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Health and Care Excellence

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 Healthcare
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Scotland | **SIGN**



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

NICE guideline

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The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

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Overview

This guideline covers identifying, assessing and managing the long-term effects of COVID-19, often described as 'long COVID'. It makes recommendations about care in all healthcare settings for adults, children and young people who have new or ongoing symptoms 4 weeks or more after the start of acute COVID-19. It also includes advice on organising services for long COVID.

This guideline has been developed jointly by NICE, the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP).

To develop the recommendations, we have used the following clinical definitions for the initial illness and long COVID at different times:

- **Acute COVID-19:** signs and symptoms of COVID-19 for up to 4 weeks.
- **Ongoing symptomatic COVID-19:** signs and symptoms of COVID-19 from 4 to 12 weeks.
- **Post-COVID-19 syndrome:** signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.

When using this guideline, follow the usual professional guidelines, standards and laws (including those on equalities, safeguarding, communication and mental capacity), as described in [making decisions using NICE guidelines](#).

Who is it for?

- Health and care practitioners
- Health and care staff involved in planning and delivering services
- Commissioners

Guideline development process

We are using a 'living' approach for the guideline, which means that targeted areas will be continuously reviewed and updated in response to emerging evidence.

We developed this guideline using the interim process and methods for guidelines developed in response to health and social care emergencies.

Context

This guideline has been developed collaboratively by NICE, the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP). It covers care for people who have signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 4 weeks and are not explained by an alternative diagnosis.

This new and emerging condition, which has been described using a variety of terms including 'long COVID', can have a significant effect on people's quality of life. It also presents many challenges when trying to determine the best-practice standards of care based on the current evidence. There is no clinical definition or clear treatment pathway, and there is a minimal, though evolving, evidence base. This guideline provides clinical definitions of the effects of COVID-19 at different times (see below). It also provides advice on diagnosis and management based both on the best available evidence and the knowledge and experience of the expert panel.

NICE, SIGN and the RCGP have developed the guideline using a 'living' approach, which means that targeted areas of the guideline will be continuously reviewed and updated in response to emerging evidence.

Terms used in the guideline

To effectively diagnose, treat and manage a condition it needs to be defined and distinguished from other conditions. A set of definitions has been used to distinguish 3 phases following infection consistent with COVID-19, and to define the term 'long COVID'. These phases are defined below.

Acute COVID-19

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 after 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.

Long COVID

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).

For more information about these definitions see the [rationale for terms used in the guideline](#).

1 Identifying people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome

These recommendations are for healthcare professionals caring for people who have had suspected or confirmed [acute COVID-19](#) and present to any healthcare setting, irrespective of whether they were hospitalised or had a positive or negative SARS-CoV-2 test (PCR, antigen or antibody).

- 1.1 Give people who have had suspected or confirmed acute COVID-19 (and their families or carers, as appropriate) advice and written information on:
- the most common new or ongoing symptoms after acute COVID-19 (see [the section on common symptoms of ongoing symptomatic COVID-19 and post-COVID-19 syndrome](#))
 - what they might expect during their recovery, including that:
 - recovery time is different for everyone but for many people symptoms will resolve by 12 weeks
 - the likelihood of developing [ongoing symptomatic COVID-19 or post-COVID-19 syndrome](#) is not thought to be linked to the severity of their acute COVID-19 (including whether they were in hospital)
 - if new or ongoing symptoms occur they can change unpredictably, affecting them in different ways at different times
 - how to self-manage ongoing symptomatic COVID-19 or post-COVID-19 syndrome (see the [recommendations on self-management](#) and supported self-management)
 - symptoms to look out for that mean they should contact their healthcare professional
 - who to contact if they are worried about new, ongoing or worsening symptoms, especially if they have them more than 4 weeks after the start of acute COVID-19.
- 1.2 Provide all information in accessible formats so that people can understand and take part in decisions about their care. Follow relevant national guidance on communication, providing information (including different formats and languages) and shared decision making, for example, [NICE's guideline on patient](#)

experience in adult NHS services.

