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# National commissioning guidance for post COVID services

Version 3, July 2022

## Please note

We have updated the previous version of this guidance published in April 2021 to reflect the extended service provision set out in the updated [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#) from November 2021, and the updated [NHS plan for improving long COVID services](#).

Local services, referral pathways and protocols should now be reviewed and updated to reflect this guidance. The substantive updates are:

- clarity on delivery of consistent, integrated pathways and referral criteria with consideration of the experience of people living with long COVID
- the role of triage in optimising the post COVID service pathway
- a dedicated section on multidisciplinary rehabilitation including vocational rehabilitation
- a standalone pathway for children and young people with ongoing symptoms of COVID-19, following the establishment of specialist paediatric post COVID hubs
- advice on collecting data on service outcomes and evaluation.

We acknowledge the vital contribution of people with lived experience of long COVID, charity sector partners, clinicians, academics and a range of other stakeholders in developing and updating this guidance and other long COVID plans. We will continue to revise this guidance as further evidence emerges.

## Equality and health inequalities statement

Promoting equality and addressing health inequalities are at the heart of NHS England'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.

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# 1. Purpose and scope

This document informs the commissioning of post COVID services in England. It will assist local healthcare systems to plan and deliver services that meet the varied and often complex needs of people living with long COVID and is being published alongside [the NHS plan for improving long COVID services](#).

Post COVID services should offer an integrated multidisciplinary service including physical, cognitive and psychological assessments, diagnostic tests, and management or appropriate onward referral to post COVID rehabilitation, treatment and other support. This improves patient experience while maximising efficiencies and maintains a clear line of responsibility for continuity of care.

## 2. Background

Latest Office of National Statistics (ONS) estimates (published on 7 July 2022) suggest there are around 1.6 million people in England experiencing symptoms following COVID-19 for more than four weeks; 685,000 of whom for over 12 months. An estimated 336,000 people in England report that long COVID is significantly impacting on their day-to-day activities.

Knowledge of the range and clustering of symptoms associated with long COVID, and evidence for the treatment and management of the condition, are evolving as research and clinical practice advances.

The [NICE/SIGN/RCGP COVID-19 rapid guideline NG188](#) describes the common symptoms of ongoing symptomatic COVID-19 and post COVID-19 syndrome.

Following COVID-19 infection, a small number of children and young people may develop a delayed onset systemic inflammatory response known as [paediatric multisystem inflammatory syndrome \(PIMS-TS or PIMS for short\)](#). Long COVID symptoms can occur in children and young people who have had PIMS (TS) or mild illness. From the latest ONS COVID infection survey data, an estimated 125,000 people aged two to 16 years have self-reported long COVID of any duration.

NHS England investment to develop and deliver services for people experiencing long COVID totals £224 million for the period October 2020 to March 2023.

- In October 2020 a five-point plan was launched with a £10 million investment to create specialist post COVID services. The website and online rehabilitation service, Your COVID Recovery, was launched. The National Institute for Health Research committed £50 million to support research specifically designed to improve understanding of long COVID and a national taskforce was formed to drive this.
- The Long COVID Plan 2021/22 was subsequently published to support the ongoing development of post COVID services from primary to specialist care, underpinned by a further £124 million.
- The NHS Operational Planning Guidance for 2022/23 committed a further £90 million to maintain post COVID services for those who need them.
- The NHS plan for improving long COVID services that is published alongside this guidance includes NHS England's intention to fund post COVID services in 2023/24. During 2022/23, we will work with integrated care boards (ICBs), post COVID service providers and others to review the most appropriate service model for the care of people with long COVID, and determine the quantum of funding required for 2023/24. This will enable ICBs to plan for sustainable provision of long COVID services funded through core budgets from April 2024.

### 3. Clinical case definition of post COVID-19 syndrome

This guidance refers to patients who meet the clinical case definition of ongoing symptomatic COVID-19 or post COVID-19 syndrome as described in the National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP) [rapid guideline](#) on managing the long-term effects of COVID-19 (December 2020):

- **Ongoing symptomatic COVID-19:** signs and symptoms of COVID-19 lasting from four 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.

The term 'long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19 (defined as signs of COVID-19 for up to four weeks). It includes both ongoing symptomatic COVID-19 and post COVID-19 syndrome. Long COVID and post COVID-19 syndrome are used interchangeably in this document.

The World Health Organization has also developed [a clinical case definition of post COVID-19 condition by a Delphi consensus](#) (October 2021).

## 4. Post COVID service requirements

We recommend that post COVID services meet the following requirements:

### Referrals and triage

- Be available if required following primary care or other clinician referral to all affected patients from four weeks after the start of acute COVID-19 illness, regardless of whether or not they were hospitalised.
- Triage can ensure patients are seen by the right service in the pathway to meet their needs and allows clinical prioritisation of urgent cases and delivery of self-management advice while they wait for an initial assessment.
- To address the unwarranted variation in waiting times around the country, triage should be offered if waiting time to first assessment is longer than six weeks.
- Triage should be undertaken by a registered healthcare professional with experience in post COVID medicine.
- Standardised triage approaches appropriate to local pathways should be developed. Having a single point of access could be considered to enable consistent approaches.

## Post COVID service components

Post COVID services are recommended to:

- Provide a coordinated whole pathway of assessment, treatment and multifaceted rehabilitation and psychology support with direct access to required diagnostics (see [Appendix B](#)).
- Include clinical leadership from a doctor with relevant skills and experience. See section 9 for a full description of the various professions supporting the post COVID services pathway.
- Consider face-to-face assessments where helpful, dependent on the patient presentation and clinical judgement.
- Be able to interpret or have access to clinical support for interpretation of diagnostic test results.
- Be able to refer onto specialist services, including mental health services, as well as the voluntary, community and social enterprise (VCSE) sector as needed.
- Provide information to patients on how to re-access services on discharge from treatment or rehabilitation services, given that patients can experience relapses in their illness.
- Ensure that post COVID services are accessible to people from communities and sub-populations who experience health inequalities (see Service accessibility and inclusion section below) by being:
  - predicated on an assessment framework (such as equality and health inequalities assessment framework)
  - monitored (via clinic data and the health equity audit)<sup>1</sup> – acted on urgently if discrepancies are identified.
- Have an internal and external communication plan<sup>2</sup> to help raise awareness within the clinical community and key stakeholders including:
  - people living with long COVID, their parents, family or carers
  - employers and schools

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<sup>1</sup> Information on the health equity audit is available on the NHS Long COVID FutureNHS platform.

