



COVID-19 guideline scope: managing the long-term effects of COVID-19

NHS England and the Chief Medical Officer of the Scottish Government asked NICE and SIGN to develop a guideline on the long-term effects of COVID-19. This UK-wide guideline is developed collaboratively by NICE, SIGN and the RCGP.

We acknowledge that there is still uncertainty in what is known about the long-term effects of COVID-19. Therefore, this guideline is being developed using a 'living' approach, which means that targeted areas of the guideline (including the case definition) will be continuously reviewed and updated in response to a developing and emerging evidence base.

1 Case definitions

For the purposes of this guideline, we will be using the terms described below to define the effects of COVID-19 at different time points. These definitions will be continuously reviewed as evidence emerges and we begin to understand more about the long-term effects of COVID-19.

Acute COVID-19 infection

Signs and symptoms of COVID-19 for up to 4 weeks.

Ongoing symptomatic COVID-19

Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks.

Post-COVID-19 syndrome

Signs and symptoms that develop during or following an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with 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.

In addition to the clinical case definitions, the term 'long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).

Rationale for the case definition of post-COVID-19 syndrome

Post: Signs and symptoms that continue after the acute phase of COVID-19. This does not assume that the COVID-19 illness is over or that people have recovered, but the acute phase has usually ended.

COVID-19: The person was diagnosed with COVID-19 based on clinical symptoms with or without a positive SARS-CoV-2 test (PCR, antigen or antibody). This clinical diagnosis can be made retrospectively based on symptoms alone for those who self-managed their acute illness.

Syndrome: Signs or symptoms that exist together. People may have 1 or more ongoing symptoms and still be included in the definition.

12 weeks: Recovery from any infective illness can take time. Although some studies address prevalence, these are subject to bias and the prevalence of COVID-19 symptoms at different time points remains unclear. The 12-week time period used for the purposes of this guideline has been developed by consensus and aligns with other related guidance on appropriate follow-up and discharge.

Clusters: Signs and symptoms may arise from any system in the body, often overlap, and may change over time. This includes but is not limited to the cardiovascular, respiratory, gastrointestinal, neurological, musculoskeletal, metabolic, renal, dermatological, otolaryngological, haematological and autonomic systems, in addition to psychiatric problems, generalised pain, fatigue and persisting fever.

2 Who the guideline will cover

Recommendations in the guideline will cover:

Adults, young people and children diagnosed with COVID-19, based on clinical signs and symptoms, with or without a positive SARS-CoV-2 test (PCR, antigen or antibody) whose symptoms continue for more than 4 weeks from the start of an [acute COVID-19 infection](#).

3 Who the guideline is for

The guideline will be of interest to:

- Health and social care practitioners, commissioners and providers of NHS-funded healthcare services
- People using services, their families and carers.

It may also be relevant to:

- providers of private healthcare services
- third-sector organisations
- people developing digital technologies to manage the long-term effects of COVID-19.

4 Equality considerations

An [equalities impact assessment](#) was carried out during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities relating to accessing healthcare services and prevalence of ongoing symptoms in different population groups.

5 Proposed themes and questions

This section lists the proposed key themes and questions that we will consider when developing the guideline. We will look at evidence in these areas when developing the guideline, but it may not be possible to make recommendations in all areas. This section also lists themes that will be excluded; these are outside the scope of the guideline, and we will not look at evidence in these areas.

Key themes

- Case definition
- Investigation and assessment
- Management and rehabilitation
- Referral
- Service organisation
- Lived experience
- Inequalities

Key questions

- Case definition
 - What is the trajectory of post-COVID-19 syndrome? Does this differ based on patient characteristics? For example, age, sex, ethnicity, comorbidities, severity of acute COVID-19
 - Are fluctuating symptoms and episodes of disability features of post-COVID-19 syndrome? Does this differ based on patient characteristics? For example, age, sex, ethnicity, comorbidities, severity of acute COVID-19
- Investigation and assessment
 - What risk factors are associated with developing post-COVID-19 syndrome?
 - What is the prevalence of symptoms or clusters of symptoms (physical and mental health) and problems of functioning and disability (as defined by the [World Health Organization's International classification of functioning, disability and health](#)) among people who have symptoms of COVID-19 for 4 to 12 weeks?