- 1.3 Suspect previous COVID-19 illness as a possible underlying cause of new or ongoing symptoms in people after acute COVID-19 as follows:
 - ongoing symptomatic COVID-19 if people present with symptoms 4 to 12 weeks after the start of acute COVID-19 or
 - post-COVID-19 syndrome if the person's symptoms have not resolved 12 weeks after the start of acute COVID-19.
- 1.4 For people who are concerned about new or ongoing symptoms 4 weeks or more after acute COVID-19, offer an initial consultation and use shared decision making to discuss and agree with the person whether it should be by video, phone or in person.
- 1.5 Consider using a screening questionnaire as part of the initial consultation to help capture all of the person's symptoms. These should only be used in conjunction with clinical assessment.
- 1.6 Be aware that some people (including children and older people) may not have the most commonly reported new or ongoing symptoms after acute COVID-19.
- 1.7 Based on the initial consultation, use shared decision making to discuss and agree with the person whether they need a further assessment and whether this should be by phone, video or in person. Take into account whether they may have symptoms that need investigating in person or require urgent referral to an appropriate service.
- 1.8 Support access to assessment and care for people with new or ongoing symptoms after acute COVID-19, particularly for those in underserved or vulnerable groups who may have difficulty accessing services, for example by:
 - providing extra time or additional support (such as an interpreter or advocate) during consultations

- raising awareness about possible new or ongoing symptoms of COVID-19 – this may include working with local community leaders or organisations – particularly in vulnerable groups and black, Asian and minority ethnic groups.

See the [equality impact assessment](#) for more information about the equality issues considered.

- 1.9 Consider follow-up by primary care or community services for people in vulnerable or high-risk groups who have self-managed in the community after suspected or confirmed acute COVID-19.
- 1.10 A healthcare professional in secondary care should offer a video or phone follow-up consultation at 6 weeks after discharge to people who have been in hospital with acute COVID-19 to check for new or ongoing symptoms or complications.

For a short explanation of why the panel made these recommendations see the [rationale section on identifying people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome](#).

Full details of the evidence and the panel's discussion are in [evidence reviews 2 and 3: prevalence](#), [evidence review 4: investigations](#), [evidence reviews 6 and 7: monitoring and referral](#), and [evidence review: views and experiences of patients, their families and carers](#).

2 Assessing people with new or ongoing symptoms after acute COVID-19

These recommendations are for healthcare professionals assessing people in any healthcare setting, 4 weeks or more after the start of suspected or confirmed [acute COVID-19](#).

- 2.1 For people with [ongoing symptomatic COVID-19](#) or suspected [post-COVID-19 syndrome](#) who have been identified as needing an assessment, use a holistic, person-centred approach. Include a comprehensive clinical history and appropriate examination that involves assessing physical, cognitive, psychological and psychiatric symptoms, as well as functional abilities.
- 2.2 Include in the comprehensive clinical history:
- history of suspected or confirmed acute COVID-19
 - the nature and severity of previous and current symptoms
 - timing and duration of symptoms since the start of acute COVID-19
 - history of other health conditions.
- 2.3 Be aware that people can have wide-ranging and fluctuating symptoms after acute COVID-19, which can change in nature over time.
- 2.4 Discuss how the person's life and activities, for example their work or education, mobility and independence, have been affected by ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome.
- 2.5 Discuss the person's experience of their symptoms and ask about any feelings of worry or distress. Listen to their concerns with empathy and acknowledge the impact of the illness on their day-to-day life, for example activities of daily living, feelings of social isolation, work and education, and wellbeing.
- 2.6 For people who may benefit from support during their assessment, for example to help describe their symptoms, include a family member or carer in discussions if the person agrees.

- 2.7 Do not predict whether a person is likely to develop post-COVID-19 syndrome based on whether they had certain symptoms (or clusters of symptoms) or were in hospital during acute COVID-19.
- 2.8 When investigating possible causes of a gradual decline, deconditioning, worsening frailty or dementia, or loss of interest in eating and drinking in older people, bear in mind that these can be signs of ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome.
- 2.9 If the person reports new cognitive symptoms, use a validated screening tool to measure any impairment and impact.

For a short explanation of why the panel made these recommendations see the [rationale section on assessing people with new or ongoing symptoms after acute COVID-19](#).

Full details of the evidence and the panel's discussion are in [evidence review 1: risk factors](#), [evidence reviews 2 and 3: prevalence](#), [evidence review 4: investigations](#) and [evidence review: views and experiences of patients, their families and carers](#)

3 Investigations and referral

These recommendations are for healthcare professionals carrying out initial investigations in primary care or community services for people with new or ongoing symptoms 4 weeks or more after the start of suspected or confirmed [acute COVID-19](#).