<sup>2</sup> The communications strategy should prioritise health access and inequalities through the use of patient educational material.



- primary care networks (PCNs), community pharmacy and other community services, VCSE sector, secondary care services and mental health services.
- Have a care coordinator who will support patients through the pathway from receipt of referral through to discharge. They will be a point of contact for the patient, advise on waiting times and support co-ordination of investigations and onward referrals.
- Have a named lead to provide data in line with national requirements (see section 10).
- Routinely collect outcomes data and carry out local evaluations.
- Share information on patient care with primary care. Specialist services that receive referrals from the post COVID services should provide both the referring post COVID service and primary care with a discharge summary.

## Service design

It is recommended that post COVID services:

- Agree integrated referral pathways between primary care and post COVID services, specialist services and mental health services.
- Personalise care to support and enable self-care; see section 6.
- Where possible, develop models of care that minimise waiting times and multiple appointments, e.g. via multidisciplinary team (MDT) case discussion.
- Share learning in terms of knowledge, skills and training across providers in their pathway, e.g. through webinars, video content or shared learning events.
- Support new and ongoing research.
- Follow the [Accessible Information Standard](#) and consider providing access to interpreters, including British Sign Language interpreters.

## Service accessibility and inclusion

In planning and delivering post COVID services healthcare systems should consider how they will minimise health inequalities, including for those with a [protected characteristic](#) as well as underserved or marginalised communities:

- socio-economically deprived, especially those in the lowest 20% as measured by the Index of Multiple Deprivation (IMD)
- inclusion health groups (homeless and Traveller communities)
- rural and coastal communities
- those with language and cultural barriers, particularly those with lower literacy levels (they will need the same information as others but in accessible formats)
- people in secure units, prisons and other incarcerated people.

We advise post COVID services to be aware of diagnostic overshadowing and make reasonable adjustments as required for people with:

- a learning disability and/or who are autistic, or pre-existing mental health problems
- another disability such as visual or hearing impairment.

To tackle inequalities in access to services, local healthcare systems and services are advised to consider proactive case finding approaches and referral pathways for vulnerable people experiencing long COVID.

## Post COVID services support for primary care

Post COVID services are recommended to:

- Offer dedicated training to primary care, highlighting the referral routes into post COVID services.
- Ensure clear communication with primary care following both assessment and discharge from the pathway.
- Co-design referral processes and pathway components with primary care.

Consideration should be given to funding primary care leadership for this purpose. Practices identified to have lower than expected coding or referral of patients with post COVID syndrome should be offered outreach support.

## 5. Referral routes and criteria for post COVID services

### Referral routes

There are three main referral routes into post COVID services:

#### **A. People whose acute illness was managed at home or in the community and were never admitted to hospital (see Figure 1 below)**

- People with new or ongoing symptoms four weeks or more after they first had suspected or confirmed acute COVID-19 symptoms will be signposted to contact their primary care team – by community pharmacy, the NHS.uk website, occupational health, the Your COVID Recovery website, VCSE sector, other community settings such as schools and churches, or following discharge from an emergency department.
- Patients who present to their primary care team should be assessed using a holistic, person-centred approach. This should include a comprehensive clinical history and appropriate examination to assess physical, cognitive, psychological symptoms and functional abilities.
- Investigations (see [Appendix B](#)) that are tailored to a person's signs and symptoms should be offered 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 a new, unrelated diagnosis, as per [NICE/SIGN/RCGP COVID-19 rapid guideline NG188](#).
- If further investigations or support are required, patient who meet the referral criteria may be referred into a post COVID service.

#### **B. People hospitalised with COVID-19 (see Figure 2 below)**

- Discharging hospitals are responsible for ensuring appropriate follow-up pathways are in place for patients being discharged from hospital following admission with COVID-19. If COVID-19 was not the patient's primary discharge diagnosis and they have a normal chest X-ray (CXR) at discharge, usual care pathways are to be used.

- Primary care should be provided with a detailed discharge summary of the admission and ongoing related conditions and previous social care arrangements which need to be re-instated.
- Be able to assess any respiratory complications according to British Thoracic Society guidance.
- All patients who required respiratory support should be reviewed at six weeks and the discharging hospital should consider a review at six weeks (virtual or face-to-face) for others based on clinical judgement and patient preference. This review should include a holistic assessment of physical and mental health, and signposting to self-management advice. Patients who are to be discharged from the pathway and in whom previous CXR changes were extensive will require a repeat CXR.
- Patients with new or persisting symptoms require additional follow-up at 12 weeks in secondary care outpatients services. This is to rule out alternative diagnosis, and if no alternative diagnosis is made, the need for referral to post COVID services should be considered. The 12-week review will include a CXR where clinically indicated, review of symptoms and consideration of further investigations and rehabilitation requirements.
- People who develop new symptoms after the 12-week review should be asked to seek help from their general practice.

### **C. People cared for in an intensive care unit (ICU) or high dependency unit (HDU) with COVID-19**

- Many hospitals have a post-intensive care pathway as part of routine care that patients can be referred to if they meet the local criteria for follow-up. People with COVID-19 cared for in an ICU/HDU setting should undergo a MDT assessment of their rehabilitation needs at the point they are stepped down to other inpatient facilities. Inpatient rehabilitation with defined goals should begin immediately.
- On discharge from hospital ongoing needs should be assessed; and the patient referred to appropriate community services if needed.
- Patients should be reviewed four to six weeks post discharge either in a post ICU MDT clinic or in post COVID services depending on local pathways. Their need for rehabilitation or onward referral to mental health or other services will be assessed.

## Referral criteria

Children, young people and adults with ongoing symptoms lasting for four weeks or more following COVID-19 illness should be considered for referral, particularly if the following criteria are met:

- severe presentations where symptoms are having a significant impact on normal activities of daily living, including attendance at work or, for children and young people, access to education or attendance at school
- non-improving trend
- atypical presentations where further assessment is needed to confirm the diagnosis/consider alternative diagnoses
- further assessment is needed to confirm safety and appropriateness of either self-management or supported rehabilitation.

Typically, referral will not be immediate due to the need to rule out alternative diagnoses and undertake relevant investigations before doing so. People who experience spontaneous recovery will not require referral.