- What is the prevalence of symptoms or clusters of symptoms (physical and mental health) and problems of functioning and disability among people who have symptoms of COVID-19 beyond 12 weeks?
- What investigations should be carried out to determine appropriate management or treatment of symptoms?
- Management and rehabilitation
 - What pharmacological and non-pharmacological interventions (including but not limited to vaccines, olfactory training and breathing techniques) improve ongoing physical and mental health symptoms and problems of functioning and disability following acute COVID-19?
 - What monitoring is helpful to assess deterioration or recovery in people with ongoing physical and mental health symptoms and problems of functioning and disability following acute COVID-19?
- Referral
 - What symptoms or signs indicate that referral to specialist care is needed for assessment or management of post-COVID-19 syndrome?
 - Which signs and symptoms in people with ongoing symptoms or post-COVID-19 syndrome may be exacerbated by rehabilitation and need further assessment before a referral is made?
 - What are the barriers to, and facilitators of, timely referral to specialist care?
- Service organisation
 - What components should be included in a service model for the delivery of services to adults, children and young people with post-COVID-19 syndrome?
- Lived experience
 - What are the views and experiences of people, their families and carers about:
 - signs and symptoms of post-COVID-19 syndrome?
 - access to services?
 - how their symptoms were assessed?
 - management of symptoms and rehabilitation?
 - the patient care pathway?
 - information and support provided?

Themes to be excluded from the evidence search

- Management of acute COVID-19 (symptoms experienced for up to 4 weeks)
- Management of other conditions with similar features to post-COVID-19 syndrome, for example post-intensive care syndrome and myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS)
- Management of end-organ damage, which already has defined pathways of care.

6 Related NICE and SIGN guidance

Table 1 lists related NICE and SIGN guidance (both published and in development) and any overlaps with this guideline.

Table 1 Related NICE and SIGN guidance and overlaps

| Guidance title | Publication date | Nature of overlap | What NICE plans to do |
|---|------------------|--|--|
| NG191 COVID-19 rapid guideline: managing COVID-19 | March 2021 | General advice on managing COVID-19 symptoms and managing breathlessness | Ensure links/signposting between guidance |
| NG116 Post-traumatic stress disorder | December 2018 | Recognition of PTSD, assessment and care of people with PTSD. May be relevant for people with post-COVID-19 syndrome | Ensure links/signposting between guidance |
| QS158 Rehabilitation after critical illness in adults | September 2017 | May be overlap with rehabilitation goals | Assess overlap and determine if signposting or review of quality statements needed |
| NG74 Intermediate care including reablement | September 2017 | May be overlap with some assessment and reablement principles | Assess overlap and determine if signposting or review of recommendations needed |
| CG83 Rehabilitation after critical illness in adults | March 2009 | May be overlap with some recommendations on principles of rehabilitation | Assess overlap and determine if signposting or review of recommendations needed |
| SIGN Decision Support Tool Assessment of COVID-19 in primary care | February 2021 | General advice on identifying and triaging patients presenting with potential COVID-19 | Ensure links/signposting between guidance |

7 About COVID-19 rapid guidelines

Both NICE and SIGN have published COVID-19 rapid guidelines containing recommendations on managing known or suspected COVID-19.

NICE COVID-19 rapid guidelines include general measures to reduce exposure to infection and areas of the patient pathway where management will be different because of COVID-19.

They do not generally include recommendations on:

- staff training needed to deliver care if workforce capacity is reduced
- procuring, distributing and using personal protective equipment
- procuring and distributing COVID-19 tests.

SIGN COVID-19 rapid guidelines have been developed in response to the COVID-19 pandemic situation and do not follow the standard process used by SIGN to develop guidelines. The recommendations are based on available evidence and expert opinion, with fast expert peer review as assurance.

© NICE 2021. All rights reserved. Subject to [Notice of rights](#).