- 3.1 Refer people with [ongoing symptomatic COVID-19](#) or suspected [post-COVID-19 syndrome](#) urgently to the relevant acute services if they have signs or symptoms that could be caused by an acute or life-threatening complication, including (but not limited to):
- severe hypoxaemia or oxygen desaturation on exercise
 - signs of severe lung disease
 - cardiac chest pain
 - multisystem inflammatory syndrome (in children).
- 3.2 Offer tests and investigations tailored to people's signs and symptoms to rule out acute or life-threatening complications and find out if symptoms are likely to be caused by ongoing symptomatic COVID-19, post-COVID-19 syndrome or could be a new, unrelated diagnosis.
- 3.3 If another diagnosis unrelated to COVID-19 is suspected, offer investigations and referral in line with relevant national or local guidance.
- 3.4 Offer blood tests, which may include a full blood count, kidney and liver function tests, C-reactive protein test, ferritin, B-type natriuretic peptide (BNP) and thyroid function tests.
- 3.5 If appropriate, offer an exercise tolerance test suited to the person's ability (for example the 1-minute sit-to-stand test). During the exercise test, record level of breathlessness, heart rate and oxygen saturation. Follow an appropriate protocol to carry out the test safely (see the [rationale section on investigations and referral](#) for suggested protocols). For advice on sharing skills between services to help community services manage these assessments, see the [recommendation on sharing skills and training in the section on service](#)

organisation.

- 3.6 For people with postural symptoms, for example palpitations or dizziness on standing, carry out lying and standing blood pressure and heart rate recordings (3-minute active stand test, or 10 minutes if you suspect postural tachycardia syndrome, or other forms of autonomic dysfunction).
- 3.7 Offer a chest X-ray by 12 weeks after acute COVID-19 if the person has not already had one and they have continuing respiratory symptoms. Chest X-ray appearances alone should not determine the need for referral for further care. Be aware that a plain chest X-ray may not be sufficient to rule out lung disease.
- 3.8 Refer people with ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome urgently for psychiatric assessment if they have severe psychiatric symptoms or are at risk of self-harm or suicide.
- 3.9 Follow relevant national or local guidelines on referral for people who have anxiety and mood disorders or other psychiatric symptoms. Consider referral:
- for psychological therapies if they have common mental health symptoms, such as symptoms of mild anxiety and mild depression or
 - to a liaison psychiatry service if they have more complex needs (especially if they have a complex physical and mental health presentation).
- 3.10 After ruling out acute or life-threatening complications and alternative diagnoses, consider referring people to an integrated multidisciplinary assessment service (if available) any time from 4 weeks after the start of acute COVID-19.
- 3.11 Do not exclude people from referral to a multidisciplinary assessment service or for further investigations or specialist input based on the absence of a positive SARS-CoV-2 test (PCR, antigen or antibody).

For a short explanation of why the panel made these recommendations see the [rationale section on investigations and referral](#).

Full details of the evidence and the panel's discussion are in [evidence review 4: investigations](#), [evidence reviews 6 and 7: monitoring and referral](#), and [evidence review: views and experiences of patients, their families and carers](#).

4 Planning care

These recommendations are for healthcare professionals caring for people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome who have been assessed in primary care or a multidisciplinary assessment service.

- 4.1 After the holistic assessment, use shared decision making to discuss and agree with the person (and their family or carers, if appropriate) what support and rehabilitation they need and how this will be provided. This should include:
- advice on self-management, with the option of supported self-management (see the section on self-management and supported self-management) and
 - one of the following, depending on clinical need and local pathways:
 - 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.
- 4.2 When discussing with the person the appropriate level of support and management:
- think about the overall impact their symptoms are having on their life, even if each individual symptom alone may not warrant referral
 - look at the overall trajectory of their symptoms, taking into account that symptoms often fluctuate and recur so they might need different levels of support at different times.

For a short explanation of why the panel made these recommendations see the rationale section on planning care.

Full details of the evidence and the panel's discussion are in evidence review 5: interventions and evidence reviews 6 and 7: monitoring and referral.

5 Management

These recommendations are for healthcare professionals providing care for people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome in primary care and community settings or in multidisciplinary assessment and rehabilitation services.

Self-management and supported self-management

- 5.1 Give advice and information on self-management to people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome, starting from their initial assessment. This should include:
- ways to self-manage their symptoms, such as setting realistic goals
 - who to contact if they are worried about their symptoms or they need support with self-management
 - sources of advice and support, including support groups, social prescribing, online forums and apps
 - how to get support from other services, including social care, housing, and employment, and advice about financial support
 - information about new or continuing symptoms of COVID-19 that the person can share with their family, carers and friends (see the section on common symptoms of ongoing symptomatic COVID-19 and post-COVID syndrome).
- 5.2 Explain to people that it is not known if over-the-counter vitamins and supplements are helpful, harmful or have no effect in the treatment of new or ongoing symptoms of COVID-19.
- 5.3 Support people in discussions with their employer, school or college about returning to work or education, for example by having a phased return. For advice on returning to work, follow national guidance, for example NICE's guideline on workplace health: long-term sickness absence and capability to work.