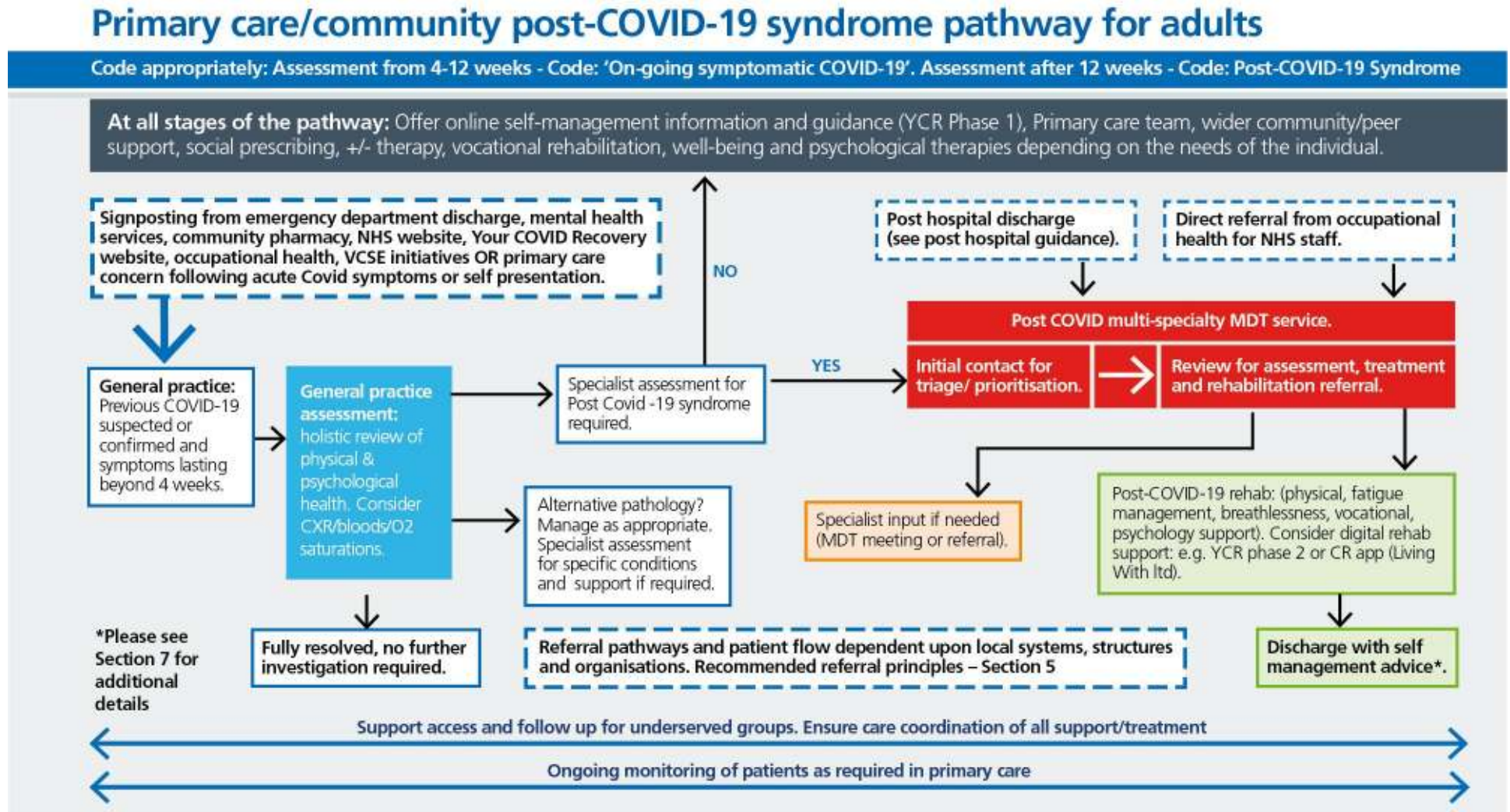
## 6. Pathways of care and the role of primary care

### Pathways of care

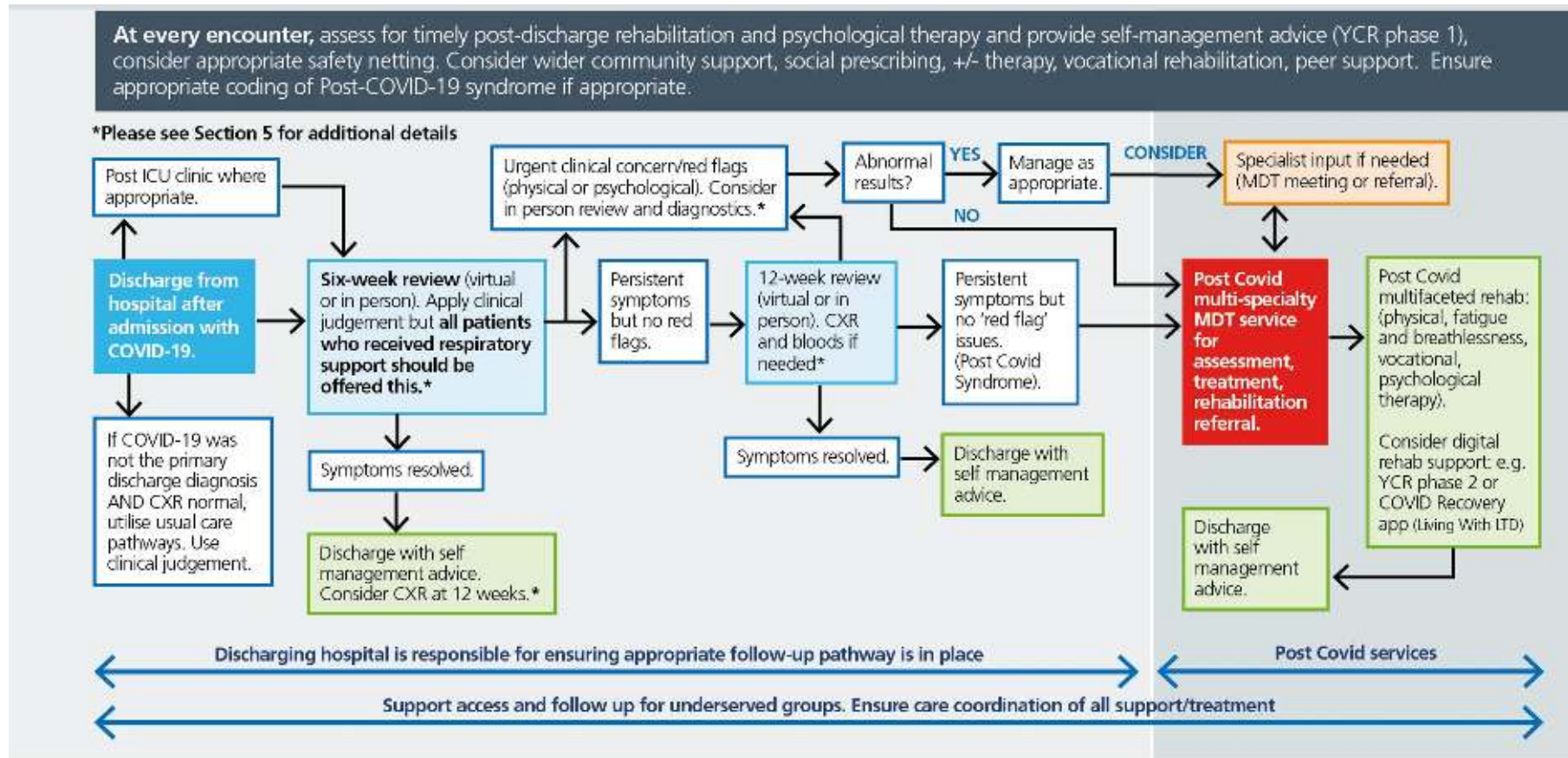
We have designed the adult care pathways (Figures 1 and 2 below) to help the NHS and local healthcare systems plan and deliver streamlined post COVID services that address any variation in service delivery and patient experience.

