

Classification: Official

Publications approval reference: C1248



# National guidance for post-COVID syndrome assessment clinics

Version 2, 26 April 2021

## Please note – this document has been updated

This document has been updated following the release of the [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#) by the National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP) in December 2020.

Local services, referral pathways and protocols should now be reviewed and updated to reflect this guidance. It covers identifying, assessing and managing the long-term effects of COVID-19 and should be read in addition to this document.

This guidance will continue to be revised as further evidence emerges.

Below is a list of substantive updates:

- The **clinical case definition** and **evidence summary** has been updated in line with NICE/SIGN/RCGP guidance and recent advances in understanding of the condition.
- A clear **clinical pathway** has been developed and is detailed here.
- Further information on **service design** has been included, based on consensus of established services and NICE/SIGN/RCGP guidance.
- A specific section on **children and young people** is included here.
- Further developments on **data and information** are included here including minimum datasets for coding in primary care and post-COVID assessment services.
- Further clarification on the **data strategy including coding**, registry, and reporting.
- A review of **patient reported outcome and experience measures**.
- Further details on addressing health inequalities have been included throughout.

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# Equality and Health Inequalities Statement

Promoting equality and addressing health inequalities are at the heart of NHS England and NHS Improvement's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

## 1. Purpose

The purpose of this document is to inform the commissioning of post-COVID syndrome assessment clinics. This guidance will assist local healthcare systems in establishing and maintaining post-COVID assessment services for patients experiencing long-term health effects following COVID-19 infection.

Clinics should offer physical, cognitive, psychological and psychiatric assessments with the aim of providing consistent services for people with post-COVID syndrome ('Long COVID'). These services should support those who need them, irrespective of whether they were hospitalised and regardless of whether clinically diagnosed or by a SARS-CoV-2 test.

## 2. Background

- People of all ages and backgrounds can experience ongoing health effects following COVID-19 infection, including those who were not hospitalised during acute illness or did not have a positive SARS-CoV-2 test. Symptoms of Long COVID are wide ranging and can fluctuate and change over time.
- It is estimated that around 1 in 7 people testing positive for COVID-19 have ongoing symptoms at 12 weeks. Results from the latest Office for National

Statistics Coronavirus Infection Survey show that, based on the number of people self-reporting Long COVID of any duration, 932,000 in England had ongoing symptoms in the four weeks to the beginning of March 2021. They estimate that 601,000 experienced Long COVID more than 12 weeks after the first (suspected) infection with COVID-19.

- There is evidence that long term adverse health effects of COVID-19 may disproportionately impact people from ethnic minority groups.
- NHS England and NHS Improvement launched a five-point plan to support people with Long COVID in October 2020. As part of this, NICE has produced a clinical case definition and guidance to help healthcare professionals diagnose and treat people experiencing Long COVID symptoms.
- The NHS has established post-COVID assessment clinics in England to offer holistic assessment and help patients access the right specialist services and the Your COVID Recovery website and online rehabilitation service has been launched. In addition, £50 million has now been committed to supporting research directly designed to improve understanding of and deliver specific support to individuals affected by Long COVID.
- A National Taskforce has been formed to drive forward work on Long COVID.
- NHS England and NHS Improvement acknowledges the vital contribution of patient advocacy groups and clinicians in developing this guidance and other Long COVID support plans.

### 3. Clinical case definition of post-COVID syndrome

This guidance refers to patients who meet the clinical case definition of ongoing symptomatic COVID-19 and post-COVID-19 syndrome.

The National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP) produced a rapid guideline on managing the long term effects of COVID-19 in December 2020.<sup>1</sup> This set out the following clinical definitions:

1. **Acute COVID-19:** signs and symptoms of COVID-19 for up to four weeks.
2. **Ongoing symptomatic COVID-19:** signs and symptoms of COVID-19 from 4 to 12 weeks.
3. **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.

The term 'Long COVID' is also commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 and post-COVID-19 syndrome.

## 4. Summary of evidence base

There is increasing evidence that people can experience ongoing symptoms following acute infection with COVID-19. This is irrespective of age, sex, medical history or severity of acute infection.

Symptoms of Long COVID are highly variable and wide ranging and may fluctuate in intensity and change over time. The condition can affect multiple systems in the body. [NICE/SIGN/RCGP guidance describes the common symptoms of ongoing symptomatic COVID-19 and post-COVID-19 syndrome.](#)

Prevalent symptoms are fatigue and shortness of breath, reported by 77% and 54% of respondents respectively in the International Severe Acute Respiratory and Emerging Infection Consortium (ISARIC) study of individuals who were hospitalised with COVID-19. Over half of participants in this study reported not feeling fully

<sup>1</sup> [www.nice.org.uk/guidance/ng188](http://www.nice.org.uk/guidance/ng188)

recovered from COVID-19 at a median follow up of seven months.<sup>2</sup> Evidence suggests that psychological symptoms are also common, and people may have increased risk of mental health problems after COVID-19 infection.<sup>3</sup> Long COVID can be disabling and affect people's functional independence and ability to work.

COVID-19 may be associated with post-acute organ impairment. A study by the Office of National Statistics (ONS) found that hospitalised COVID-19 patients have elevated rates of diabetes, major cardiovascular events and respiratory disease post-discharge, and risk was greater for younger age groups and ethnic minority groups.<sup>4</sup> Research internationally shows that COVID-19 patients may have persistent impaired lung function,<sup>5</sup> or ongoing myocardial inflammation after acute infection.<sup>6</sup>

Long COVID may consist of a number of distinct syndromes, which could include post-ICU syndrome, post-viral fatigue syndrome, long-term COVID syndrome and permanent organ damage.<sup>7</sup>

The ONS's Coronavirus Infection Survey of households found that:

- 21% of respondents who tested positive for COVID-19 still reported symptoms at 5 weeks after infection
- 13.7% of respondents who tested positive for COVID-19 still reported symptoms at 12 weeks after infection.<sup>8</sup>

Ongoing symptoms occurred in all age groups, although were most prevalent in people aged between 35-69. Evidence from the ISARIC study and others suggest that women may be more likely to develop Long COVID than men.

Most children and young people (CYP) are asymptomatic or exhibit only mild symptoms following COVID-19 infection, though a small number may develop a delayed onset systemic inflammatory response known as [Paediatric Inflammatory Multisystem Syndrome \(PIMS\)](#). CYP may also be affected by 'Long COVID'.

<sup>2</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/968923/s1138-isaric4c-long-covid-preliminary-results.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/968923/s1138-isaric4c-long-covid-preliminary-results.pdf)

<sup>3</sup> [www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(20\)30462-4/fulltext](http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(20)30462-4/fulltext)

<sup>4</sup> [www.bmj.com/content/372/bmj.n693](http://www.bmj.com/content/372/bmj.n693)

<sup>5</sup> [www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)32656-8/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)32656-8/fulltext)

<sup>6</sup> <https://jamanetwork.com/journals/jamacardiology/fullarticle/2768916>

<sup>7</sup> <https://evidence.nihr.ac.uk/themedreview/living-with-covid19-second-review/>

<sup>8</sup> [www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1april2021](http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1april2021)

Evidence is still evolving, though symptoms are thought to be similar to those experienced by adults, with fatigue being most commonly reported.<sup>9</sup> Long COVID symptoms in CYP can occur in those who have had mild or asymptomatic illness. Around 9.8% of children aged two to 11 years and 13% of those aged 12 to 16 years have continued symptoms at five weeks after infection.

## 5. Why is this guidance being issued?

In October 2020 NHS England and NHS Improvement announced a £10 million investment to help local services in every part of the country bring together the right professionals to help people requiring healthcare for Long COVID. These professionals will provide physical, cognitive, psychological and psychiatric assessments, as well as testing functional abilities, of those experiencing suspected post-COVID syndrome, so that they can be referred to the right specialist help.