Multidisciplinary rehabilitation

- 5.4 Assess people who have been referred to integrated multidisciplinary rehabilitation services to guide management. Include physical, psychological and psychiatric aspects of rehabilitation. Ensure that any symptoms that could affect the person being able to start rehabilitation safely have been investigated first. See also the [recommendation on multidisciplinary rehabilitation teams](#).
- 5.5 Work with the person to develop a personalised rehabilitation and management plan that is recorded in a rehabilitation prescription and should include:
- areas of rehabilitation and interventions based on their assessment
 - helping the person to decide and work towards goals
 - symptom management for all presenting symptoms, for example advice and education on managing breathlessness, fatigue and 'brain fog'.
- 5.6 Encourage people to keep a record of, or use a tracking app to monitor, their goals, recovery and any changes in their symptoms (also see the [section on follow-up and monitoring](#)).

Support for older people and children

- 5.7 Consider additional support for older people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome, for example short-term care packages, advance care planning and support with social isolation, loneliness and bereavement, if relevant.
- 5.8 Consider referral from 4 weeks for specialist advice for children with ongoing symptomatic COVID-19 or post-COVID-19 syndrome.

For a short explanation of why the panel made these recommendations see the [rationale section on management](#).

Full details of the evidence and the panel's discussion are in [evidence review 5: interventions](#), [evidence reviews 6 and 7: monitoring and referral](#), and [evidence review 8: service models](#).

6 Follow-up and monitoring

These recommendations are for healthcare professionals providing care for people with [ongoing symptomatic COVID-19](#) or [post-COVID-19 syndrome](#) in any setting, including primary care and community settings, secondary care and rehabilitation services.

- 6.1 Agree with the person how often follow-up and monitoring are needed and which healthcare professionals should be involved. Take into account the person's level of need and the services involved.
- 6.2 Using shared decision making, offer people the option of monitoring in person or remotely depending on availability, the person's preference and whether it is clinically suitable for them.
- 6.3 Tailor monitoring to people's symptoms and discuss any changes, including new or worsening symptoms and the effects of these on the person's life and wellbeing.
- 6.4 Consider supported self-monitoring at home, for example heart rate and blood pressure and pulse oximetry, if this is agreed as part of the person's assessment. Ensure that people have clear instructions and parameters for when to seek further help.
- 6.5 Be alert to symptoms developing that could mean referral or investigation is needed, following [recommendations in the section on assessing people with new or ongoing symptoms after acute COVID-19](#).

For a short explanation of why the panel made these recommendations see the [rationale section on follow-up and monitoring](#).

Full details of the evidence and the panel's discussion are in [evidence review 5: interventions](#), [evidence reviews 6 and 7: monitoring and referral](#), [evidence review 8: service models and evidence review: views and experiences of patients, their families and carers](#).

7 Sharing information and continuity of care

- 7.1 Ensure effective information sharing and integrated working by sharing clinical records and care and rehabilitation plans promptly between services and through multidisciplinary meetings, either virtual or in person.
- 7.2 Give people a copy of their care plans or records to keep, including their discharge letters, clinical records and rehabilitation plans and prescriptions.
- 7.3 Include baseline measures as well as ongoing assessments in information shared between services, including when the person is discharged from hospital. For example, resting oxygen saturation and heart rate, and the results of functional assessment.
- 7.4 Provide continuity of care with the same healthcare professional or team as much as possible, for example, by providing a care coordinator or a single point of contact.

For a short explanation of why the panel made these recommendations see the [rationale section on sharing information and continuity of care](#).

Full details of the evidence and the panel's discussion are in [evidence reviews 6 and 7: monitoring and referral](#), and [evidence review: views and experiences of patients, their families and carers](#).

8 Service organisation

- 8.1 Provide access to multidisciplinary services (these could be 'one-stop' clinics) for assessing physical and mental health symptoms and carrying out further tests and investigations. They should be led by a doctor with relevant skills and experience and appropriate specialist support, taking into account the variety of presenting symptoms.
- 8.2 Provide integrated, multidisciplinary rehabilitation services, based on local need and resources. Healthcare professionals should have a range of specialist skills, with expertise in treating fatigue and respiratory symptoms (including breathlessness). Additional expertise may be needed depending on the age and symptoms of the person. The core team could include, but not be limited to, the following specialist areas:
- occupational therapy
 - physiotherapy
 - clinical psychology and psychiatry
 - rehabilitation medicine.
- 8.3 Share knowledge, skills and training between services to help practitioners in the community provide assessments and interventions, such as 1-minute sit-to-stand tests and breathlessness training.
- 8.4 Agree local, integrated referral pathways between primary and community care, multidisciplinary rehabilitation services and specialist services, multidisciplinary assessment clinics and specialist mental health services.