The pathway for children and young people with long COVID is given in section 8.

Figure 1: Post COVID-19 syndrome primary care/community pathway for adults



**Figure 2: Post COVID-19 syndrome post hospital discharge pathway for adults**



## Role of primary care

Primary care plays a key part in the long COVID clinical pathway including identifying long COVID in patients who may not link their symptoms with previously confirmed or suspected COVID-19. They can present with a wide range of symptoms including breathlessness, fatigue, chest pains, cognitive impairment or psychological symptoms.

The initial role of the primary care healthcare professional is to investigate and exclude acute or life-threatening complications and other unrelated diagnoses before referral into post COVID services. Given the constellation of possible symptoms, an in-person assessment including examination and observations as per [NICE/SIGN/RCGP](#) (e.g. to measure observations, sitting/standing blood pressure) may be beneficial.

The primary care healthcare professional should tailor investigations to symptom presentation in line with NICE guidance. See [Appendix B](#) for suggested diagnostics in primary care.

As symptoms can relapse and remit, and new symptoms appear, 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 four weeks after infection), the following may be discussed with the patient and offered:

- self-management advice including the option of using Your COVID Recovery or other online resources
- support from the primary care team or network, including referral to the social prescribing service (which can provide onward referral to other community-based support and advice) and/or health and wellbeing coaching if available.

If other causes for symptoms have been excluded and if the person requires further support or investigations, they may be referred into a post COVID service or to paediatric services as appropriate.

## Referral into other services from a post COVID service

While some symptoms can be addressed immediately in the post COVID 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 (see section 7)
- MDT review and advice
- initiation of treatment, rehabilitation and psychological support and vocational rehabilitation, if needed
- specialist referral for specific conditions.

Healthcare professionals should work together to deliver joined-up physical and psychological therapies. Where appropriate, patients may benefit from psychological assessment and support in addition to referral to Improving Access to Psychological Therapies (IAPT-LTC) or children and young people's mental health services.

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 transition is considered, to ensure continuity of care.

Services for which referral pathways should be available include:

- respiratory services, sleep services and pulmonary rehabilitation
- cardiac services including cardiac rehab
- neurology
- rheumatology
- dermatology
- ENT
- infectious disease services
- gastroenterology
- speech and language therapy services
- co-morbidity management, eg for diabetes or obesity
- pharmacy
- occupational health
- multidisciplinary rehabilitation services
- physiotherapy
- occupational therapy
- dietetics and nutrition services
- pain management
- fatigue services
- social care support services
- social prescribing link workers
- health and wellbeing coaches
- IAPT and other mental health services including cognitive management.

## Discharge from post COVID services

People with long COVID can experience an exacerbation of their symptoms after they have been discharged from a post COVID service. On discharge patients should be provided with a self-management plan and details of who to contact in the event of a relapse or development of a new symptom.

Services should consider the option of patient initiated follow-up (PIFU)/open referral in the pathway for a period to enable patients to re-access the service as they transition to self-management. This will mitigate against unnecessary re-referral.

An effective discharge will also help avoid patients contacting their general practice about any outstanding concerns.

## Principles of care for long COVID

### Personalised care

An individual personalised care plan is one of the most important aspects of supporting recovery for people living with long COVID. Actively listening to people and asking, 'what matters to you?' supports planning and shared decision-making based on what matters most to individuals.

- Staff training can be accessed via 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.
- More information can be found at [NHS England » Personalised care](#).

### Multidisciplinary support and rehabilitation

A MDT 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 digital programmes such as Your COVID Recovery interactive rehabilitation
- access to clinical review and more specialist advice or rehabilitation when needed
- care co-ordination for streamlined care.

## Supporting and enabling self-care

Shared decision-making conversations, where clinical expertise, patient preferences and values come together, can enable people to help themselves through supported self-management approaches. These conversations might incorporate health coaching or motivational interviewing techniques.

Supported self-management may be appropriate for people with mild symptoms to support them to identify their own goals, what is important to them and how to manage their own health. This can help inform a decision about what additional support might be most useful alongside self-management. Options include:

- Signposting to the Your COVID Recovery website (see section 7).
- Referring to social prescribing link workers based in primary care and/or in the VCSE sector; they connect people with activities, groups and services in their community to meet practical, social and emotional needs, including peer support, in recognition of the wider factors that affect health. Social prescribing link workers are included in the additional roles reimbursement scheme in primary care, and all PCNs should provide access to this service.
- Referring to a health and wellbeing coach based in primary care.
- Access to peer support networks, where they exist.

## 7. Multidisciplinary rehabilitation

Multidisciplinary rehabilitation services are required to evaluate rehabilitation needs and develop an integrated rehabilitation care plan encompassing both specific treatments and other support, education and guidance resources for people with long COVID. MDTs have a role in supporting access to required adjustments and supporting patients to advocate for this. Effective rehabilitation should take a holistic and individualised approach.

Individuals with long COVID often have very different abilities and needs, not only because their symptoms are heterogeneous and can fluctuate but also because of a complex interaction between their long COVID symptoms, pre-existing health conditions, the environments they live in, their values and beliefs, and their aspirations

and motivations. Also, the interaction between an individual's mental and physical health means one has the potential to significantly affect the other.

