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

NICE guideline
Published: 18 December 2020
Last updated: 25 January 2024

www.nice.org.uk/guidance/ng188

Your responsibility

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.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the Yellow Card Scheme.

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.

Contents

Overview

This guideline covers identifying, assessing and managing the long-term effects of COVID-19, often described as 'long COVID'. It makes recommendations on 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.

NICE has also produced COVID-19 rapid guidelines on managing COVID-19 and haematopoietic stem cell transplantation.

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

1 Identification

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). Be aware that both children and adults can be affected by ongoing symptomatic COVID-19.

Case definition

1.1 Use the following clinical case definitions to identify and diagnose the long-term effects of COVID-19:

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.

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). **[2021]**

To support recording of clinical information and enable data extraction and exchange, codes have been developed that align with the case definition and support diagnosis, management and referral. These can be found in NHS England's national commissioning guidance for post-COVID services, as part of the primary care coding minimum dataset.

The Scottish Government's implementation support note for clinicians to support the management of the long-term effects of COVID-19 in primary and community care in Scotland provides information on the relevant codes for EMIS PCS and Vision. It also includes targeted information for clinicians and support for healthcare teams, including information and links to resources to support a consistent approach in Scotland to clinical assessment, shared decision making and individualised care planning conversations, including self-management and further referral where needed.

Advice and written information

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.2 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 section 9 on common symptoms)
- what they might expect during their recovery, including that:
  - recovery time is different for everyone but for most people symptoms will

  resolve by 12 weeks
  - the likelihood of developing ongoing symptomatic COVID-19 or post-COVID-19 syndrome is not considered 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 fluctuate, affecting them in different ways at different times
- how to self-manage ongoing symptomatic COVID-19 or post-COVID-19 syndrome (see section 5.1 on self-management and supported self-management)
- who to contact if they are worried about new, ongoing or worsening symptoms, or if they are struggling to return to education, work or other usual activities, especially if it is more than 4 weeks after the start of acute COVID-19.

For signs or symptoms that could be caused by an acute or life-threatening complication, see recommendation 3.2 on referral. **[2020, amended 2021]**

1.3 Give people information on COVID-19 vaccines (see NHS information on COVID-19 vaccines). Encourage them to follow current government guidance for vaccination but explain that it is not known if vaccines have any effect on ongoing symptomatic COVID-19 or post-COVID-19 syndrome. **[2021]**

1.4 Provide all information in accessible and age-appropriate 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 guidelines on patient experience in adult NHS services and shared decision making
- Healthcare Improvement Scotland's website 'What Matters To You'
- NHS England's Accessible information standard.

The NICE, RCGP (Royal College of General Practitioners) and SIGN (Scottish

Intercollegiate Guidelines Network) patient booklet on long COVID provides accessible information for people who have had acute COVID-19 and have ongoing signs and symptoms. **[2020, amended 2021]**

New and ongoing symptoms after acute COVID-19

1.5 For people with new or ongoing symptoms after acute COVID-19, suspect:

- 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. **[2020, amended 2021]**

1.6 For people who are experiencing 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 remote or in person. **[2020, amended 2021]**

1.7 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. **[2020]**

Some people (including children and older people) may not have the most commonly reported new or ongoing symptoms after acute COVID-19.

The following symptoms and signs are less commonly reported in children and young people than in adults:

- shortness of breath
- persistent cough
- pain on breathing
- palpitations
- variations in heart rate
- chest pain.

In addition to clinical symptoms, people who report increased absence or reduced performance in their education, work or training after acute COVID-19 may have ongoing symptomatic COVID-19 or post-COVID-19 syndrome and may need extra support and recovery time.

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.

Need for further assessment

1.8 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 remote or in person. Take into account whether they may have symptoms that need investigating in person or require urgent referral to an appropriate service. **[2020, amended 2021]**

For advice on working with people to make decisions about their treatment and care, see NICE's guidelines on shared decision making and decision making and mental capacity, and Healthcare Improvement Scotland's 'What Matters To You' website.