For a short explanation of why the panel made these recommendations see the [rationale section on service organisation](#).

Full details of the evidence and the panel's discussion are in [evidence review 8: service models](#).

Common symptoms of ongoing symptomatic COVID-19 and post-COVID-19 syndrome

Symptoms after acute COVID-19 are highly variable and wide ranging. The most commonly reported symptoms include (but are not limited to) the following.

Respiratory symptoms

- Breathlessness
- Cough

Cardiovascular symptoms

- Chest tightness
- Chest pain
- Palpitations

Generalised symptoms

- Fatigue
- Fever
- Pain

Neurological symptoms

- Cognitive impairment ('brain fog', loss of concentration or memory issues)
- Headache
- Sleep disturbance
- Peripheral neuropathy symptoms (pins and needles and numbness)
- Dizziness

- Delirium (in older populations)

Gastrointestinal symptoms

- Abdominal pain
- Nausea
- Diarrhoea
- Anorexia and reduced appetite (in older populations)

Musculoskeletal symptoms

- Joint pain
- Muscle pain

Psychological/psychiatric symptoms

- Symptoms of depression
- Symptoms of anxiety

Ear, nose and throat symptoms

- Tinnitus
- Earache
- Sore throat
- Dizziness
- Loss of taste and/or smell

Dermatological

- Skin rashes

Recommendations for research

Key recommendations for research

1 Risk factors for post-COVID-19 syndrome

What factors, including identifiable clusters of symptoms, influence:

- the risk of developing post-COVID-19 syndrome
- the trajectory of post-COVID-19 syndrome?

2 Interventions for post-COVID-19 syndrome

What are the most clinically effective interventions (including social prescribing and structured community support) for managing post-COVID-19 syndrome?

Does effectiveness vary for different population groups (for example sex, age, socioeconomic group, black, Asian and minority ethnic group communities or people with learning disabilities)?

Do any symptoms of post-COVID-19 syndrome predict the need for specialist intervention?

Are there clusters of symptoms that identify response to interventions in post-COVID-19 syndrome?

What is the clinical effectiveness of different service models of multimodality/multidisciplinary post-COVID-19 syndrome rehabilitation in improving patient-reported outcomes (such as quality of life)?

What is the clinical effectiveness of exercise interventions for people with post-COVID-19 syndrome? Does effectiveness vary for different population groups (for example sex, age, socioeconomic group, black, Asian and minority ethnic group communities or people with learning disabilities)?

Does early exercise rehabilitation assist in improving symptoms of post-COVID-19 syndrome?

3 Prevalence of post-COVID-19 syndrome

What is the prevalence and incidence of post-COVID-19 syndrome? Does it differ from the prevalence and incidence across different population groups (for example in black, Asian and minority ethnic group communities)?

Other recommendations for research

Prognostic markers of developing post-COVID-19 syndrome

What is the clinical effectiveness of D-dimer and other blood tests and clinical features as prognostic markers of developing post-COVID-19 syndrome?

Presentation of post-COVID-19 syndrome in children, young people, pregnant women and older people

What symptoms do children, young people, pregnant women and older people with suspected post-COVID-19 syndrome present with?

Natural history of post-COVID-19 syndrome

What is the natural history of post-COVID-19 syndrome?

Validated tools for screening for post-COVID-19 syndrome

Develop and validate new and existing screening tools (including physical, psychological and psychiatric aspects) for post-COVID-19 syndrome in a UK population.

What tools are validated for screening for post-COVID-19 syndrome, which are the most accurate at identifying post-COVID-19 syndrome in a UK population and what is their effectiveness in guiding management?

Rationales

Rationale for terms used in the guideline

When developing the terms used in this guideline, many different factors were taken into account. The aim was to reduce the existing confusion about how to define the disease for clinical guidance. The panel recognised the significant progress made by patient groups using the term 'long COVID'. However, the term 'long COVID' has been used in multiple ways across the literature. Other terms have also been used. [Greenhalgh et. al \(2020\)](#) uses the terms 'post-acute COVID-19' (from 3 to 12 weeks) and 'chronic COVID-19' for symptoms extending beyond 12 weeks. The [National Institute for Health Research themed review](#) notes the possibility of a number of different syndromes.