## Models of care

There is increased demand for NHS rehabilitation services, and we advise to work together on a co-operative rehabilitation model based on the following key principles:

- equitable and consistent access to rehabilitation services with a single point of assessment of rehabilitation needs
- strong partnerships with the VCSE sector
- integrated care planning across multiple agencies including joined-up health and social care so that patients benefit from seamless pathways
- enhanced delivery of personalised care that empowers patients to participate in decisions regarding their care and increases their confidence in and ability to self-care
- strong leadership from integrated care boards and across regions where appropriate to bring people together to collaborate, devise solutions and create capacity, consistency and improved outcomes.

## Digital supported self-management

Long COVID rehabilitation services range from supervised multidisciplinary interventions to digital supported self-management platforms such as [Your COVID Recovery](#), [Living With Covid Recovery](#) and other locally available on-line resources.

Your COVID Recovery is an online information and rehabilitation platform designed for and with people with post COVID-19 symptoms. It offers:

- general information, advice, and guidance on all aspects of recovering from COVID-19, including physical, emotional and psychological wellbeing.
- once referred, a tailored self-management rehabilitation plan that is remotely supported by healthcare professionals to reduce symptom burden.

The Living With Covid Recovery platform combines evidence-based methods from physiotherapists, psychologists, dietitians and respiratory physicians to create bespoke

treatment plans for each patient, while enabling clinicians to review patient progress and communicate with them remotely.

## Rehabilitation interventions

Rehabilitation interventions should be specifically designed for people living with long COVID. Interventions can be delivered simultaneously or in combination as part of an individualised and co-ordinated rehabilitation programme.

The rehabilitation offered should be flexible and adapted to suit the individual, considering their digital competency, preference, and clinical need. Individuals may choose to flex between a supervised and remotely supervised programme.

While evidence is lacking for the effectiveness of any interventions in treating long COVID overall, there are established treatments for managing the common symptoms, and these can be used to give symptom relief. Examples include:

- **Fatigue management:** Fatigue is the commonest reported symptom following COVID-19. Fatigue management involves working closely with the individual to identify their energy limits, with the aim of promoting recovery and improving sleep. It supports patients to address 'boom and bust' cycles with pacing strategies, prioritisation and effective rest.
- **Psychological and psychologically informed interventions:**
  - These aim to reduce the psychological impact of the condition on the patient by increasing their understanding of the impact of psychosocial factors (eg interpersonal factors, emotional dysregulation, fixed or limiting beliefs) and helping them respond to symptoms adaptively and flexibly, drawing on all sources of support and resources available to them. They can include adjustment to symptom, alongside treating the anxiety and/or depression that may co-occur with long COVID, to enable effective engagement with rehabilitation goals; for example, supporting individuals to appropriately pace activity levels, improve sleep quality, improve lifestyle balance and communicate effectively about lifestyle adjustments.
  - Psychological supervision and training in conducting psychological consultations may enable clinical staff to provide psychologically informed assessment and rehabilitation.

- **Breathing pattern retraining:** Breathlessness is a common symptom of long COVID. Breathing pattern retraining treats breathlessness by optimising an individual's breathing pattern. This includes reducing the rate and volume of tidal breathing back to normal, correcting to nose breathing at rest and breathing with a diaphragmatic pattern. This is then progressed to retraining breathing on exertion to reduce exertional breathlessness.

## Occupational health support and vocational rehabilitation

Most people experiencing long COVID are of working age, and long COVID can have a detrimental effect on their ability to work, care for others and carry out their usual activities.

Occupational health support and vocational rehabilitation are a core component of rehabilitation to support individuals with long COVID to return to work sooner and remain in work. Employers need to make reasonable adjustments for people with long COVID to allow them to return to work safely.

Post COVID services should collect information on employment status and the impact of rehabilitation and treatment on a person's ability to work and carry out their usual activities.

## Discharge from rehabilitation

At discharge from rehabilitation services people need to be provided with information about how to contact the service again if they need to. Some people may later experience long-term sequelae and may need to re-access rehabilitation services