In March 2021 NHS England and NHS Improvement provided a further contribution of £24 million for post-COVID assessment clinics to support the anticipated demand for these services in 2021/22.

Funding will be allocated by NHS England and NHS Improvement's regional teams to healthcare systems to agree the best models for delivery of these services, including how children and young people will be assessed. This allows for pooling of the funding where joint services across healthcare systems would be deemed appropriate.

## 6. Scope

This guidance sets out the considerations for the establishment of post-COVID assessment clinics, so that they meet the varied needs of this patient population.

This includes:

- Patients who remained at home or in a care setting during their acute COVID-19 illness and who had positive SARS-Cov-2 serology or clinically diagnosed in the absence of a positive test or were not tested at all.

<sup>9</sup> <https://pubmed.ncbi.nlm.nih.gov/33205450/>

- Those who were hospitalised during their COVID-19 infection and have been discharged.
- Children and young people (CYP).

Some patients will need further therapeutic input, rehabilitation, psychological support, specialist investigation or treatment once they have been assessed, and it is the responsibility of the assessment service to refer patients on to existing services as needed, so that care is coordinated and joined-up. Advice or signposting as a one-off intervention in the assessment service may also be offered.

The setting of service delivery is for local determination and may be based in primary, secondary or community services, as long as there is prompt access to appropriate diagnostics and treatments. A virtual element to the services should also be considered.

As a minimum the post-COVID assessment services should:

- Ensure coverage of the population in each system.
- Be available, following general practice or other clinician, referral, to all affected patients, whether hospitalised or not from 4 weeks after the start of acute COVID-19 illness if required.
- Have locally agreed thresholds for referral, based on NICE/SIGN/RCGP guidance.
- Ensure that access to the post-COVID assessment services of groups<sup>10</sup> who experience health inequalities are:
  - predicated upon an assessment framework (such as Equality and Health Inequalities Assessment Framework; EHIA)
  - monitored (via clinic data and the health equity audit)<sup>11</sup>
  - acted upon urgently if discrepancies are identified.
- Have an internal and external communication plan<sup>12</sup> for raising awareness within the clinical community and key stakeholders including:

<sup>10</sup> Groups include deprived groups, people with disabilities (including Learning Disabilities and Severe Mental Illness), Ethnic minorities (including Black, Asian and minority ethnic groups), inclusion health (homeless and Traveller communities), people with pre-existing long-term conditions

<sup>11</sup> Information on the health equity audit is available on the NHS Long COVID futures platform

<sup>12</sup> The communications strategy must prioritise health access and inequalities through the use of patient educational material

- patients, and the public
- primary care networks, community services, voluntary services, secondary care services, mental health services.
- Have access to a multidisciplinary team of professionals to account for the multi-system nature of post-COVID syndrome.
- Have access to diagnostic tests as recommended by NICE/SIGN/RCGP.
- Support collaboration across localities where patients' needs require this.
- Have access to direct referrals to specialist services in the community and secondary care, multidisciplinary rehabilitation services and specialist mental health services.
- Have a named lead to provide data in line with national requirements (see section 12).

These requirements will be included in service audits throughout 2021.

### **Service accessibility and inclusion**

All healthcare systems should consider how they will minimise health inequalities in the planning and delivery of post-COVID assessment services. This includes, but is not limited to:

- Being supportive to those with learning disability and/or autism or pre-existing mental health problems and being aware of diagnostic overshadowing
- Socio-economic inequalities; including those in the bottom 20% as measured by Index of Multiple Deprivation (IMD)
- Ethnic minority group inequalities
- Inclusion health groups (homeless and traveller communities)
- Lesbian, gay, bisexual and transgender plus (LGBT+) people
- Sex
- Gender reassignment
- Language and cultural barriers
- People with an existing disability such as visual or hearing impairment
- People in secure units
- Marriage and civil partnership
- Pregnancy and maternity

- Religion or belief
- Age.

Healthcare systems should monitor the demographic data of those who have been referred and adapt communications and referral pathways as needed. The foundation for this will be appropriate coding and completion of all SITREP fields.

All services should develop plans for ensuring equity of access, utilizing an assessment framework for example EHIA.

Equity of access must be a key objective of the service. Consideration should be given to disadvantaged groups with regards to how they access and utilise healthcare services and to ensure that no one is discouraged or unable to benefit. This may require a proactive, potentially case finding approach in some populations to identifying those who may typically be less likely to access healthcare. Virtual or out-of-hospital services should be considered.

Patients should not be disadvantaged from accessing services due to financial costs or language barriers and cultural beliefs or digital literacy or digital access. Consideration should also be paid to access for children and young people; services should have safeguarding policies in place and work closely with local authorities if social care needs are to be considered.

An Equalities and Health Inequalities Impact Assessment has been completed for this post-COVID assessment services guidance.

## 7. Referral routes into the patient pathway

Clinicians should be advised to 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).

There are three main referral routes into the post-COVID assessment services:

### **1. People never admitted to hospital with their acute illness but managed independently or in the community**

Many people reporting post-COVID syndrome symptoms were not admitted to hospital during the acute phase of their infection.

- Patients will be signposted to contact their GP via community pharmacies, the NHS website, Your Covid recovery website and the Test and Trace service if they have new or ongoing symptoms developed 4 weeks or more after the start of suspected or confirmed acute COVID-19.
- Many people will self-manage or access self-support directly (without a referral), such as the online platform Your COVID Recovery (YCR).
- An assessment should be carried out by the GP, using a holistic, person-centred approach. This should include a comprehensive clinical history and appropriate examination that involves assessing physical, cognitive, psychological and psychiatric symptoms, as well as functional abilities.
- Tests and investigations should be offered that are 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 as per NICE/SIGN/RCGP guidance.
- If further investigations or support are required, the patient may be referred into a post-COVID assessment service. While this may be most appropriate from 12 weeks for many, there may be some people who need it earlier (from 4 weeks as per NICE/SIGN/RCGP guidance). The timing is based on individual need and is at the discretion of the assessing clinician. However, although recovery time is different for everyone, for many people symptoms will resolve by 12 weeks.

## **2. People hospitalised with COVID-19**

A detailed discharge summary of the admission and ongoing related conditions should be provided to primary care, and social needs should include caring responsibilities the affected person had prior to hospitalisation that they may return to. Arrangements to assess any respiratory complications should be made according to [British Thoracic Society guidance](#).

- As per the post hospital discharge pathway detailed below (figure 2), these patients should initially undergo a 12-week post hospital discharge assessment which will include a chest X-ray, review of symptoms and consideration of further investigations and rehabilitation requirements.

## **3. People cared for in an Intensive Care Unit (ICU) or High Dependency Unit (HDU) with COVID-19.**

People with COVID-19 cared for in an ICU/HDU setting should undergo a multidisciplinary team (MDT) assessment of rehabilitation needs at the point of step down to other inpatient facilities. Inpatient rehabilitation with defined goals should begin immediately.

- On discharge from hospital an assessment of ongoing needs with appropriate community service referral if needed.
- A post ICU multidisciplinary clinic re-assessment should be undertaken at 4-6 weeks post discharge to review early symptoms as per figure 2 with consideration of early referral to rehabilitation or mental health services as required.
- If patients are continuing to improve at the early review then as per the post hospital discharge pathway detailed below (figure 2) they will be asked to attend a 12-week post hospital discharge assessment which will include a chest X-ray, review of symptoms and consideration of further investigations and rehabilitation requirements.
- People who develop new symptoms after the 12-week follow up should be reviewed by their GP.