1.9 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 symptomatic COVID-19 or post-COVID-19 syndrome – 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. **[2020]**

Proactive follow-up after acute COVID-19

1.10 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. **[2020]**

1.11 A healthcare professional in secondary care should offer a 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. **[2020, amended 2021]**

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

Full details of the evidence and the panel's discussion are in:

- evidence review G: risk factors
- evidence review H: case definition
- evidence review I: signs, symptoms and prevalence
- evidence review J: children and young people
- evidence review K: impact of vaccines
- evidence review: views and experiences of patients, their families and carers.

2 Assessment

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.

Include in the comprehensive clinical history:

- history of acute COVID-19 (suspected or confirmed)
- 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
- exacerbation of pre-existing conditions. **[2020]**

2.2 Be aware that people can have wide-ranging and fluctuating symptoms after acute COVID-19, which can change in nature over time (see section 9 on common symptoms). **[2020]**

2.3 Discuss the person's experience of their symptoms and how their life and activities have been affected, including work, education, mobility and independence. Ask about any feelings of worry or distress. Listen to their concerns with empathy and acknowledge the impact on their day-to-day life. **[2020, amended 2021]**

2.4 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.

For more advice on supporting adults to make their own decisions if they lack mental capacity, see NICE's guideline on decision making and mental capacity and the Adults with Incapacity (Scotland) Act 2000, with further guidance available from the Mental Welfare Commission for Scotland. **[2020]**

2.5 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. **[2020]**

2.6 If the person reports new cognitive symptoms, use a validated screening tool to measure any impairment and impact. **[2020]**

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

Full details of the evidence and the panel's discussion are in:

- evidence review G: risk factors
- evidence review H: case definition
- evidence review I: signs, symptoms and prevalence
- evidence review J: children and young people
- evidence review K: impact of vaccines
- 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. See the NICE guideline on shared decision making for advice on how to make appropriate investigations and referrals.

3.1 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. **[2020]**

3.2 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):

- hypoxaemia or oxygen desaturation on exercise
- signs of severe lung disease
- cardiac chest pain
- paediatric inflammatory multisystem syndrome – temporally associated with SARS-CoV-2 (PIMS-TS). **[2020]**

3.3 If another diagnosis unrelated to COVID-19 is suspected, offer investigations and referral in line with relevant national or local guidance. **[2020]**

3.4 Decisions about blood tests should be guided by the person's symptoms. If clinically indicated, offer blood tests, which may include a full blood count, kidney and liver function tests, C-reactive protein, ferritin, B-type natriuretic peptide (BNP), HbA1c and thyroid function tests. **[2020, amended 2021]**

3.5 Consider supported self-monitoring at home, if this is agreed through shared decision making as part of the person's assessment. This may include heart rate, blood pressure, pulse oximetry or symptom diaries. Ensure that people have clear instructions on how to use any equipment and parameters for when to seek further help.

Be aware that some pulse oximeters can underestimate or overestimate oxygen saturation levels, especially if the saturation level is borderline. Overestimation has been reported in people with dark skin. For more information about this, see NHS England's guide on how to look after yourself at home if you have COVID-19 or symptoms of COVID-19. **[2020, amended 2021]**

3.6 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 for suggested protocols).

Sharing skills between services can help community services to manage these assessments; for advice, see recommendation 8.3 on sharing skills and training in the section on service organisation. **[2020]**

3.7 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 for orthostatic hypotension, or 10 minutes if you suspect postural tachycardia syndrome, or other forms of orthostatic intolerance). **[2020]**

3.8 Offer a chest X-ray by 12 weeks after acute COVID-19 only if the person has continuing respiratory symptoms and it is clinically indicated. Chest X-ray appearances alone should not determine the need for referral for further care.