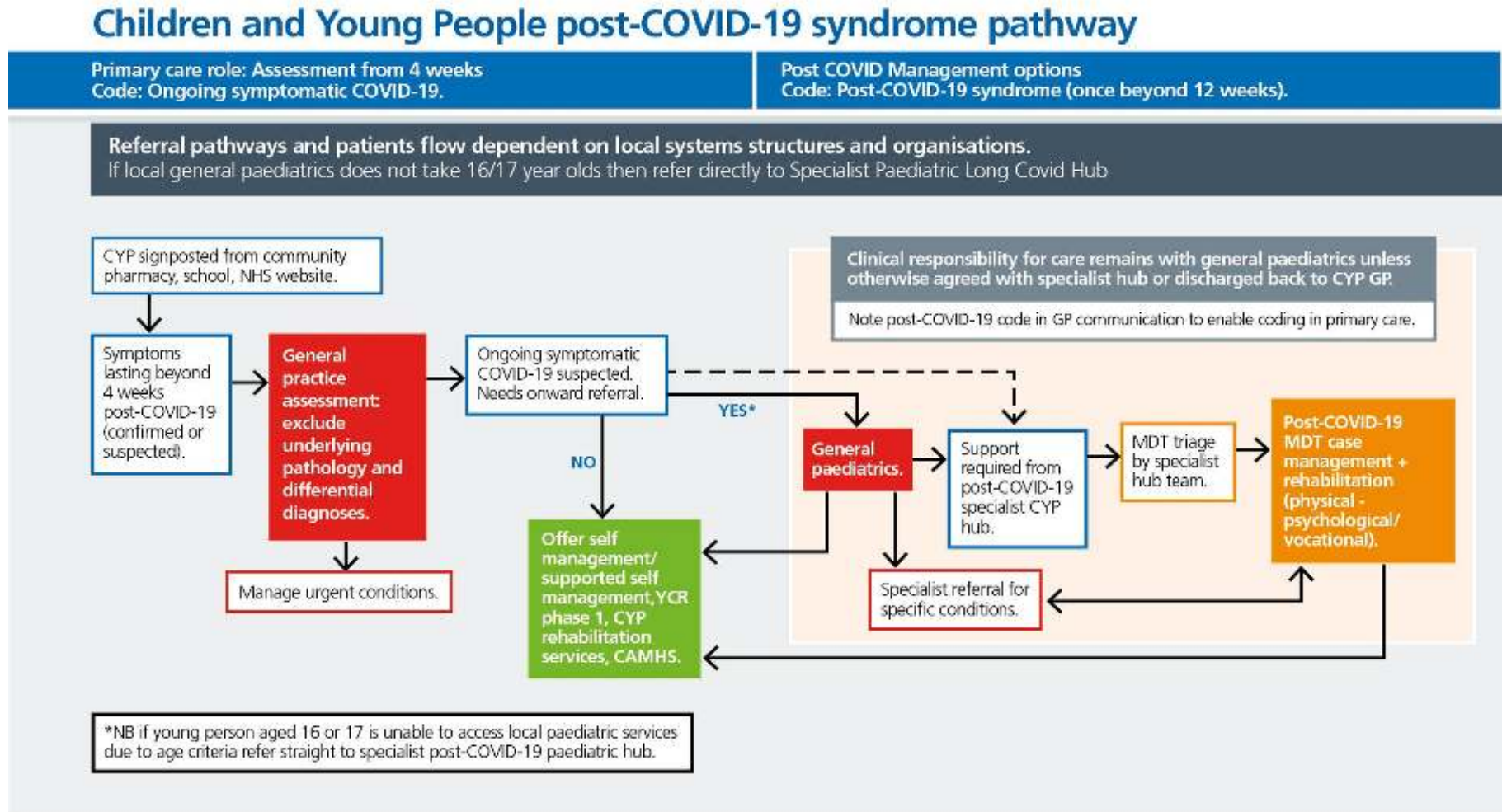
# 8. Children and young people

Children and young people (CYP) with suspected long COVID need an early holistic assessment to identify those who require further specialist assessment to exclude other conditions and management of rare complications such as organ impairment, as well as to offer appropriate support for the wide-ranging symptoms that may significantly affect their quality of life.

## The CYP patient pathway

- Most children with long COVID symptoms will improve or recover within 12 weeks following the acute infection. The timing of onward referral where needed should be based on clinical judgement: some may need to be referred for further assessment from 12 weeks post infection and some earlier.
- Following appropriate assessment by a GP or other healthcare professional to exclude any other pathology, children with suspected long COVID who require further assessment or treatment may be referred to general paediatrics and for MDT assessment at a specialist post COVID hub or a standard post COVID service, where appropriate.
- Fourteen specialist paediatric post COVID hubs have been established across England to provide expert advice to local paediatric services supporting CYP with long COVID.
- For young people aged 16 and 17, referral should be direct to the specialist paediatric hub where they are unable to access the specialist paediatric hubs and local post COVID services do not accept referrals for those under 18.
- Regional teams are advised to work with healthcare systems to agree the best models for delivery of post COVID services for CYP, which should include easy access to advice from a specialist paediatric hub or direct access to a hub for CYP with complex needs. Figure 3 below outlines a CYP pathway adapted from current models in use in some local areas.
- 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 into existing services as needed and locally where possible.
- Services employing a virtual consultation model should have the flexibility to offer a face-to-face service depending on patient need and the circumstances of the patient and family.

Figure 3: Children and young people post COVID-19 syndrome pathway





## Referral routes

Long COVID may be identified by the child or young person and their family or agencies including school, community child development services, community therapy services, child and adolescent mental health services (CAMHS) and primary care.

Where there are concerns that a CYP may have long COVID, they/their parents should be advised in the first instance to seek advice from their primary care team unless there is concern for their immediate welfare.

Children with special educational needs or neurodisability may not be able to verbally express that they are experiencing new symptoms, so changes in their behaviour should be considered.

Primary care should carry out an assessment using a holistic, person-centred approach. This should include a comprehensive clinical history and appropriate examination to assess physical, cognitive and psychological symptoms, as well as functional abilities. A psychosocial screening tool such as the [HEADDSS assessment tool](#) may be useful as part of the assessment to identify psychosocial risks and resilience factors.

Tests and investigations that are tailored to young people's signs and symptoms should be offered to rule out acute or life-threatening complications and find out if symptoms are likely to be caused by ongoing symptomatic COVID-19 or post COVID-19 syndrome, or a new, unrelated diagnosis that requires further assessment and treatment.

It is not expected that all CYP with long COVID symptoms will need onward referral from primary care – many can be managed by their primary care team with simple measures including advice (symptom management, general lifestyle advice, liaison with school, support for wellbeing), common investigations and treatment.

Referral for further assessment for investigation of alternative diagnoses is recommended if concerns are not settling with simple interventions.

Referral to paediatric services can be via:

- primary care referral to general paediatrics in secondary care for advice
- primary care referral directly to the specialist CYP post COVID-19 hub for further assessment/advice/treatment (if agreed locally, with a concurrent referral to local

general paediatric services, or for young people aged 16 or 17 who are ineligible to access post COVID services)

- primary care to an adult post COVID service where the paediatric service is provided alongside adult care.

The specialist paediatric post COVID hub should regularly hold a virtual MDT; participation by the referring paediatrician or primary care team to discuss the case is encouraged.

## 9. Workforce supporting the post COVID pathway

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

- NICE/SIGN/RCGP guidance 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, considering the variety of presenting symptoms.
- Post COVID-19 syndrome medicine is an emerging field and requires generalist skills with access to advice from multiple specialties. Doctors in post COVID services may have a primary care or physician background. The medical workforce needs to stay abreast of latest treatment and management advice and have access to appropriate training opportunities.
- Post COVID 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).
- 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, deconditioning, fatigue and dizziness, and can provide specific guidance on pacing, rest and recovery time.

- Speech and language therapists provide holistic assessments to identify the specific needs of the patient and agree a personalised plan with them. They support the rehabilitation and self-management of individuals with common post COVID-19 symptoms, including cognitive communication ('brain fog'), swallowing, voice (including muscle tension dysphonia) and respiratory difficulties.
- Occupational therapists provide occupation-focused assessment of physical and mental health needs and cognition, offering self-management approaches to, for example, fatigue, brain fog, sleep disturbances, cognitive and psychological difficulties. They offer personalised advice and rehabilitation, enabling people to maintain and regain independence in daily activities, and vocational rehabilitation to support return to work and education.
- Psychologists can assess cognition and mental health. They can support 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.
- Specialist nursing functions and roles such as district nursing, community nursing, mental health nursing, clinical nurse specialists, nurse consultants and general practice nurses can support holistic assessment and treatment of both the patient's and wider family's needs, while also supporting the co-ordination of services more widely where appropriate.
- Dietitians can support people living with post COVID-19 syndrome in a range of ways, including advice on the impact of COVID-19 on nutritional status, and support to address malnutrition because of loss of appetite, breathlessness, swallowing difficulties or other long COVID symptoms.
- Pharmacists can support people on medication for other long-term conditions experiencing long COVID. People can be referred to pharmacy for a structured medication review (primary care) or for 'new medicines service' (community). They can also be signposted for self-care and over-the-counter symptomatic relief. Patients newly discharged from hospital can be referred to pharmacies for the 'discharge medication service'.
- Care co-ordinators in post COVID services are support staff who have a good understanding of the post COVID pathway. They provide a point of contact for

patients, advising patients about the pathway and supporting them through it, from receipt of referral to discharge.