Clinicians should consult the NICE/SIGN/RCGP guidance for recommendations on appropriate investigations and referral.

## 8. The patient pathway

Many healthcare systems have designed their own models and patient pathways for managing people with post-COVID syndrome and these existing models may form the basis for the development of post-COVID assessment services.

### Three principles of care for Long COVID

#### 1. Personalised care

By listening to people and asking, ‘what matters to you?’ a personalised care and support planning process based on what matters most to individuals is a crucial initial step in providing personalised care.

- To help health and care staff with the knowledge, skills and confidence to deliver personalised care, they can access the [Personalised Care Institute \(PCI\)](#). This allows clinicians to access PCI accredited eLearning, view accredited training providers and programmes as well as access high quality resources (to support learning) in the core skills of personalised care, personalised care and support planning and shared decision making.
- More information can be found [NHS England » Personalised care](#).

#### 2. Multidisciplinary support and rehabilitation

A multidisciplinary team should tailor support and rehabilitation for the person to enable:

- the development of individual care plans for physical, mental and social needs which may include supporting people through the Your COVID recovery interactive rehabilitation platform; and
- access to clinical review in primary care and more specialist advice or rehabilitation when needed.

### 3. Supporting and enabling self-care

Some people with milder symptoms may be able to help themselves through self-management. Options to enable people with self-care include:

- signposting to [Your COVID Recovery](#) online platform to enable ongoing support and enhance self-care, or other NHS-endorsed online support services.
- techniques such as shared decision making, SMART goal setting, health coaching, virtual group consultations for peer support and social prescribing, linking with the third sector in recognition of the whole-person biopsychosocial needs; and
- using Patient Activation Measures (PAM) to help to determine the level of support required.

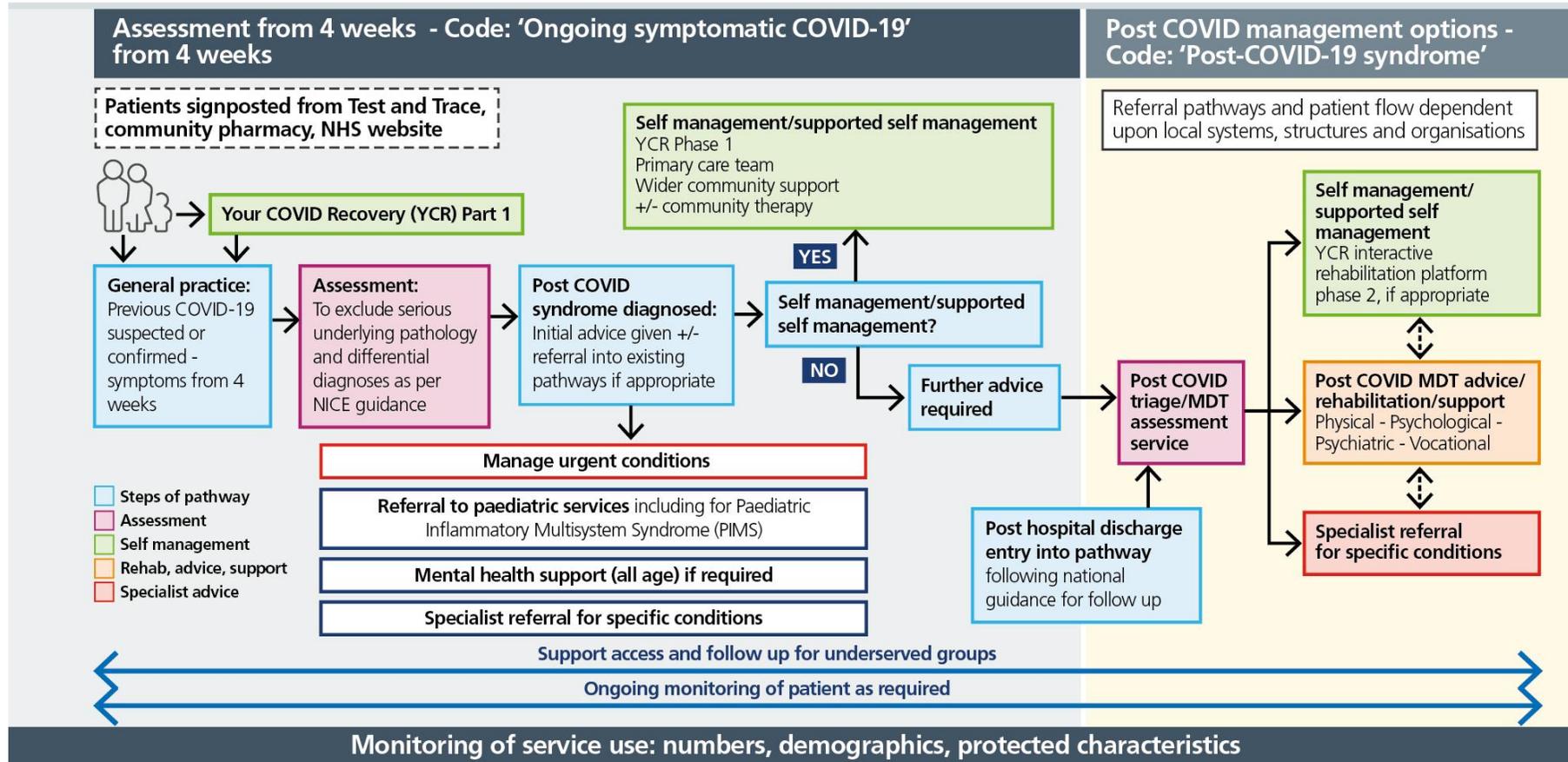
#### Post-COVID syndrome pathways

The updated care pathways below have been amended following the publication of the COVID-19 rapid guideline: managing the long-term effects of COVID-19 by NICE/SIGN/RCGP in December 2020.

The pathways are designed to help the NHS improve people's physical, psychological and cognitive outcomes and to signpost to social support (for all ages). This is through offering a holistic, needs-based, person-centred, integrated care approach which has access to a clinical assessment or intervention as required. There is also recognition of the importance of minimising inequities of access and outcomes and of continuing to learn about this new condition as our understanding grows.

# Primary/community care post-COVID syndrome pathway all ages

Incorporating NICE/SIGN/RCGP guidance 2020



## The role of General Practice

General practice plays a key part in the Long COVID clinical pathway. Patients, with previously confirmed or suspected COVID-19, may present with a wide range of symptoms including breathlessness, fatigue, chest pains, cognitive impairment or psychological symptoms.

The initial role of the general practice clinician is to exclude acute or life-threatening complications and other unrelated diagnoses. Assessment may include blood tests, chest X-rays or clinical tests, including sit-to-stand or lying and standing blood pressure, depending on the person's signs and symptoms (as per NICE/SIGN/RCGP guidance). Treatment or referral to the relevant acute or specialist services may be required.

Where an assessment in general practice identifies a mental health condition as the predominant symptom a referral should be considered in line with existing local mental health pathways, both for adults and children.

As symptoms can be relapsing and remitting, with new symptoms appearing, assessment may not be a one-off occurrence. All assessments, whether the first or on an ongoing basis, should consider physical, psychological and cognitive problems.

If ongoing symptomatic COVID-19 is diagnosed (from >4 weeks after infection), the patient may be offered the following:

- Signposted to self-management including the online platform Your Covid Recovery (YCR) Phase 1.
- Supported self-management which may include support from the practice or primary care network team and linking into community groups.