The evidence on and pros and cons of different terms were reviewed. Specific clinical diagnostic criteria were needed to facilitate access to support, provide the basis for planning services and to enable formal codes to be developed for clinical datasets. Three definitions were developed: acute COVID-19 (0 to 4 weeks), ongoing symptomatic COVID-19 (4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or longer).

In deciding these time periods, the panel were aware of evidence showing that most people's symptoms will resolve before 12 weeks from the start of acute COVID-19 while for a smaller proportion of people they will continue for longer. People may also develop signs or symptoms of a life-threatening complication at any time and these need to be investigated urgently.

The panel concluded that most people who have symptoms or had a positive COVID-19 test would no longer be self-isolating after 4 weeks and could be investigated for ongoing symptomatic COVID-19 (4 to 12 weeks) with the possibility of later being diagnosed with post-COVID-19 syndrome (12 or more weeks).

There is currently no long-term evidence base to help determine how long the ongoing effects currently seen after a SARS-CoV-2 infection will last. The term 'post' COVID-19 syndrome was agreed to reflect that the acute phase of the illness has ended, not that the person has recovered. Because it is not clear how long symptoms may last the panel agreed that time-specific terms such as 'chronic' or 'persistent' were not appropriate. 'Syndrome' was agreed to reflect the 'running together' or concurrence of the multisystem, fluctuating and often overlapping 'clusters' of symptoms that people present with.

SNOMED CT codes

For the purposes of this guideline the following SNOMED CT codes have been developed, shown as Preferred term (ConceptId):

- Acute COVID-19 infection (1325171000000109)
- Ongoing symptomatic COVID-19 (1325181000000106)
- Post-COVID-19 syndrome (1325161000000102)

SNOMED CT is the standard clinical terminology for the NHS to support recording of clinical information. This supports data management and analysis to support patient care, while enabling data extraction and data exchange.

[Return to terms used in the guideline](#)

Identifying people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome

[Recommendations 1.1 to 1.10](#)

Why we made the recommendations

People need good information after acute COVID-19 so they know what to expect and when to ask for more medical advice. This could help to relieve anxiety if people do not recover in the way they expect. Evidence from patient experience and the panel's own experiences supported this, particularly because symptoms can fluctuate and there are so many different symptoms reported. Information may be provided by GPs or community services, or by secondary care for people who were in hospital. Accessibility of information is a legal requirement and is particularly important after acute COVID-19 because people may have cognitive symptoms ('brain fog') or fatigue, making it difficult for them to take in long or complex information.

Healthcare professionals in all services need to be alert to whether people may need support. Although most people with ongoing symptoms will start to improve between 4 and 12 weeks, some will need further investigation and others will need rehabilitation to help them recover.

The expert panel agreed that an initial consultation would help identify people who need further assessment. Some screening questionnaires are being used in practice, but none are validated for

this use. Questionnaires can be useful during the initial consultation but the panel did not want them to be used on their own to decide if further assessment is needed. Examples of questionnaires include the [Yorkshire rehab questionnaire](#) and the [Newcastle screening tool](#) (see appendix B), recommended by NHS England. Questionnaires should ideally be developed in partnership with patients and be validated.

In the panel's experience, some people, including children and older people, may report different symptoms from those most commonly seen in other age groups. The panel highlighted this to make sure their needs are still identified.

There was evidence supporting further assessment in person after initial assessment and the panel agreed this was important to fully assess people who need it. A consultation in person might not be suitable for everyone, so this should be agreed as a shared decision.

The panel agreed on the need to address health inequalities in care for people after acute COVID-19. Some people are less likely to seek help for symptoms or may be at risk of not being followed up after hospital care, for example because of language barriers, mental health conditions, mobility or sensory impairments, a learning disability or cultural differences in seeking help. Providing extra support and raising awareness could improve access to care, as could more proactive follow-up of people from underserved or vulnerable groups who are known to have had acute COVID-19 in the community and could be at increased risk of complications.

[Return to recommendations](#)

Assessing people with new or ongoing symptoms after acute COVID-19

[Recommendations 2.1 to 2.9](#)

Why we made the recommendations

The evidence suggested that healthcare professionals should use a holistic approach to assessment and the panel agreed assessment should cover both symptoms and how they affect the person overall. Evidence from patient experience showed many people feel their symptoms are not taken seriously. There are also people who don't realise that their symptoms are connected with COVID-19, so taking time to listen, showing empathy, taking a careful history and making an assessment are important.

The panel wanted to raise awareness about people who may have less common symptoms, particularly older people. They also highlighted the value of talking to family members or carers, with the person's agreement, to help get a full clinical picture for people who need extra support with communication.