Patients may also be supported by care co-ordinators in primary care who provide extra time, capacity and expertise to help patients prepare for clinical conversations or follow-up discussions with primary healthcare professionals. They work closely with primary healthcare professionals to identify appropriate support for patients and their carers, ensuring that changing needs are addressed.

- Social prescribing is a key component of universal personalised care and a way for local agencies to refer people to a link worker. Link workers connect people to community groups and statutory services for practical and emotional support. They can receive referrals from several professions across health, care and public services and people can self-refer.
- Physician associates are an increasing part of the workforce within primary care, supporting the identification, referral and support of people living with long COVID.
- Healthcare professionals working in primary care should be supported to access training and education on managing long COVID. They should have knowledge and understanding of local clinical pathways and engage in any quality improvement work to further develop the local pathways.

## 10. Data and management information

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 data quality is a key component of the commission for post COVID services.

### Data reporting for post COVID services

Provider-level data collection has been established to assess the referral to and activity within post COVID services.

The data collection requirements and data specification are available to providers on the [Long COVID Network FutureNHS website](#).

## Responsibilities for data collection

Due to the nature of post COVID-19 syndrome management, with pathways spanning the entire health system (primary, secondary and community care), we recognize that collecting data is challenging. Local and regional leadership is key.

- **Each provider** should have a data lead (focal point) who ensures:
  - data is submitted via established collection routes fortnightly
  - local data trends, key indicators in relation to performance (referrals, assessments) and health access (IMD, age, sex, ethnicity) are acted on monthly
  - quality and completeness of data reporting
  - escalation of data submission or data quality problems to regional teams in a timely fashion
  - promotion of clinical coding locally to support automation of data collection.
- **Each region** should have a data lead who:
  - ensures quality and completeness of data reporting among providers
  - monitors the regional dashboard of key indicators of performance (referrals, assessments, completion rates) and health access (IMD, age, sex, ethnicity)
  - ensures key indicators are acted on in conjunction with the relevant team if they fall below the region's expectations, eg working with the regional health inequalities senior responsible officer
  - quality assures regional data against other collections
  - promotes clinical coding regionally to support automation of data collection.
- **National data responsibilities:**
  - support the data collection process and report on regional performance
  - maintain and update regional dashboards, to ensure regions are provided with service data in a timely fashion
  - support regions with 'coding counts' to reduce variation in coding
  - publish activity data monthly for transparency and to encourage continuous improvement.

To enhance the data collection, we will derive additional aggregate reporting across primary and secondary care 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 use.

## Primary care coding

It is important to accurately capture data on primary care activity related to long COVID, to support demand modelling, service planning and research. Primary care should code for all the following data categories (the 'minimum dataset'), if applicable, when delivering care for people with ongoing symptomatic COVID-19 or post COVID-19 syndrome:

- 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).

Primary care clinicians 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-19 syndrome codes to be used.

## Secondary care coding

A treatment function code (TFC) for post COVID services has been available since 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 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 services should use the TFC for their service, which will enable tracking of service activity and associated onward diagnostic and referral activity. Services should also ensure complete demographic data (age, sex, ethnicity, postcode) is recorded for each patient.

## Community care coding

Post COVID services should ensure implementation of SNOMED CT coding where compatible clinical information systems are in place. A post COVID service coding minimum dataset to guide coding can be found on the [Long COVID Network FutureNHS website](#). Clinics should ensure complete demographic data (age, sex, ethnicity, postcode) is recorded for each patient.

## Further support

Resources to support data and data collection are available on the [Long COVID Network FutureNHS website](#). These include:

- frequently asked questions
- information on recommended codes
- data definitions.

Updates and changes to the method of data collection will be communicated to providers via NHS Digital and regional teams.

# 11. Key service outcomes

Services should gather and analyse outcomes data for children, young people and adults identified with long COVID within primary care, secondary care and specialist services. Data capture should span assessment through to rehabilitation and discharge from the post COVID services pathway.

Patient reported outcome measures, clinical measurements and patient reported experience measures help monitor patient progress, facilitate communication between professionals and improve the quality of services. This data also contributes to the

evidence base on management of long COVID symptoms and efforts to reduce unwarranted variation in post COVID services.

## Outcome measures for adults with long COVID

- 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, should be completed for all patients on assessment, three monthly during follow-up or rehab support, and at discharge from treatment and/or rehabilitation, wherever possible.
- Additional outcome measures can also be used where clinically indicated, depending on symptom presentation, and to personalise the management or treatment approach.
- Post COVID services regularly collecting other measures in clinical practice should continue to do so to develop a psychometric analysis of the scale and calculate the minimal clinically important difference (MCID). Such measures may include the [COVID-19 Yorkshire Rehabilitation Scale](#), a validated symptom measure for long COVID.

Patient reported outcome measures are available for a wide range of post COVID-19 syndrome symptoms that can impact on physical, psychological and cognitive health. While validated outcome measures for post COVID-19 syndrome are being developed, common symptom measures are recommended to assess the severity of symptoms, monitor recovery and aid the communication between healthcare professionals. .

## Patient experience measures

All providers are expected to collate information on patient experience in post COVID services via the Friends and Family Test and a specific question on patient access.

Of particular interest will be the experience of groups from underserved populations and those that experience health inequalities, as outlined in section 4. Aggregate reporting of patient experience will occur regionally and nationally.

### Questionnaire completion by CYP

Completion of standardised questionnaires by CYP is recommended at baseline and at six months, and as a core outcome measure for services running a treatment model.



Services should be aware of the risk of over-burdening CYP and their families with questionnaires, and as far as possible the questionnaires used should be consistent with those used in current research.

Recommended questionnaires include:

- a shortened ISARIC form (symptoms) at baseline only
- EQ-5D-Y
- SF-36 physical function sub-scale
- short RCADS
- 11-item Chalder Fatigue Questionnaire (CFQ)
- Visual Analogue Pain Scale.

## Post COVID service evaluation

We request providers of post COVID services to locally evaluate their services through the collection and review of outcome measures used in the service.