Be aware that a normal plain chest X-ray does not rule out lung disease. **[2020, amended 2021]**

3.9 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 displaying high risk of self-harm or suicide. **[2020]**

3.10 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). **[2020]**

3.11 After ruling out acute or life-threatening complications and alternative diagnoses, consider referring people to an appropriate service, such as an integrated multidisciplinary assessment service, any time from 4 weeks after the start of acute COVID-19.

Many people experience a spontaneous improvement in symptoms between 4 and 12 weeks after the start of acute COVID-19 and should be offered self-management support and monitoring during this time, with consideration of onward referral to further services if they do not improve. People with concerning symptoms during this time may need referral for assessment by acute medical services. **[2020, amended 2021]**

3.12 Do not exclude people from referral to an integrated 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) as long as the case definition criteria are met. **[2020, amended 2021]**

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:

- evidence review C: investigations
- evidence review E: monitoring and referral
- 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, discuss with the person (and their family or carers, if appropriate) the options available and what each involves. These should include:

- advice on self-management, with the option of supported self-management (see section 5.1 on self-management and supported self-management) **and**
- 1 or more 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. **[2020, amended 2021]**

4.2 Use shared decision making to agree what support and rehabilitation the person needs, including how and when it should be provided. **[2021]**

4.3 When discussing with the person the appropriate level of support and management:

- take account of the overall impact their symptoms are having on their life and usual activities, 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. **[2021]**

For advice on working with people to make decisions about their treatment and care, see NICE's guidelines on shared decision making and decision making and mental capacity and Healthcare Improvement Scotland's 'What Matters To You' website.

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 D: interventions
- evidence review E: 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.

There are established treatments for managing the common symptoms often seen with ongoing symptomatic COVID-19 and post-COVID-19 syndrome, as set out in current national and local guidance, which can be followed for symptomatic relief. However, there is a lack of evidence for pharmacological interventions to treat the condition itself.

5.1 Self-management and supported self-management

5.1.1 Give advice and information on self-management to people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome, starting from their holistic 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 section 9 on common symptoms).

Advice for patients on managing common symptoms is available from the

Your COVID Recovery website and NHSinform website. **[2020]**

5.1.2 Explain 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 symptomatic COVID-19 or post-COVID-19 syndrome.

5.1.3 Support people in discussions with their school, college or employer about returning to education or work, 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. **[2020]**

For a short explanation of why the panel made these recommendations, see the rationale section on self-management and supported self-management.

Full details of the evidence and the panel's discussion are in:

- evidence review D: interventions
- evidence review E: monitoring and referral
- evidence review F: service models.

5.2 Multidisciplinary rehabilitation

Definition

Rehabilitation: a set of interventions designed to optimise functioning, health and wellbeing, and reduce disability in people with health conditions in interaction with their environment. In the context of ongoing COVID-19 symptoms, this may include providing information, education, supported self-management, peer support, symptom management strategies and physical rehabilitation. (Informed by the World Health Organization's fact sheet on rehabilitation.)

5.2.1 Use a multidisciplinary approach to guide rehabilitation, including physical, psychological and psychiatric aspects of management. 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 in section 8 on service organisation. **[2020, amended 2021]**

5.2.2 Work with the person (and their family or carers, if appropriate) 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
- how to manage and monitor their symptoms, taking into account that these may fluctuate, and what to do if symptoms return or change. **[2020, amended 2021]**

5.2.3 Provide extra time or additional support (such as an interpreter or advocate) to people who would benefit during their consultations. **[2020, amended 2021]**

5.2.4 Encourage people to keep a record of, or use a tracking app to monitor, their goals, recovery and any changes in their symptoms (see also section 6 on follow-up, monitoring and discharge). **[2020]**

For a short explanation of why the panel made these recommendations, see the rationale section on multidisciplinary rehabilitation.

Full details of the evidence and the panel's discussion are in:

- evidence review D: interventions
- evidence review E: monitoring and referral
- evidence review F: service models.