There were too many uncertainties in the evidence to provide any symptoms that could predict whether people might develop post-COVID19 syndrome. The panel also did not want healthcare professionals to assume that people who had been hospitalised were more likely to develop post-COVID-19 syndrome because, at the moment, the evidence and the panel's own experience do not support this.

Many people experience cognitive symptoms, such as 'brain fog', confusion and loss of memory. The panel agreed that validated screening tools are useful for measuring and monitoring any impairment and the impact of this. The panel were aware of several tools but were unable to recommend any specifically because the evidence was not reviewed. They also agreed that the type of tool will differ depending on the setting and level of assessment needed.

Investigations and referral

[Recommendations 3.1 to 3.11](#)

Why we made the recommendations

Investigations are important to identify symptoms that could be caused by an acute or life-threatening complication, and to assess for other underlying conditions and complications. The panel agreed that no one set of investigations and tests would be suitable for everyone because of the wide range of symptoms and severity. Investigations need to be tailored to the person's signs and symptoms and whether they are being assessed in primary or secondary care. They agreed that blood tests and exercise tolerance tests (if safe and appropriate for the person) would be useful for most people as investigations and baseline measures, and could be carried out in primary care. These were also the tests most commonly reported in the evidence, along with chest X-rays. The panel suggested some blood tests, such as a full blood count and kidney, liver and thyroid function tests, that are commonly carried out to help rule out (or confirm and treat) other conditions.

The evidence suggested that not all pathology shows up on a chest X-ray so the panel agreed it should only be used as part of a holistic assessment to decide if referral or further care are needed in people with respiratory symptoms.

The panel discussed the usefulness of carrying out a sit-to-stand test but also agreed clinical judgement would be needed because it is not suitable for everyone (for example, people with chest pain or severe fatigue). They agreed skill sharing between services could help with gaps in knowledge and that a protocol should be followed in order to carry a sit-to-stand test out safely. The panel discussed that appropriate protocols could be found in these studies: [Ozalevli S, Ozden A, and Akkoclu A \(2007\) Comparison of the sit-to-stand test with 6 min walk test in patients with chronic obstructive pulmonary disease](#) and [Briand J, Behal H, Chenivresse C et al. \(2018\) The 1-minute sit-to-stand test to detect exercise-induced oxygen desaturation in patients with interstitial lung disease](#). They could not recommend any one in particular as their effectiveness had not been reviewed.

Postural symptoms are common, so the panel agreed that these should be investigated by taking lying and standing blood pressure and heart rate. Advice on carrying this out is available from the Royal College of Physicians' brief guide on measuring lying and standing blood pressure.

Evidence suggested that many people struggle to adjust to changes in their life, abilities and self-identity and reported feelings of helplessness and isolation. This was also supported by expert testimony, which suggested that symptoms of low mood and anxiety are common. The panel agreed that when mental health symptoms are identified during assessment, people need to be referred for support in line with relevant guidance (see the [Royal College of Psychiatrists' position statement \[2019\] The role of liaison psychiatry in integrated physical and mental healthcare](#)).

The patient experience evidence described how some people were not offered tests and other people were refused a referral by healthcare professionals because they did not have a positive SARS-CoV-2 test result. Many people who had acute COVID-19 were not tested, particularly earlier in the pandemic. The panel were clear that access to services should not be restricted by the need for a positive SARS-CoV-2 test (PCR, antigen or antibody).

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Planning care

[Recommendations 4.1 and 4.2](#)

Why we made the recommendations

There was not enough evidence to recommend specific criteria for referral and the panel agreed the right level of care would be agreed in shared decision making with the person after their holistic

assessment. To ensure people get the right care and support, a tiered approach could be used in which everyone gets advice for self-management, with the additional option of supported self-management if needed. People can then also be offered care from different services to match the level of their needs.

For many people with ongoing symptomatic COVID-19 and post-COVID-19 syndrome, this will mean referral to an integrated multidisciplinary assessment service for investigation, support to manage their symptoms and rehabilitation. Prompt referral is needed to avoid delays in getting people the support they need. In the panel's experience, the earlier people received help the more effective the interventions. The panel were also concerned that a lack of support could negatively affect people's mental health. They agreed that referral should be offered to those who would benefit from these services from 4 weeks after the start of acute COVID-19.

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Management

[Recommendations 5.1 to 5.8](#)

Why we made the recommendations

There was very little evidence on interventions, but the panel agreed that everyone should have self-management support and information. There was a lack of COVID-19-specific evidence on managing many of the common symptoms related to COVID-19, such as fatigue, dizziness and cognitive problems (such as 'brain fog'), but the panel agreed that support, such as setting achievable goals, should be tailored to the person's needs.