NHS England will periodically ask for information regarding local outcomes and evaluations.

## 12. NHS Standard Contract

Commissioners may use the NHS Standard Contract to commission post COVID 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 about using the contract can be sent to: [nhscontractshelp@nhs.net](mailto:nhscontractshelp@nhs.net).

## 13. Communications

To ensure clinical communities are aware of the long COVID pathway, we ask commissioners to develop communications plans that set out how post COVID services are accessed.

These plans should cover communications to primary care teams, 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 to local systems should regularly include updates on data (such as the development of new post COVID-19 syndrome codes) and data collection.

Communications should also be targeted at reducing variation in coding among PCNs and systems.

Healthcare systems can use existing communications platforms, including formal NHS platforms and those of professional membership bodies and VCSE organisations.

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

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

## 14. Governance and assurance

NHS England regional teams will continue to work with healthcare systems, commissioners and providers on the best arrangements for service delivery to ensure universal geographical coverage, communications with patients and stakeholders, and future delivery of service.

## Integrated care boards

Integrated care boards (ICBs) are responsible for ensuring the delivery of consistently high quality post COVID services. Post COVID services will participate in a quarterly assurance process against the service requirements outlined in section 4 and across this guidance as a whole.

## Regional long COVID teams

Regional teams will support the submission of data and assurance templates by each post COVID service in their area.

## National long COVID team

The national Long COVID Programme team provides information on post COVID activity and coding through a quarterly focus pack. An assurance template that has been agreed by regional colleagues is disseminated to providers by their regional teams.

The national team will meet regional colleagues monthly to review assurance templates and activity data, and to understand operational challenges.

## Appendix A: Supporting resources

Post COVID-19 syndrome is a new illness, which we are learning more about every day. The following list of resources have been developed to help teams adapt to and learn about the condition.

Please note these resources, or their online location, may be updated. Please contact [england.clinicalpolicy@nhs.net](mailto:england.clinicalpolicy@nhs.net) if you have difficulty 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-19 syndrome to self-manage their rehabilitation
- Long COVID network on the FutureNHS platform:  
[https://future.nhs.uk/L\\_C\\_N/grouphome](https://future.nhs.uk/L_C_N/grouphome)
- Health Education England (HEE) e-learning modules: Long COVID programme  
<https://www.e-lfh.org.uk/programmes/long-covid/>.
- RCGP: Management of the long term effects of COVID-19  
<https://elearning.rcgp.org.uk/course/view.php?id=492>
- Patient safety learning and RCGP resource: Post COVID-19 syndrome: What support can patients expect from their GP?  
<https://www.pslhub.org/learn/coronavirus-covid19/patient-recovery/resources-for-patients/post-covid-19-syndrome-what-support-can-patients-expect-from-their-gp-r3581/>
- Queen's Nursing Institute: [Living with COVID19 – Community and Primary Care Nursing Resource](#)  
<https://www.qni.org.uk/news-and-events/news/qni-publishes-a-resource-for-community-nurses-caring-for-people-living-with-covid-19/>
- Managing the long-term effects of COVID-19. Pharmacists in community and primary care should be able to provide patients with appropriate advice and support to manage their symptoms.  
<https://pharmaceutical-journal.com/article/ld/managing-the-long-term-effects-of-covid-19>

- NIHR resources  
<https://evidence.nihr.ac.uk/themedreview/living-with-covid19/>  
<https://evidence.nihr.ac.uk/themedreview/living-with-covid19-second-review/>
- The Faculty of Occupational Medicine guidance for return to work for patients with Long-COVID
- [COVID-19: information for the respiratory community | British Thoracic Society | Better lung health for all \(brit-thoracic.org.uk\)](https://www.brit-thoracic.org.uk/better-lung-health-for-all)
- NHS England: [Allied health professionals' role in rehabilitation during and after COVID-19](#)
- [The Faculty of Occupational Medicine: Guidance for return to work for patients with post-COVID syndrome](#)
- [Occupational therapy and adults with long Covid \(post COVID-19 syndrome/condition\)](#)
- [Occupational therapy and children and young people with long Covid \(post COVID-19 Syndrome/Condition\)](#)
- [How to conserve your energy: Practical advice for people during and after having COVID-19](#)

## Appendix B: Post COVID-19 syndrome diagnostic pathway

Investigations should be tailored to the patient's symptoms and exclude other causes as far as possible, in line with NICE guidance. The lists below are intended as a guide to investigations that may be required, depending on the patient's presentation, and are not intended to be prescriptive or exhaustive.

Primary care diagnostics	
<p><b>Key aim:</b> To rule out serious underlying pathology or alternative diagnosis that would prompt referral other than to post COVID services.</p>	
As standard	Other investigations as appropriate according to symptoms
<p><b>General bloods:</b></p> <ul style="list-style-type: none"> <li>• FBC</li> <li>• U&amp;E</li> <li>• LFT</li> <li>• TSH</li> <li>• HbA1c</li> <li>• ferritin</li> <li>• vitamin D</li> <li>• lipid profile</li> </ul>	<p><b>Breathlessness:</b> chest X-ray, oxygen saturation, echo, NT-BNP</p>
	<p><b>Chest pain:</b> ECG/echo; consider acute medicine referral</p>
	<p><b>Palpitations:</b> ECG; consider direct referral to cardiology</p>
	<p><b>Dizziness/light-headedness:</b> lying and standing blood pressure, pulse oximetry, medicines review</p>
	<p><b>Tiredness:</b> STOP-Bang questionnaire (consider direct referral to sleep services)</p>
Post COVID service	
<p>Investigations should be directed by presenting problems, based on clinical assessment and judgement.</p> <p>Post COVID services should have <b>direct access to, be able to interpret and act on</b> the investigations suggested below.</p>	
<p><b>Blood panel:</b> As per primary care + D-dimer, troponin, clotting studies, CK, autoimmune profile</p>	
<p><b>Breathlessness:</b> Chest X-ray, oxygen saturation, spirometry, lung volumes and gas transfer, CTPA/HRCT, FeNO, sleep studies, walk test</p>	
<p><b>Palpitations:</b> Holter, 24-h blood pressure, ECG</p>	
<p><b>Chest pain:</b> ECG, NT-BNP, echo, troponin, NT-BNP (acute medicine access)</p>	
<p><b>Fatigue:</b> TSH, ferritin, ESR</p>	
<p><b>Abnormal LFTs:</b> US abdomen, hepatitis screen</p>	
<p><b>Dizziness:</b> Holter, 24-h blood pressure</p>	

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