5.3 Additional support

5.3.1 Consider additional support for people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome who may be vulnerable, for example, older people and people with complex needs. Additional support may include short-term care packages, advance care planning and support with social isolation, loneliness and bereavement, if relevant. **[2020, amended 2021]**

5.3.2 Consider referral from 4 weeks for specialist advice for children and young people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome. **[2020, amended 2021]**

For a short explanation of why the panel made these recommendations, see the rationale section on additional support.

Full details of the evidence and the panel's discussion are in:

- evidence review D: interventions
- evidence review E: monitoring and referral
- evidence review F: service models.

6 Follow-up, monitoring and discharge

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 Use shared decision making to decide how often follow-up and monitoring are needed, which healthcare professionals should be involved and whether appointments should be carried out in person or remotely. Take into account:

- the person's needs and the services involved
- the person's symptoms, including new or worsening symptoms, and the effects of these on the person's life and wellbeing
- availability, clinical suitability and the person's preferences for in-person or remote appointments. **[2020, amended 2021]**

6.2 Be alert to symptoms developing that could mean referral or investigation is needed, following recommendations in section 2 on assessment. **[2020]**

6.3 Use shared decision making to discuss and agree plans for discharge from rehabilitation and care, taking into account the person's preferences, goals and social support. Follow local referral pathways to enable re-referral if needed. **[2021]**

For a short explanation of why the panel made these recommendations, see the rationale section on follow-up, monitoring and discharge.

Full details of the evidence and the panel's discussion are in:

- evidence review D: interventions
- evidence review E: monitoring and referral
- evidence review F: service models
- 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. **[2020]**

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. **[2020]**

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. **[2020]**

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. **[2020]**

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 review E: monitoring and referral
- evidence review: views and experiences of patients, their families and carers.

8 Service organisation

8.1 Provide access to multidisciplinary services, if available, (these could be 'one-stop' clinics) for assessing physical and mental health symptoms and carrying out further tests and investigations. Services should be led by a doctor with relevant skills and experience and appropriate specialist support, taking into account the variety of presenting symptoms. **[2020, amended 2021]**

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 managing 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. **[2020]**

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. **[2020]**

8.4 Agree local, integrated referral pathways between primary and community care, rehabilitation services and specialist services, multidisciplinary assessment clinics (where available) and specialist mental health services. **[2020]**

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 F: service models.

9 Common symptoms

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)
- Mobility impairment

- Visual disturbance

Gastrointestinal symptoms

- Abdominal pain
- Nausea and vomiting
- Diarrhoea
- Weight loss and reduced appetite

Musculoskeletal symptoms

- Joint pain
- Muscle pain

Ear, nose and throat symptoms

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

Dermatological symptoms

- Skin rashes
- Hair loss

Psychological/psychiatric symptoms

- Symptoms of depression
- Symptoms of anxiety
- Symptoms of post-traumatic stress disorder

The following symptoms and signs are less commonly reported in children and young people than in adults:

- shortness of breath
- persistent cough
- pain on breathing
- palpitations
- variations in heart rate
- chest pain.

For a short explanation of why the panel made these recommendations, see the rationale section on common symptoms.

Recommendations for research

Key recommendations for research

1 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? **[2020]**

Does effectiveness vary for different population groups (for example, sex, age, socioeconomic group, black, Asian and minority ethnic group communities or people with a learning disability)? **[2020]**

Do any symptoms of post-COVID-19 syndrome predict the need for specialist intervention? **[2020]**

Are there clusters of symptoms that identify response to interventions in post-COVID-19 syndrome? **[2020]**

What is the clinical effectiveness of different service models of multimodality or multidisciplinary post-COVID-19 syndrome rehabilitation in improving patient-reported outcomes (such as quality of life)? **[2020]**

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 a learning disability)? **[2020]**

Does early exercise rehabilitation assist in improving symptoms of post-COVID-19 syndrome? **[2020]**