Patient organisations and online support groups can help to support self-management. [NHS website Your COVID recovery](#) was also highlighted as a potential source of reliable, up-to-date information and support.

The panel agreed that multidisciplinary rehabilitation teams should work with people to make a plan for their rehabilitation once any symptoms had been investigated that could affect the safety of rehabilitation. Physical, psychological and psychiatric aspects of rehabilitation should be addressed, with fatigue management being a key component of this. The evidence showed that breathlessness, fatigue and 'brain fog' are among the most commonly reported long-term symptoms, so support for these should be part of the person's rehabilitation plan.

A personalised rehabilitation and management plan records the person's needs and how they will be met. In some settings a 'rehabilitation prescription' may be used to capture this information. The rehabilitation prescription is held by the person and includes an individualised description of rehabilitation needs or recommendations to inform the future planning and delivery of a person's ongoing rehabilitation. Based on their experience, the panel agreed on the value of symptom diaries and symptom tracking apps in self-monitoring. The evidence for different symptom tracking apps was not reviewed so the panel could not recommend a specific product.

There was a lack of evidence on specific age groups in relation to ongoing symptomatic COVID-19 or post-COVID-19 syndrome, so the panel made recommendations for children and older people based on their clinical experience.

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Follow-up and monitoring

[Recommendations 6.1 to 6.5](#)

Why we made the recommendations

There was a lack of evidence on monitoring, but the panel agreed it is important so that people's support can be adapted if their symptoms or ability to carry out their usual activities change. The patient experience evidence highlighted the importance of follow-up and 'check ins' to access further care. The panel did not want to limit monitoring to specific tests or symptoms, or to a particular timeframe, because people with ongoing symptomatic COVID-19 and post-COVID19 syndrome have such a wide range of care needs. They decided it should be tailored to each person.

In the panel's experience, self-monitoring at home can be useful and is used in practice. But it might not be suitable for everyone, and without the right information and support can cause unnecessary anxiety. People need good guidance to use equipment, interpret the results and understand when to contact a healthcare professional.

The evidence on when to refer was also limited and based mostly on people who had been hospitalised, so it was not relevant to everyone. The panel agreed that healthcare professionals should be alert to any changes and that the recommendations in the assessment section would also apply to monitoring.

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Sharing information and continuity of care

[Recommendations 7.1 to 7.4](#)

Why we made the recommendations

There was evidence that people struggled to access appropriate care and some had experienced fragmented care. The panel agreed on the need to improve integration and coordination of care across different services. Having regular multidisciplinary meetings would help share information more efficiently and allow professionals to make decisions quickly about tests and referral. Sharing clinical records and care plans between services, with the agreement of the person, will help healthcare professionals provide integrated care, and avoid gaps in care or duplication of effort. In particular, sharing baseline measures is essential for monitoring as people move between services. The panel wanted to make sure that information is also shared with people using services so that they know what is happening with their care. The patient experience evidence also described how people could benefit from continuity of care, and the panel agreed this should always be an aim for well-integrated services.

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Service organisation

[Recommendations 8.1 to 8.4](#)

Why we made the recommendations

The limited evidence described different models of rehabilitation services. The panel agreed that some of the common elements, such as integration and multidisciplinary team working, would help provide effective, well-organised care for people with ongoing symptomatic COVID-19 and post-COVID-19 syndrome.

As well as ensuring the right breadth of expertise, having a multidisciplinary team with input from other services and clear referral pathways can prevent disjointed care and people waiting a long time for appointments with multiple specialists. This was supported by the patient experience evidence, which described the challenges of getting support for such a wide range of symptoms and a lack of coordinated care.

The panel agreed the core expertise that a multidisciplinary team could include. Because symptoms are so wide ranging, many other areas of expertise could also be added as needed, for example

rheumatology, neurology rehabilitation, cardiology, paediatrics, dietetics, speech and language therapy, nursing and pharmacy.

Different regional and geographical challenges mean that areas have different service needs and resources, so the panel agreed that one model would not fit all areas. However, the panel agreed a multidisciplinary service for assessment could avoid multiple referrals and would provide a single point for care. This could be a 'one-stop' clinic to help keep appointments to a minimum, although this might not be feasible for all services or wanted by all patients.

Based on their experience, the panel wanted to encourage different services to share knowledge and expertise with each other, to help expand the choice of tests and interventions available in the community. This could be done through local clinical networks or clinical hubs.

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