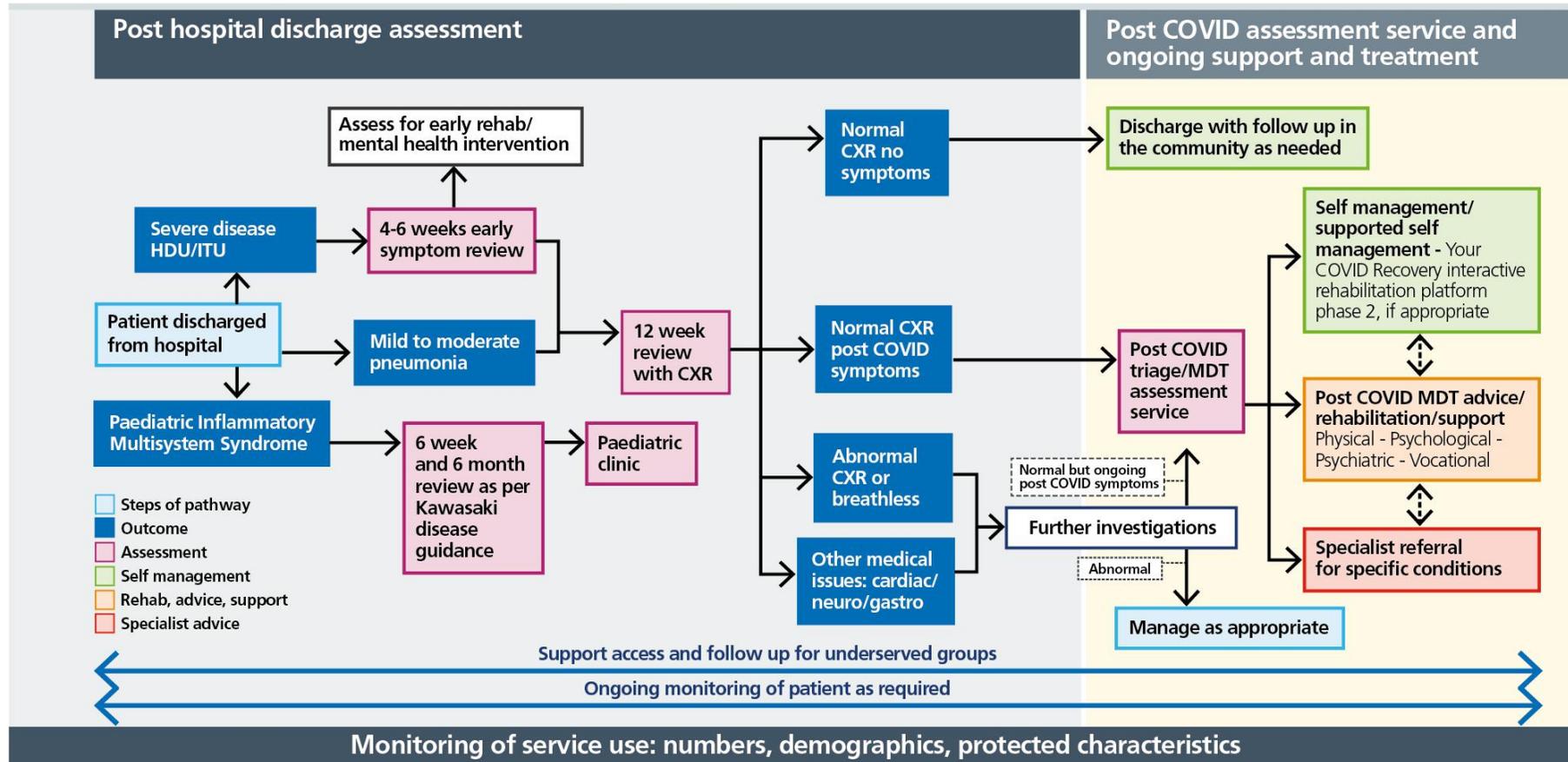
If further investigations or support are required, the patient may be referred into a post-COVID assessment service. While this may be most appropriate from 12 weeks for many, there may be some people who need it earlier (from 4 weeks as per NICE guidance). The timing is based on individual need and is at the discretion of the assessing clinician. However, although recovery time is different for everyone, for many people symptoms will resolve by 12 weeks.

### **Post hospital pathway:**

- A healthcare professional in secondary care should offer a video or phone follow-up consultation at 12 weeks after discharge to people who have been in hospital with acute COVID-19 to check for new or ongoing symptoms or complications.
- People whose symptoms persist after the 12-week follow up should be reviewed by their GP.
- An assessment and investigation of new or ongoing symptoms after 12 weeks, in secondary care outpatient services or in primary care, should rule out alternative diagnosis, and if no alternative diagnosis is made, the patient should be referred to the post-COVID assessment service.

# Post hospital discharge pathway for COVID-19

Incorporating British Thoracic Society (BTS) guidelines



## The post-COVID assessment service:

- NICE/SIGN/RCGP guidance advises that the post-COVID syndrome assessment clinic should provide multidisciplinary services for assessing physical and mental health symptoms and carrying out further tests and investigations.
- Post-COVID assessment clinics could act as ‘one stop shops’ which provide specialist assessment, diagnosis and treatment. Some healthcare systems have developed tailored rehab packages for Long COVID patients which are delivered by therapists working in the post-COVID assessment clinics.
- The multi-system nature of COVID-19 and its psychological impact mean that a broad holistic assessment is most beneficial. The [British Thoracic Society guidance](#) identified that the post-COVID syndrome holistic assessment should at least include:
  - Assessment and management of breathlessness
  - Symptom or palliative care management where required
  - Assessment and management of oxygen requirements
  - Consideration of rehabilitation needs and onward referral where required
  - Psychosocial assessment (depression, anxiety disorders, PTSD, traumatic bereavement, psychosis screen, risk to self and/or others, COVID related life stresses such as debt, unemployment, relationship issues) and onward referral where required
  - Assessment and management of dysfunctional breathing
  - Cognitive function
  - Post-exertion malaise, fatigue and neurological symptoms
  - Consideration of a new diagnosis of venous thromboembolic disease (VTE)

## Referral on to other services from the post-COVID assessment service

While some issues can be addressed immediately in the post-COVID assessment service, some patients will need further therapeutic input. After a holistic assessment, clinicians should 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 referral to Your COVID Recovery, an online tailored interactive self-management programme developed by NHS England and NHS Improvement with the University Hospitals Leicester NHS Trust. A paper based version is being developed for those unable to access the digital platform which will be available in summer 2021. Patients may also be signposted by their clinician to other interactive digital rehabilitation platforms.
- post-COVID multidisciplinary advice and rehabilitation
- a specialist referral for specific conditions.

Services should have clear pathways to ensure referral into appropriate services which may include rehabilitation, psychological support, specialist investigation or treatment, or to social care support services or the voluntary, community and social enterprise sector. Prioritisation should be based on clinical need not condition.

The GP should receive communication from the assessment service on the patients care, and consideration should be given to the provision of Med3/fitness for work to avoid further appointments, unless the patient is discharged back to the care of primary care for ongoing management.

Clinicians should work together to ensure that physical and mental healthcare are integrated as closely as possible. Where available, patients with mental health and psychological issues with persisting physical problems may benefit from referral to integrated IAPT-LTC (Improving Access to Psychological Therapies) services or in the case of an under 18-year-old, the relevant children and young people's mental health service.

Transition between children's and adult services should be supported and services should work flexibly to provide support based on the needs of the young person. Where possible an episode of treatment should be completed before consideration of transition to ensure continuity of care.