2 Prevalence of post-COVID-19 syndrome

What is the prevalence and incidence of post-COVID-19 syndrome in people who have received single, double or boosted doses of the approved vaccinations in the UK? Does this vary across different population groups (for example in black, Asian and minority ethnic group communities)? **[2021]**

Other recommendations for research

3 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? **[2020]**

4 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? **[2020]**

5 Clinical course of post-COVID-19 syndrome

What is the natural history of post-COVID-19 syndrome? **[2020]**

What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome? For example, generalised fatigue, breathlessness and 'brain fog'? **[2021]**

6 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. **[2020]**

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? **[2020]**

Rationales

These sections briefly explain why the committee made the recommendations.

Identification

Why we made the recommendations

Case definition

Recommendation 1.1

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

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).

The cumulative long-term evidence remains inconclusive for the trajectory and duration of the ongoing effects currently seen after a SARS-CoV-2 infection. 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.

Advice and written information

Recommendations 1.2 to 1.4

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.

The panel noted that 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.

The panel heard expert testimony that absence from or poor performance at work or education was associated with poor outcomes for people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome. Awareness of this may be helpful to healthcare professionals in identifying people who may need further assessment. The panel agreed that it is important for people to contact a health professional if they are struggling with returning to work or education after acute COVID-19 to ensure they receive support with any continuing symptoms.

The panel discussed whether there were any symptoms in particular that people should look out for that may suggest they have ongoing symptomatic COVID-19 or post-COVID-19 syndrome. The panel agreed that people should contact a healthcare professional if they are concerned about any new, ongoing or worsening symptoms. The panel also noted that there is some helpful information available such as the Your COVID Recovery website that outlines when people should contact their healthcare professional.

Observational evidence and expert testimony on the safety and therapeutic benefit of COVID-19 vaccines in the context of treating long-term effects of COVID-19 (see evidence review K: impact of vaccines) were inconclusive for the outcomes of duration and change in symptoms, quality of life and mental wellbeing. The population included people with existing long-term effects of COVID-19 and people infected after vaccination who reported symptoms of 28 days or longer since vaccination.

The expert panel agreed that the findings could not justify a positive recommendation for COVID-19 vaccination to treat the long-term effects of COVID-19, nor a negative recommendation against this intervention in the absence of evidence of harm.

However, the panel recognised the safety and effectiveness of vaccines in preventing acute infection and the importance of the national COVID-19 vaccination programme to protect all people, particularly those who are at highest risk from serious illness or death from COVID-19 or at risk of transmitting infection. Therefore, the panel emphasised the need to encourage patients with long-term effects of COVID-19 who have not been vaccinated to have the vaccination to reduce the risk of a further SARS-CoV-2 infection, but to explain the uncertainty about the effect of vaccination on ongoing symptomatic COVID-19 and post-COVID-19 syndrome.

New and ongoing symptoms after acute COVID-19

Recommendations 1.5 to 1.7

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 panel therefore agreed that ongoing symptomatic COVID-19 and post-COVID-19 syndrome should be considered as part of the differential diagnosis at 4 to 12 weeks and beyond 12 weeks, respectively. The panel also emphasised that this applies to children and young people as well as adults.

In the panel's experience, some people, including children and older people, may report different symptoms from those most commonly seen in the adult population. The panel highlighted this to make sure their needs are still identified. For example, the panel did note that some cardiac and respiratory symptoms were less commonly reported in children than adults and agreed that these symptoms should be noted to inform investigation of alternative diagnoses.

The expert panel agreed that an initial consultation would help identify people who need further assessment. A detailed discussion between the person and a healthcare professional is an important part of understanding their symptoms, and the way in which the symptoms affect their daily life. This discussion will form the first part of an assessment, and inform decisions about whether further assessment and investigations are needed (see section 2 on assessment). The panel also agreed that the format of the consultation should be discussed and agreed with the person according to their needs and preferences and local availability of services.

