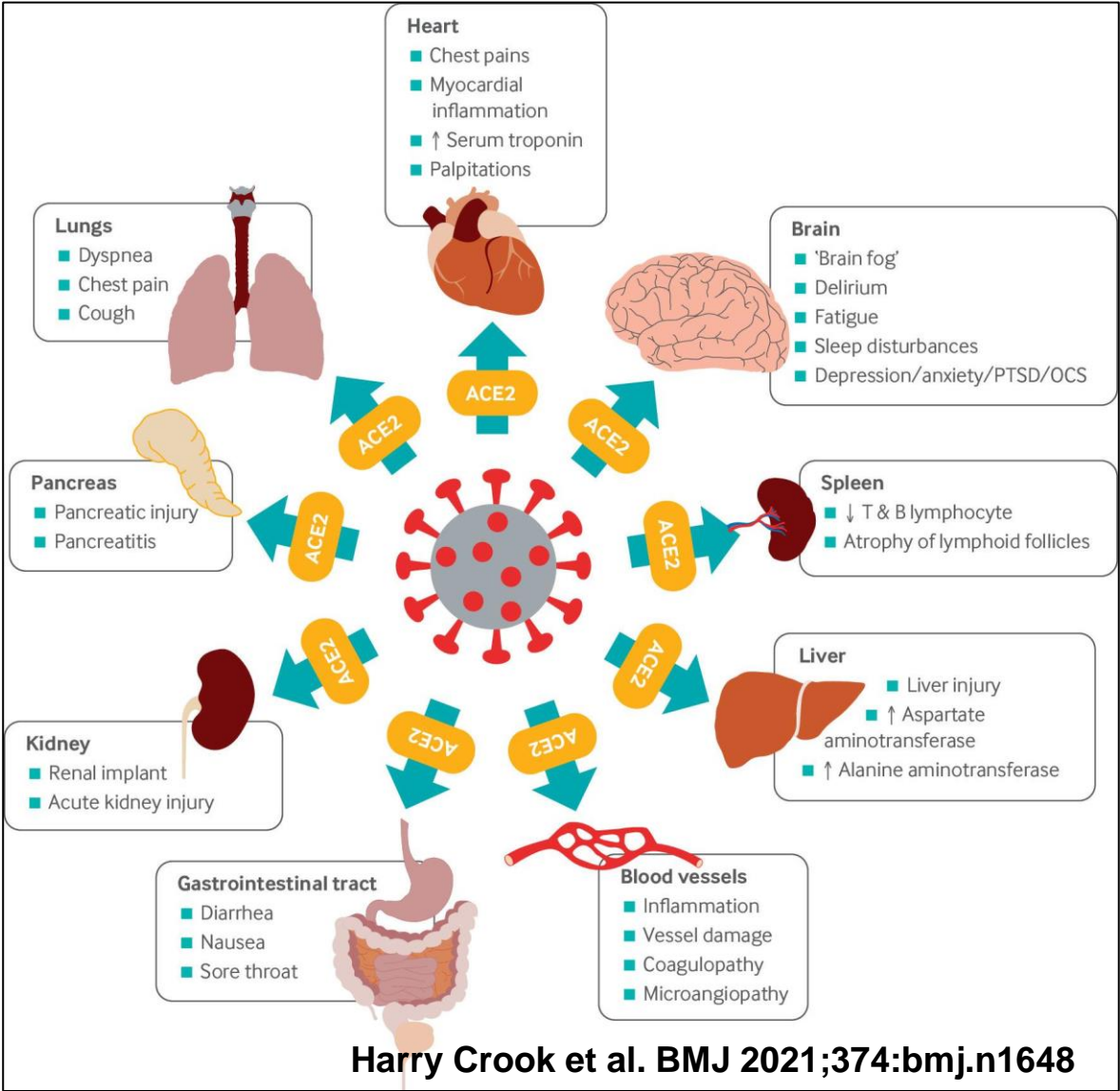
# Signs and symptoms of long COVID

Long COVID presents with clusters of symptoms, often overlapping and fluctuating.

Common symptoms can include fatigue, breathlessness, cough, fever, palpitations, chest tightness, pain, anxiety, loss of taste, loss of smell.

Long COVID patients report more than 200 different symptoms.

Some cardiac and respiratory symptoms are less common in children and young people than in adults



## Who does long COVID affect?

- Generally, long COVID cases follow (with a lag) the pattern of COVID-19 infections, nationally and regionally.
- Continuing symptoms are more prevalent in women, people living in deprived areas and those with an existing health condition or disability.
- The most deprived areas show The picture on age and other demographic factors is more mixed but suggestive of long COVID being more prevalent in middle age and white ethnicities.
- Those with long COVID in higher deprived areas are also more likely to have greater impacts on their daily activities.