Services for which referral pathways should be available that might be of particular benefit include:

- Specialist lung disease services, sleep services, and pulmonary rehabilitation
- Cardiac services including cardiac rehab
- Neurology
- Rheumatology
- Dermatology
- ENT
- Infectious disease services
- Gastroenterology
- Co-morbidity management eg for diabetes or obesity
- Occupational health
- Multidisciplinary rehabilitation services
- Physiotherapy
- Occupational therapy
- Dietetics and nutrition services
- Pain management
- Fatigue services
- Social care support services
- Primary care led care including care coordinators and social prescribers
- Improving Access to Psychological therapies (IAPT) and other mental health services including cognitive management

### **Multidisciplinary rehabilitation**

Long COVID has highlighted the importance of rehabilitation services in the treatment of chronic conditions.

- Multidisciplinary rehabilitation services should be integrated and based on local need and resources.
- Details of the workforce recommended by NICE/SIGN/RCGP guidance are described in section 11.
- On referral, physical, psychological and psychiatric aspects of rehabilitation should be assessed to guide management.

- A personalised rehabilitation and management plan should be recorded in a rehabilitation prescription and include details of the areas of interventions, goals and symptom management as per NICE guidance.

## 9. Children and young people (CYP)

It is important that an early holistic medical assessment is performed in CYP with suspected Long COVID to identify those in need of further specialist input and management for organ impairment, as well as offering appropriate support for other wide-ranging symptoms that may significantly affect quality of life.

As with adult services, some CYP may need further therapeutic input, rehabilitation, psychological support, specialist investigation or treatment once they have been assessed, and patients should be referred to existing services as needed.

### **The patient pathway**

Regional teams should work with healthcare systems to agree the best models for delivery of post-COVID assessment and management services for CYP. To support with this, suggested pathways currently in use by local areas are available on the NHS Futures website.

To inform a case definition, standardised data should be gathered nationally from those identified within primary care, educational settings, secondary care and specialist assessment services. A standardised questionnaire has been developed incorporating elements of the Strengths and Difficulties Questionnaire (SDQ) the EQ-5D-Y, the 11-item Chalder Fatigue Questionnaire (CFQ). Completion of the questionnaire at baseline, 3 months and 6 months can be used as an outcome measure.

For all CYP, the impact of the illness on the child and family as a whole unit should be assessed, including day-to-day functioning and access to education. It may help to consider the following as part of the assessment:

- Be aware of wide-ranging and fluctuating symptoms after acute COVID-19, which can change in nature over time.
- Be aware of possible symptoms and signs suggestive of possible specific organ impairment such as chest pain, palpitations, breathlessness and

symptoms or signs suggestive of possible ongoing inflammatory or autoimmune response, eg recurrent fever, rashes, joint symptoms, weight loss. These children may need specific investigations and timely discussion/referral to tertiary paediatric specialists.

- Consider alternate diagnoses for their symptoms.
- Discuss how the child's life and activities have been affected by ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome, eg education, mobility and independence.
- Listen to the CYP's concerns with empathy and acknowledge the impact of the illness on their day-to-day life, education, and wellbeing.
- Discuss the CYP's experience of their symptoms and ask about any feelings of worry or distress.

## **Referral routes**

Most CYP with persistent symptoms will not have been hospitalised during the acute phase of their illness. Referral may be from many routes, including school, community child-development service, community therapies, CAMHS, primary care etc. Initial assessment should be by their GP and symptoms appropriately investigated for an alternative diagnosis.

Post-COVID syndrome may involve changing symptoms or new symptom development. In particular, children with SEN or neurodisability may not be able to express new symptoms, so careful consideration of changes in behaviour etc should be reviewed.

- An assessment should be carried out by the GP, using a holistic, person-centred approach. This should include a comprehensive clinical history and appropriate examination that involves assessing physical, cognitive, psychological and psychiatric symptoms, as well as functional abilities.
- Tests and investigations should be offered that are 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.

- If further investigations or support are required, the patient may be referred onwards. While this may be most appropriate from 12 weeks for many, there may be some CYP who need it earlier. The timing is based on individual need and is at the discretion of the assessing clinician. However, most patients will improve or recover by 12 weeks.
- It is not expected that all CYP will need referral from primary care onwards – many of these young people can be managed by their GP with simple measures including advice (sleep hygiene, gentle exercise, liaison with school), common investigations and treatment.
- In the first instance, it is recommended that primary care links in through established routes to secondary care for advice – this may be through integrated care, or through advice lines, depending on the local arrangements.
- Referral to a local general paediatrician for investigation of alternative diagnoses is recommended if there are ongoing concerns which are not settling with simple interventions.
- It is not expected that all CYP will need referral from secondary care to the virtual MDT/specialist assessment clinics. Many general paediatricians are experienced in the management of CYP with persistent symptoms, but where there is significant functional impact, or concerning symptoms, it may be appropriate to refer onwards.
- A virtual MDT will be held regularly by the post-COVID assessment clinic team and participation by the referring paediatrician to discuss the case is encouraged.
- Self-management tools should be made available to the CYP and their families while awaiting referral
- All children and their families should be invited to complete the composite questionnaire. This can be completed at home and the clinician is not expected to do this in clinic. For those whose first language is not English,

support answering the questions may be required and provided by those involved with the CYP – such as the school nurse, AHP, health visitor, SENCO, etc.

Pathway for CYP hospitalised with severe COVID pneumonia or PIMS (Paediatric inflammatory multisystem syndrome).

- Routine follow up of these children in MDT clinics is recommended for one year following admission.
- For many of these young people, intensive input is not required.
- For a subset, access to therapies and psychology support is invaluable.
- Access to the self-management tools is recommended.

## 10. Post-COVID assessment service design

- The multi-system nature of post-COVID syndrome means that holistic assessment and treatment are likely to be needed, so services should be able to draw on multi-professional expertise and have access to a range of assessment and diagnostic tests.
- The services may be located on a single site, delivered across multiple sites or where appropriate, virtually. Accessibility should be a priority both in terms of geographical location and service delivery models. There will need to be the opportunity for patients to have a multidisciplinary assessment plus diagnostics, at least for the initial physical assessment.

Addressing psychosocial and cognitive issues may be done at the same time or subsequently, and potentially remotely using digital platforms or telephone. This should be determined by clinical need and especially considered if a full assessment is too onerous for the patient.

- Diagnostics and testing availability should include all tests deemed appropriate for the presentation of the patient. This may include imaging, cardiac investigation, physiological measurement and phlebotomy.

- Integrated referral pathways between primary and community care, multidisciplinary rehabilitation services and specialist services, multidisciplinary assessment clinics and specialist mental health services should be agreed.
- Services should share knowledge, skills and training to help practitioners in the community provide assessments and interventions.
- Services treating children and young people should address safeguarding.
- Services should follow the [Accessible Information Standard](#) and have access to interpreters, including British Sign Language interpreters.

## 11. Workforce

There is the opportunity for local systems to consider innovative and locally appropriate approaches to service leadership and skill-mix. It is recognised that different regional and geographical challenges mean that areas have different service needs and resources, so one model may not be suited to all areas.

However, a multidisciplinary service for assessment can avoid multiple referrals and would provide a single point for care. This could be a 'one-stop' service to help keep appointments to a minimum, although this might not be feasible for all services or wanted by all patients. NICE/SIGN/RCGP have made recommendations around multidisciplinary team working in their guidance.

1. NICE/SIGN/RCGP guidance currently recommends that access to multidisciplinary services is provided (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.
2. Post-COVID syndrome services should 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).