Some screening questionnaires are being used in practice to capture a person's symptoms, but none are fully validated for this use. Questionnaires can be useful in preparation for or 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 COVID-19 Yorkshire rehabilitation questionnaire, recommended by NHS England, and the modified International Severe Acute Respiratory and emerging Infection Consortium (ISARIC) global paediatric COVID-19 follow-up questionnaire. Questionnaires should ideally be developed in partnership with patients and be fully validated.

Need for further assessment

Recommendations 1.8 and 1.9

There was evidence supporting further assessment in person after the initial consultation 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. However, the panel agreed that decisions about whether consultations should be remote or in person should always take into account any safeguarding concerns.

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, learning disabilities or cultural differences in seeking help. Providing extra support and raising awareness could improve access to care.

Proactive follow-up after acute COVID-19

Recommendations 1.10 and 1.11

The panel agreed, based on expert testimony and their experience, that proactive follow-up of people from underserved or vulnerable groups who are known to have had acute COVID-19 in the community could improve access to care and identify people who could be at increased risk of complications.

The panel recommended active follow-up at 6 weeks to help identify if people are still struggling with symptoms. It may not be needed for all patients, but it would be backed up by the information about self-referring for reassessment if people felt their health was not improving. The panel agreed that this consultation can be in person or remote.

Return to recommendations

Assessment

Recommendations 2.1 to 2.6

Why we made the recommendations

The evidence suggested that healthcare professionals should use a holistic approach to assessment and the panel agreed that assessment should cover both symptoms and how they affect the person overall. Evidence from patient experience showed that many people feel their symptoms are not taken seriously. There are also people who do not 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 noted that the evidence and patient experience showed that symptoms can fluctuate and healthcare professionals should be aware of this when carrying out a holistic assessment. Some people may need help to describe their symptoms, including those who experience cognitive symptoms, such as 'brain fog', confusion and loss of memory, after acute COVID-19. The panel 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-COVID-19 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 the current evidence and the panel's own experience do not support this.

The panel discussed and agreed that healthcare professionals should be aware that older people may not present with the common symptoms associated with ongoing symptomatic COVID-19 or post-COVID-19 syndrome. The panel agreed on signs that might prompt a healthcare professional to consider ongoing symptomatic COVID-19 or post-COVID-19 syndrome alongside other possible causes in an older person.

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.

Return to recommendations

Investigations and referral

Recommendations 3.1 to 3.12

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.

For signs and symptoms to help identify paediatric multisystem inflammatory syndrome temporally associated with SARS-CoV-2 (PIMS-TS), see the guidance on PIMS from the Royal College of Paediatrics and Child Health.

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 care (blood tests, the 1-minute sit-to-stand test) or secondary care (exercise tolerance tests). 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. These were also the tests most commonly reported in the evidence, along with chest X-rays.

The panel agreed that when carrying out investigations for ongoing symptoms following acute COVID-19, it is important that other potential diagnoses are not ignored. Healthcare professionals should follow relevant clinical guidance if a diagnosis unrelated to COVID-19 is suspected.

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 other conditions.

The panel agreed that blood tests should only be offered if clinically indicated. They discussed that tests should be carried out as needed when an alternative diagnosis is suspected. However, they recognised that multiple tests can be a negative experience for some people and may not always be needed to inform management of the person's symptoms. They agreed that testing should be guided by the person's symptoms and used to supplement a detailed holistic assessment.

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 panel agreed that this advice also applies to parents or carers monitoring children at home.

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, Chenivesse C et al. (2018) The 1-minute sit-to-stand test to detect exercise-induced oxygen desaturation in patients with interstitial lung disease. The panel could not recommend any one in particular as their effectiveness is undetermined.

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.

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 agreed that a chest X-ray should not be carried out if the person has already had one and there have been no subsequent clinical changes.