# Severity of symptoms

- Symptom severity varies. Some people with self-reported long COVID have very minor symptoms which resolve over time; others experience debilitating symptoms which impact their daily lives.
- There is uncertainty as to the link between severity of initial COVID-19 illness and the severity or duration of long COVID symptoms. Mild infection does not mean a person will not experience long COVID.
- Also uncertain is the link between long COVID and hospitalisation
  - An NIHR evidence review suggests that around 10% of those not admitted to hospital with COVID-19 might experience at least one enduring symptom three months later. For those admitted to hospital, 50-89% might have at least one enduring symptom after two months
  - Recent data from PHOSP-COVID study suggest that the sequelae of a hospital admission with COVID-19 remain substantial one year after discharge across a range of health domains.
  - A minority of the non-hospitalised cohort will experience prolonged symptoms. With current daily case rates, this is a big enough number to pose additional public health challenges.
  - NHS long COVID assessment services are seeing people who initially had mild disease. Non hospitalised patients seen at UCLH had similar rates of onward specialist referral as post-hospitalised and post-emergency department groups.

# Long COVID Research

As a new disease, long COVID is an outcome of the pandemic that we don't yet completely understand.

The NHS and the wider scientific community have come together to work at an accelerated pace to better understand COVID-19, and the long-term impacts it may have.

£50m has been invested in a research programme to help address the physical and mental health effects of long COVID:

- £8.4 million in the 10,000 participant Post-HOSPitalisation COVID-19 study (PHOSP-COVID) being carried out at the University of Leicester. This study is one of the world's largest comprehensive research studies of previously hospitalised patients and will enable the study of novel interventions within the rehabilitation pathway.
- £18m of funding given to four research studies to better understand and address the longer-term effects of COVID-19 on physical and mental health. The studies will examine the causes, consequences and treatment of long COVID.
- A further £19.6m given to 15 research studies to accelerate development of new ways to diagnose and treat long COVID, as well as how to configure healthcare services to provide the best care.



# Research: the impact of vaccines

Evidence on the effectiveness of vaccines in protecting against, or helping to resolve, long COVID symptoms is still emerging.

- Research using self-reported data from Zoe app users (aged 18-60+) suggests that two vaccine doses reduces by half the risk of developing symptoms for more than 4 weeks (overall, 5% in double-vaccinated vs 11% in not vaccinated).
- A US study found that vaccination led to a reduction of many (but not all) long COVID symptoms
- A French study also found that vaccination lowers the severity and life impact of long COVID at 120 days amongst patients with persistent symptoms
- An ONS study analysing the relationship between COVID-19 vaccination and self-reported long COVID in 28,356 people in the UK who caught SARS-CoV-2 before being vaccinated, reported a sustained improvement of Long COVID symptoms after the second vaccine dose during a median follow up period of 67 days.
- Surveys of patient support group members also suggest a majority (56.7%) experienced improvement in symptoms following vaccination
- We do not yet have evidence available with regards to the impact of boosters, vaccination in children, and around impact on the Omicron variant.

# Research: long COVID in children and young people

- While less common than in adults, children and young people are affected by long COVID.
- Many studies conducted to date lack a control group, making it hard to separate symptoms due to infection from other pandemic effects.
- The CLoCK (children and young people with long COVID) Study is the largest study of symptoms post-COVID to date.
- Early findings suggest that up to one in seven children and young people who had COVID-19 may have symptoms linked to the virus 15 weeks later, compared to a matched control group.
- CLoCK researchers identified two classes, characterised by “few” or “multiple” symptoms at 15 weeks. The less common “multiple” class were more likely to be female, older, with poorer baseline physical and mental health, and to experience issues with mobility, self-care and usual activities.
- No differences were found in mental health, wellbeing and fatigue scores between the test-positive and test-negative cohorts studied.

# Research: long COVID treatment

While treatments are available to help manage some of the symptoms of long COVID, given its complex and multi-system nature, there is as yet no evidence on effective pharmacological treatments for the condition.

Clinical trials are underway:

- STIMULATE-ICP (Symptoms, Trajectory, Inequalities and Management: Understanding long-COVID to Address and Transform Existing Integrated Care Pathways) will work out what long COVID is, how to diagnose it and how to manage it. Within this research programme, another trial will test different drugs, such as aspirin and colchicine, to measure effects of three months treatment on symptoms, mental health, return to work and other important outcomes.
- HEAL-COVID (HElping to Alleviate the Longer-term consequences of COVID-19) is a clinical trial to compare different treatments to determine whether they can improve the longer-term outcomes of post-hospitalised patients across the UK.

There are a range of self-management tools available for patients with advice on managing symptoms, including Your Covid Recovery and NHS.UK

# An international perspective

- There is increasing attention being paid globally to long COVID
- More countries are beginning to see higher levels of public and political interest in tackling long COVID, as local prevalence increases.
- Strategies to address long Covid vary significantly:
  - Research outside the UK is primarily aimed at understanding the prevalence, causes, common symptoms and treatments for long Covid
  - Fewer studies are considering associated risk factors and socio-economic effects.
  - A number of countries have begun to adapt healthcare provision to provide long COVID services. Given the difference in healthcare systems, comparing the efficacy of different service models is not possible.