3. Physiotherapists can provide a holistic assessment to identify the specific needs of the patient and agree a personalised plan. They offer support, rehabilitation and self-management advice for patients dealing with symptoms such as breathlessness, de-conditioning, fatigue and dizziness and can include specific guidance on pacing, rest and recovery time.
4. Speech and language therapists provide holistic assessments to identify the specific needs of the patient and agree a personalised plan. They support the rehabilitation and self-management of individuals who have identified common clinical presentations seen in post-COVID syndrome, including cognitive communication (incl. brain fog), swallowing, voice (incl. muscle tension dysphonia) and respiratory difficulties.
5. Occupational therapists can provide a personalised and occupation-focused approach to assessment such as cognition, delirium, mental health and functional outcome, independence and activity measures, including support for self-management and social prescribing.
6. Psychologists can provide assessment of cognition, mental health, provide support for patients managing persistent symptoms and can also provide access into services such as IAPT, wider health, social care and third sector provision and pain, fatigue and neuro-rehab services.
7. Specialist nursing functions and roles such as district nursing, community nursing, psychiatric nursing, clinical nurse specialists and general practice nurses for example can support holistic assessment and treatment of both the patient and wider family needs while also supporting the coordination of services more widely where appropriate.
8. Dietitians can support people living with post-COVID syndrome in a range of ways, including advice on the impact of COVID-19 on nutritional status and provision of support to address malnutrition because of loss of appetite, breathlessness, swallowing difficulties or other Long COVID symptoms.

## 12. Data and management information

### Purpose

Due to the paucity of information surrounding Long COVID, there is an urgent need for data to inform clinical management and health access for those disproportionately impacted by COVID-19. Data is used to support funding, operational decisions and research, and the quality of data is a key component of the commission for post-COVID assessment services.

### Data reporting for the post-COVID assessment service

A SITREP has been established to assess the activity data within the scope of the post-COVID assessment clinic. The SITREP contains two sections:

INPUTS	Referrals – origin and number Number of assessments Demographics – age, sex, index of multiple deprivation, ethnicity A clinic list with patient identifiers
OUTPUTS	Completed assessments Diagnostics Onward referrals

Following provider feedback on how to improve data quality, an amended SITREP will be introduced in Spring 2021. This will include collection of a 'clinic list'. The clinic list involves the recording of the patient's identity and the date of their first attendance at the post-COVID assessment service. It will facilitate patient level data linkage across national data collections and form the basis of a national patient registry. This will reduce data burden on the post-COVID assessment services in the long term.

### Responsibilities for data collection

Due to the nature of post-COVID syndrome management, with pathways spanning the entire health system (primary, secondary and community care), collecting such data is recognised as challenging. Therefore, local and regional leadership is key.

- **Each provider** is encouraged to have a data lead (focal point) who ensures:
  - Data is submitted via SITREP fortnightly.
  - Local SITREP data trends, key indicators in relation to performance (referrals, assessments) and health access (IMD, age, sex, ethnicity) are acted upon monthly.
  - Quality and completeness of data reporting.
  - Escalation of SITREP problems to regional teams in a timely fashion.
  - Promotion of clinical coding locally to support automation of SITREP data collection.
  
- **Each region** is encouraged to have a data lead (focal point) who ensures:
  - Quality and completeness of data reporting among providers.
  - A regional dashboard which facilitates the accurate monitoring of key indicators in relation to performance (referrals, assessments, completion rates) and health access (IMD, age, sex, ethnicity).
  - Key indicators are acted upon in conjunction with the relevant team if they fall below the region's expectations, eg working with the regional health inequalities senior responsible officer (SRO).
  - Quality assurance of regional data against other collections (see below).
  - Promotion of clinical coding regionally to support automation of SITREP data collection.
  
- **National data responsibilities**
  - Support the data collection process and report on regional performance.
  - Ensure regions are provided with SITREP data in a timely fashion.
  - Support establishment of regional dashboards.
  - Support regions on 'coding counts' to reduce variation in coding (see below).

To enhance the SITREP, additional aggregate reporting across primary and secondary care will be derived from centrally held national data collections. The augmented reporting will be shared with providers via the regional teams, ensuring there is transparency in its content and its use.

## Primary care

It is important to accurately capture data on primary care activity related to Long COVID, in order to support modelling of demand, service planning, and research.

NHS England and NHS Improvement has worked with NHSX, NHS Digital, and the Professional Records Standards Body to develop a set of SNOMED CT codes related to post-COVID syndrome, which have been made available on all major primary care EPR systems.

General practitioners should code for all of the following data categories (the 'minimum dataset'), if applicable, when delivering care for people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome (see Appendix B for recommended codes):

- COVID-19 diagnosis (where this has not been previously recorded)
- Ongoing symptomatic COVID-19/post-COVID-19 syndrome diagnosis
- Red flag symptoms/signs
- Diagnostics/investigations
- Management/referrals
- Outcome measure score – EQ-5D-5L, EQVAS (where available)

General practitioners are encouraged to use appropriate clinical templates to support coding.

Patients **do not need** to have had a positive SARS-CoV-2 test (PCR, antigen or antibody) or a previous COVID-19 diagnosis code, for the post-COVID syndrome codes to be used.

## Secondary care

A Treatment Function Code for post-COVID-19 syndrome service is available from April 2021. It is defined as follows:

- TFC number: 348
- TFC name: Post-COVID-19 syndrome service
- TFC description: Multidisciplinary services for patients experiencing long-term health effects following COVID-19 infection, whether or not this was diagnosed at the time of acute illness or the patient was initially

asymptomatic. Post-COVID-19 syndrome has also been known as 'Long COVID'.

Providers of post-COVID assessment services should use the Treatment Function Code for their service, which will enable tracking of service activity and associated onward diagnostic and referral activity. Clinics should also ensure complete demographic data (age, sex, ethnicity, postcode) is recorded for each patient.

### **Community providers**

Assessment clinics should ensure implementation of SNOMED CT coding where compatible clinical information systems are in place. A **post-COVID assessment service coding minimum dataset** to guide coding can be found in Appendix C. Clinics should also ensure complete demographic data (age, sex, ethnicity, postcode) is recorded for each patient.

### **National patient registry**

NHS England and NHS Improvement will establish a national patient registry for patients attending the post-COVID assessment clinic by July 2021. The registry will be based on data linkage across national data collections, facilitated by clinical coding and the clinic list collected from post-COVID assessment clinics.

It will provide insight of the longitudinal patient journey and support operational, clinical and research needs. Importantly, it will also allow a more granular understanding of healthcare access for those groups who experience health inequalities.

### **Evaluation of post-COVID assessment services**

Providers are encouraged to establish post-COVID assessment services that follow commissioning guidance and best suit their local environment. In order to reduce variance between services, an audit of the post-COVID assessment services against the minimum standards set out in section 6 will commence in 2021.

Following the establishment of the post-COVID assessment service, it is envisaged that 'an impact' evaluation will take place in the Autumn of 2021.

## Further support

Resources to support data and data collection, including frequently asked questions will be made available on the Future NHS platform. Updates to the SITREP and changes to the method of data collection will be communicated to providers via NHS Digital and regional teams.

# 13. Key service outcomes

It is critical to gather and analyse data, participate in shared learning and use this information to inform future practice and reduce unwarranted variation in the management and subsequent outcomes of patients with post-COVID syndrome symptoms.

This data collected in the form of patient reported outcome measures (PROMs), clinical measurements and patient reported experience measures (PREMs) help to monitor patient progress, facilitate communication between professionals and improve the quality of services.

This data will also be used to inform service providers and commissioners in resource planning to maximise resources and service resilience.

## Outcome measures

NHS England and NHS Improvement has reviewed the instruments available to monitor patient recovery trajectories and the impact of symptoms on an individual's functional status. Further discussion with research groups and a survey of post-COVID assessment clinics identified regularly used PROMs.

Based on this review, the use of the [5-level EQ-5D version \(EQ-5D-5L\)](#), Health-Related Quality of Life (HRQOL) measure including the EQ Visual Analogue Scale (EQ VAS) component is to be completed in all patients. The EQ-5D-5L, developed by the EuroQol Group is a measure that generates a single index value for health status and is available in over 130 languages with versions for both in person and telephone interviews.

It comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems and extreme problems. The EQ

VAS records the patient's self-rated health on a visual analogue scale, ranging from 100 points for 'The best health you can imagine' and 0 points 'The worst health you can imagine'. The VAS can be used as a quantitative measure of health outcome that reflect the patient's own judgement.

Recommended collection timepoints for both tools are:

1. At the first post-COVID assessment service appointment
2. 8-12 weeks after the first service appointment
3. 6 months after the first service appointment

It is recognised that other tools have been utilised by post-COVID services therefore it is recommended that if measures are already being regularly undertaken in clinical practice including the [COVID-19 Yorkshire Rehabilitation Scale](#) they are continued to be used in order to develop a psychometric analysis of the scale and calculate the minimal clinically important difference (MCID).

Patient reported outcome measures are available for the majority of the wide range of symptoms caused by post-COVID syndrome which can impact physical, psychological and cognitive health. While validated outcome measures for post-COVID syndrome are being developed it is recommended to utilise established PROMs as required to assess the severity of symptoms, monitor recovery and aid in the communication between health care professionals.

For example, for patients requiring referral and/or treatment within psychological services this may include outcome measures recommended in [The Improving Access to Psychological Therapies Manual](#).

### **Patient experience measures**

All providers are expected to collate information on patient experience in the post-COVID assessment services via Friends and Family Testing and a question surrounding patient access.

Of interest will be the patient experience of groups who experience difficulties regarding health access and health inequality. These include people with disabilities (including those with learning disabilities and severe mental illness), Ethnic

minorities, inclusion health groups (homeless and traveller communities), and people with pre-existing long-term conditions.

Aggregate reporting of patient experience will occur regionally and nationally.

## 14. NHS Standard Contract

CCGs may use the NHS Standard Contract to commission post-COVID syndrome assessment and management services. The service specification should be recorded in Schedule 2A of the [Particulars of the Contract](#), where a non-mandatory model template for local determination and population is provided.

Guidance on developing the specification and populating the contract template is provided in the [Contract Technical Guidance](#).

Queries in using the contract can be sent to: [nhscb.contractshelp@nhs.net](mailto:nhscb.contractshelp@nhs.net).

## 15. Communications

Each commissioner should develop and implement plans to raise awareness of post-COVID assessment services in their clinical communities.

These plans should cover communications to general practitioners, hospital doctors, registered nurses, pharmacists, clinical and health psychologists, psychological therapists (especially in IAPT services) and other allied health professionals and clinicians in primary, secondary, community, and tertiary care. Other public bodies, including secure unit services such as prisons, local councils, and education, should also be included in these plans, to ensure equitable access.

Communications should regularly include updates on data (such as the development of new post-COVID syndrome codes) and data collection to local systems. Communications should also be targeted at reducing variation in coding amongst primary care networks and systems.

Healthcare systems can utilise existing communications platforms, including formal NHS platforms, membership bodies, and voluntary organisations.

Commissioners should also develop culturally relevant communications plans to raise awareness amongst patients and the public, ensuring these communications are targeted at audiences from all backgrounds to ensure equity of access to the services.

NHS England and NHS Improvement will support communications to patients, public and healthcare systems in parallel.

## 16. Governance and assurance

NHS England and NHS Improvement regional teams will continue to work with healthcare systems and commissioners on the best arrangements for service delivery to ensure universal geographic coverage, support communications with patients and stakeholders and inform future delivery of service. Services will need to provide assurance that they are meeting the service requirements detailed in section 6 and specifically:

1. Geographical coverage of the entire regional population by the services, including a plan for ensuring equity of access, and delivery of care (bearing in mind many population groups have been disproportionately affected by COVID-19).
2. Services have a nominated service lead, and appropriate MDT to account for the multi-system nature of post-COVID syndrome. As a minimum this should include specialist mental health input and ability to refer to IAPT, physiotherapy, occupational therapy, and dietetics. Patients with complex needs requiring coordinated input should have an individual rehabilitation prescription and access to specialist rehabilitation with a single point of access.
3. Referral routes should include all affected patients whether hospitalised or not and based on clinical diagnosis in the absence of a positive SARS-CoV-2 serology.
4. Evidence of internal and external communications plan for local clinical and patient community.
5. Services have a data lead who liaises with the regional data lead.

# 17. The role of respiratory clinical networks

Respiratory networks have been heavily involved in the planning for, and response to, the increase in admissions from COVID-19. Respiratory clinical networks should, via their nominated lead, continue to work in partnership across primary, community or secondary care to support the planning and implementation of the post-COVID assessment services for children and young people.

In particular, networks should continue to:

- Provide guidance and support for the establishment of the services within a coherent local pathway for post-COVID syndrome.
- Work in partnership with clinical leaders from other specialties to support implementation, recognising the multi-system nature of the condition.

# Appendices

## Appendix A: Supporting resources

Please note these resources, or their online location, may be updated.

Please contact [england.clinicalpolicy@nhs.net](mailto:england.clinicalpolicy@nhs.net) if you require further information on accessing them.

- [NICE/SIGN/RCGP COVID-19 rapid guideline: managing the long-term effects of COVID-19](#)
- [Your COVID Recovery](#): NHS online interactive platform for patients with post-COVID syndrome to self-manage their rehabilitation
- [British Thoracic Society guidance](#)
- [e-Learning for Healthcare](#): four CPD accredited 20-minute e-Learning modules on breathlessness, exercise, cough and fatigue.
- [Royal College of General Practitioners House of Lords written evidence](#)
- [Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic – relevant to all clinical specialities](#)
- [After-care needs of inpatients recovering from COVID-19](#)
- [Allied health professionals' role in rehabilitation during and after COVID-19](#)

## Appendix B: Primary care coding minimum dataset

Minimum data categories that should be coded during care episode for ongoing symptomatic COVID-19 or post-COVID-19 syndrome in primary care and recommended SNOMED CT codes. This is based on [NICE/SIGN/RCGP guidance](#) and the current guidance.

Note that not all of these codes will need to be used in each encounter (if not present) and they are not intended to be exhaustive.

Data category	Term	SNOMED CT code
COVID-19 diagnosis (where not previously recorded)	COVID-19	840539006   Disease caused by Severe acute respiratory syndrome coronavirus 2 (disorder)
Ongoing symptomatic COVID-19/post-COVID-19 syndrome diagnosis	Ongoing symptomatic COVID-19	1325181000000106   Ongoing symptomatic disease caused by severe acute respiratory syndrome coronavirus 2 (disorder)
	Post-COVID-19 syndrome	1325161000000102   Post-COVID-19 syndrome (disorder)
Red flag symptoms/signs	Peripheral blood oxygen saturation on room air at rest	866661000000106   Peripheral blood oxygen saturation on room air at rest (observable entity)
	Peripheral blood oxygen saturation on room air on exertion	866681000000102   Peripheral blood oxygen saturation on room air on exertion (observable entity)
	Respiratory disease	50043002   Disorder of respiratory system (disorder)
	Cardiac chest pain	426396005   Cardiac chest pain (finding)
Diagnostics/ investigations	Blood test	396550006   Blood test (procedure)
	Assessment using 1-minute sit-to-stand test	1321911000000103   Assessment using 1-minute sit-to-stand test (procedure)
	Lying blood pressure reading	163033001   Lying blood pressure (observable entity)
	Standing blood pressure reading	163034007   Standing blood pressure (observable entity)
	Chest X-ray	399208008   Plain chest X-ray (procedure)
Management/referrals	Referral to paediatric service	306128002   Referral to pediatric service (procedure)
<ul style="list-style-type: none"> <li>Mental health support</li> </ul>	Referral to IAPT programme	380201000000109   Referral to improving access to psychological therapies programme (procedure)
	Referral to liaison psychiatry service	306136006   Referral to liaison psychiatry service (procedure)
	Referral to mental health team	390866009   Referral to mental health team (procedure)