Evidence and expert testimonies from the Royal College of Psychiatry 2020 and Nicol 2021 (see evidence review E: monitoring and referral and supporting document 2: expert testimony for rehabilitation) highlighted that mental health symptoms are common after acute COVID-19. The committee agreed that it is important that people with severe psychiatric symptoms or at risk of harm are identified during assessment and urgently referred for psychiatric assessment and support in line with relevant guidance (see the Royal College of Psychiatrists' position statement [2019] on the role of liaison psychiatry in integrated physical and mental healthcare).

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] on the role of liaison psychiatry in integrated physical and mental healthcare).

For many people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome, this will mean referral to an integrated multidisciplinary assessment clinic 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.

The panel discussed expert testimony from Locke 2021 (see supporting document 2: expert testimony for rehabilitation), which reported that in some areas of the UK, provision of an integrated multidisciplinary assessment service is not feasible. The recommendation was updated to take into account that people may be referred to other appropriate services. Different service pathways are in place across the UK, and this guideline is not intended to cover the diagnostic or management approaches delivered by the more specialist services involved in caring for patients with persistent symptoms or complications after acute COVID-19, such as post-COVID assessment services in England or specialist clinics.

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) if the case definition criteria in section 1 on identification are met.

Return to recommendations

Planning care

Recommendations 4.1 to 4.3

Why we made the recommendations

To ensure people get the right care and support, the expert panel agreed that 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. The recommendation applies to all age groups and allows for discussion with the family or carers of the person if appropriate.

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.

Return to recommendations

Self-management and supported self-management

Recommendations 5.1.1 to 5.1.3

Why we made the recommendations

There was very little evidence on interventions such as specific pharmacological treatments for ongoing symptomatic COVID-19 or post-COVID-19 syndrome, 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'). However, there are established treatments for managing individual common symptoms. For example, antihistamines can be used to treat some skin rashes. The panel noted that, given the fluctuating nature of the symptoms, regular review and monitoring is needed for people receiving any form of treatment.

NICE will continue to monitor and review new evidence in this area as part of its living approach to maintaining the guideline.

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

The panel were concerned that people are buying over-the-counter vitamins and supplements that may not help with their symptoms. They agreed that it would be helpful to highlight the lack of knowledge in this area.

The panel agreed that support to return to education or work, such as setting achievable goals, should be tailored to the person's needs. This might involve support to work or study at home, flexible working or a phased return.

For the November 2021 update, the panel heard expert testimonies from Stark 2021 and Whittaker 2021 (see evidence review J: children and young people) describing that absence from or poor performance in education was associated with poor outcomes for children and young people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome. The panel agreed that this would also apply to adults returning to work or education. Healthcare professionals should be aware that people who are struggling to return to work or education may have symptoms that persist for longer than other people and may need additional support.

Further advice on returning to work can be found in the Society for Occupational Health Medicine guidance on COVID-19 return to work guide for recovering workers and COVID-19 return to work guide for managers.

Return to recommendations

Multidisciplinary rehabilitation

Recommendations 5.2.1 to 5.2.4

Why we made the recommendations

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. The panel recognised that some people may need additional support, such as an interpreter or advocate, in developing the rehabilitation and management plan.

The evidence highlighted the fluctuating nature of ongoing symptomatic COVID-19 and post-COVID-19 syndrome. Based on this evidence, the panel agreed that it was key that a management plan should take into account that symptoms may fluctuate.

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.

Return to recommendations

Additional support

Recommendations 5.3.1 and 5.3.2

Why we made the recommendations

There was a lack of evidence for specific age groups on managing ongoing symptomatic COVID-19 or post-COVID-19 syndrome. Based on their clinical experience, the panel made a recommendation for older people and other groups such as people with complex needs who may be vulnerable to ensure that they receive additional care and support, if needed, that is tailored to the particular needs of this population.

There was a lack of evidence on managing ongoing symptomatic COVID-19 or post-COVID-19 syndrome in children and young people. Based on their experience, the panel agreed that referral should be considered so that children and young people can be supported to manage their symptoms early and recover quickly. The recommendation covers all children and young people, including those aged 16 to 18 who should be supported to access specialist advice through either adult or paediatric services depending on local referral pathways.

Return to recommendations

Follow-up, monitoring and discharge

Recommendations 6.1 to 6.3

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-COVID-19 syndrome have such a wide range of care needs. They decided it should be tailored to each person's needs and preferences.

The evidence on when to refer was 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.

The panel discussed when a person should be discharged from rehabilitation and care. They agreed that a timepoint could not be specified, because this is dependent on the person's symptoms, the goals that were set, the progress made and the amount of social support the person has. However, they agreed that making a discharge plan with the person would support motivation, ensure the person gets the support they need and help to manage rehabilitation resources. The panel also agreed that transition to adult services should be considered in discharge planning for young people.

Expert testimony highlighted the importance of people being able to re-enter rehabilitation services after being discharged if their symptoms worsen. The panel recognised that symptoms may fluctuate and recur with patients needing to re-access support and services in the most efficient way possible. However, following shared decision making, local referral pathways would need to be followed because of variation in practice and funding.

Return to recommendations

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.

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.

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 patient experience evidence described how people could benefit from continuity of care, and the panel agreed this should always be an aim for well-integrated services.

Return to recommendations

Service organisation

Recommendations 8.1 to 8.4

Why we made the recommendations

Different regional and geographical challenges mean that areas have different service needs and resources, so the panel agreed that 1 model would not fit all areas. 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. In areas where multidisciplinary services are not available, services may be provided through integrated and coordinated primary care, community, rehabilitation and mental health services.

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. The panel considered examples of a core team could include occupational therapy, physiotherapy, clinical psychology and psychiatry and rehabilitation medicine.

Because symptoms are so wide-ranging, many other areas of expertise could also be added as needed. This could include, but are not limited to, rheumatology, neurology rehabilitation, cardiology, paediatrics, dietetics, speech and language therapy, nursing, pharmacy, social care and support to return to education or work or usual activities.

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.

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 attending multiple appointments and repeated investigations.

Return to recommendations

Common symptoms

Recommendations in the box

Why we made the recommendations

There are signs and symptoms that were consistently identified in the evidence and the panel agreed that it would be useful to provide common symptoms list. The panel also discussed that symptoms such as menstrual symptoms and 'COVID toes' are common in their experience, but noted that they were not identified in the evidence and so were not added to the common symptoms list. It was further noted that adjustment disorder was highlighted as a symptom in the patient experience review; however, this too was not commonly reported in other studies so was not added to the common symptoms list.

Expert testimonies from Stephenson 2021 and Whittaker 2021 (see evidence review J: children and young people) and evidence on signs and symptoms in children and young people indicated that cardiac and respiratory symptoms are less common in young people. The panel agreed that it is important to highlight the specific symptoms identified as less common in this population.

The panel noted that people typically experience a constellation of symptoms and the presence of an isolated symptom should prompt thorough consideration of other possible causes.

Return to recommendations

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE topic page on COVID-19.

For full details of the evidence and the guideline committee's discussions, see the evidence reviews. You can also find information about how the guideline was developed, including details of the committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting our guidelines into practice, see resources to help you put NICE guidance into practice.

Update information

25 January 2024

We transferred the guideline recommendations, evidence reviews and supporting documentation from the MAGICapp platform to the NICE website, changing the presentation. The recommendations are unchanged.

11 November 2021

We reviewed the evidence on case definitions; referral to services; children and young people; the impact of vaccines on the long-term effects of COVID-19; signs, symptoms and prevalence; and risk factors. We made new recommendations and updated existing recommendations on identification; planning care; multidisciplinary rehabilitation; follow-up, monitoring and discharge; and service organisation. We also updated the list of common symptoms, emphasising that these may be different for children.

ISBN: 978-1-4731-5716-3