<ul style="list-style-type: none"> <li>Specialist referral</li> </ul>	Referral to respiratory medicine service	306114008   Referral to respiratory medicine service (procedure)
	Referral to pulmonary rehabilitation	24461000000105   Referral to pulmonary rehabilitation (procedure)
	Referral to cardiology service	183519002   Referral to cardiology service (procedure)
	Referral to cardiac rehabilitation programme	704050007   Referral to cardiac rehabilitation program (procedure)
	Referral to pain management service	306109009   Referral to pain management service (procedure)
	Referral to gastroenterology service	183523005   Referral to gastroenterology service (procedure)
	Referral to endocrinology service	306118006   Referral to endocrinology service (procedure)
	Referral to neurology service	183521007   Referral to neurology service (procedure)
	Referral to rheumatology service	306127007   Referral to rheumatology service (procedure)
	Referral to dermatology service	183518005   Referral to dermatology service (procedure)
	Referral to ENT service	183544005   Referral to ear, nose and throat service (procedure)
	Referral to infectious diseases service	306124000   Referral to infectious diseases service (procedure)
<ul style="list-style-type: none"> <li>Self-management/ supported self-management</li> </ul>	Signposting to Your COVID Recovery	1325021000000106   Signposting to Your COVID Recovery (procedure)
	Provision of support for self-management	733810001   Provision of support for self-management (regime/therapy)
	Advised to self care	315241000000102   Advised to self care (situation)
	Primary care management	737470001   Primary care management (procedure)
	Referral to social prescribing service	871731000000106   Referral to social prescribing service (procedure)
	Community care management	781901000000106   Community care management (procedure)
<ul style="list-style-type: none"> <li>Post-COVID assessment clinic</li> </ul>	Referral to post-COVID assessment clinic	1325031000000108   Referral to post-COVID assessment clinic (procedure)
Outcome measure score (where available)	EQ-5D-5L - EuroQol five dimension five level index	736534008   EuroQol five dimension five level index value (observable entity)
	EQ-VAS - EuroQol visual analogue score	736535009   EuroQol visual analogue score (observable entity)

## Appendix C: Post-COVID assessment service coding minimum dataset

Minimum data categories that should be coded during post-COVID assessment service care episode and recommended SNOMED CT codes. This is based on [NICE/SIGN/RCGP guidance](#) and the current guidance.

Note that not all of these codes will need to be used in each encounter (if not present) and they are not intended to be exhaustive.

Data category	Term	SNOMED CT code
Ongoing symptomatic COVID-19/post-COVID-19 syndrome diagnosis	Ongoing symptomatic COVID-19	1325181000000106   Ongoing symptomatic disease caused by severe acute respiratory syndrome coronavirus 2 (disorder)
	Post-COVID-19 syndrome	1325161000000102   Post-COVID-19 syndrome (disorder)
Source of referral	Referred by general practitioner	108161000000109   Referred by general practitioner (finding)
	Referred by member of Primary Health Care Team	276491000   Referred by member of Primary Health Care Team (finding)
	Referred by hospital outpatient department	835091000000109   Referred by hospital outpatient department (finding)
	Referred by hospital emergency department	1066431000000102   Referred by hospital emergency department (finding)
	Referred by hospital ward	835101000000101   Referred by hospital ward (finding)
	Referral by mental health service	304521000000105   Referral by mental health service (procedure)
	Referred by HM Prison Service	1066011000000104   Referred by Her Majesty's Prison Service (finding)
	Referred by homeless drop-in centre	1077211000000104   Referred by homeless drop-in centre (finding)
	Referral from occupational health physician	305996002   Referral by occupational health physician (procedure)
	Self-referred	1991000124105   Referred by self (finding)
Diagnostics/ investigations	Blood test	396550006   Blood test (procedure)
	Lung function tests	23426006   Measurement of respiratory function (procedure)
	Peak expiratory flow measurement	29893006   Peak expiratory flow measurement (procedure)
	6-minute walk test	252478000   6-minute walk test (procedure)

	24 hour Holter tape	252417001   24 Hour electrocardiogram (procedure)	
	24 hr blood pressure monitoring	170599006   24 hr blood pressure monitoring (regime/therapy)	
	Tilt table test	14769009   Tilt test (procedure)	
	Chest X-ray	399208008   Plain chest X-ray (procedure)	
	Chest CT	169069000   Computed tomography of chest (procedure)	
	Ventilation-perfusion scan	37859006   Pulmonary ventilation perfusion study (procedure)	
	Echocardiogram	40701008   Echocardiography (procedure)	
	Cardiac MRI	241620005   Magnetic resonance imaging of heart (procedure)	
	MRI of brain	816077007   Magnetic resonance imaging of brain (procedure)	
	Microbial culture of sputum	104173009   Microbial culture of sputum (procedure)	
Management/referrals	Referral to Your COVID Recovery rehabilitation platform	132504100000104   Referral to Your COVID Recovery rehabilitation platform (procedure)	
	• Self-management/ supported self-management	Provision of support for self-management	733810001   Provision of support for self-management (regime/therapy)
		Advised to self care	315241000000102   Advised to self care (situation)
• Rehabilitation	Referral to rehabilitation service	307374004   Referral to rehabilitation service (procedure)	
	Patient referral to dietitian	103699006   Patient referral to dietitian (procedure)	
	Referral to physiotherapy service	306170007   Referral to physiotherapy service (procedure)	
	Referral to occupational therapy service	306166004   Referral to occupational therapy service (procedure)	
• Psychological support	Referral to IAPT programme	380201000000109   Referral to improving access to psychological therapies programme (procedure)	
	Referral to mental health team	390866009   Referral to mental health team (procedure)	
• Social and vocational support	Social services care planning	299761000000104   Social services care planning (procedure)	
	Referral to primary care service	703978000   Referral to primary care service (procedure)	
	Referral to social prescribing service	871731000000106   Referral to social prescribing service (procedure)	
	Referral to voluntary service	413125004   Referral to voluntary service (procedure)	

	Referral to community service	710915002   Referral to community service (procedure)
	Referral to occupational health service	306152009   Referral to occupational health service (procedure)
<ul style="list-style-type: none"> <li>Specialist referral</li> </ul>	Referral to respiratory medicine service	306114008   Referral to respiratory medicine service (procedure)
	Referral to pulmonary rehabilitation	2446100000105   Referral to pulmonary rehabilitation (procedure)
	Referral to cardiology service	183519002   Referral to cardiology service (procedure)
	Referral to cardiac rehabilitation programme	704050007   Referral to cardiac rehabilitation program (procedure)
	Referral to pain management service	306109009   Referral to pain management service (procedure)
	Referral to gastroenterology service	183523005   Referral to gastroenterology service (procedure)
	Referral to endocrinology service	306118006   Referral to endocrinology service (procedure)
	Referral to neurology service	183521007   Referral to neurology service (procedure)
	Referral to rheumatology service	306127007   Referral to rheumatology service (procedure)
	Referral to dermatology service	183518005   Referral to dermatology service (procedure)
	Referral to ENT service	183544005   Referral to ear, nose and throat service (procedure)
	Referral to infectious diseases service	306124000   Referral to infectious diseases service (procedure)
Outcome measure	EQ-5D-5L - EuroQol five dimension five level index	736534008   EuroQol five dimension five level index value (observable entity)
	EQ-VAS - EuroQol visual analogue score	736535009   EuroQol visual analogue score (observable entity)

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This publication can be made available in a number of other formats on request.

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Publication approval reference: C1248