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The NHS plan for improving long COVID services

July 2022

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1. Summary

Since we published the NHS Long COVID Plan for 2021/22, the NHS has made much progress in establishing new services for those suffering from debilitating, long-term effects following an episode of COVID-19. Our ambition remains to provide high quality care to help people recover from long COVID. This document builds on our original 10 key actions with the aim of continuously improving access, experience and outcomes for patients. It has been developed with stakeholders, including people with lived experience of long COVID, the National Long COVID Taskforce and associated charities, and builds on the plan for 2021/22, published in June 2021.

Office for National Statistics data for July 2022 show that since June 2021 the number of people in England living with self-reported long COVID has grown from 700,000 to 1.6 million;¹ and 20% of those asked report significant limits on their activity.

Long COVID includes both ongoing symptomatic COVID-19 (4–12 weeks) and post COVID syndrome² (12 weeks or more and are not explained by an alternative diagnosis), and can be a debilitating multi-system condition affecting an individual's physical, psychological and cognitive health, their daily life and ability to work or attend education.

This plan supports future NHS service planning, assists continuous improvement in the quality of long COVID services and addresses the wide unwarranted variation in waiting times across England for these services to reduce health inequalities. It sets out further actions, which align with the [Elective Recovery Plan](#) and focus on:

- increasing capacity
- prioritising treatment
- transforming the way we provide care
- better information and support for patients.

¹ [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK - Office for National Statistics \(ons.gov.uk\)](#)

² [Guideline COVID-19 rapid guideline: managing the long-term effects of COVID-19 \(nice.org.uk\)](#)

1.1 Key actions

Increasing capacity	
1	NHS England will invest a further £90 million in post COVID services in 2022/23.
2	In autumn 2022, NHS England will publish the long COVID multiagency framework to help integrated care systems navigate the range of non-healthcare organisations that can help improve the quality of life for people with long COVID, particularly those most likely to experience health inequalities.
3	NHS England will work to further understand unwarranted variation in access for those groups that appear less likely to access post COVID services, to improve equality of access, focusing on age, race, sex and deprivation based on the IMD.
4	NHS England will publish Friends and Family Test data for post COVID specialist services from June 2022 to chart people's experience of using long COVID services.
5	NHS England will publish long COVID resources for healthcare professionals in primary care that it has co-developed with the Royal College of General Practitioners.
6	NHS England and Health Education England will roll out a long COVID training programme for healthcare professionals from autumn 2022.
7	Post COVID specialist service providers should enrol at least one clinician in the long COVID training programme by March 2023.
8	NHS England will publish a long COVID framework for nursing, midwifery and care staff in summer 2022.
9	NHS England will review the future model for long COVID services, informed by latest evidence.
Prioritising treatment	
10	The Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) will publish quarterly reviews of evidence to help people navigate the growing range and number of research studies on long COVID.
11	Post COVID service providers will review their service models and, where average waiting times for first assessment by a registered healthcare professional are above six weeks, include a triage call in the care pathway to ensure no patient waits over six weeks. Services should also work to eradicate waits of more than 15 weeks for clinical assessment. To support this, from autumn 2022, NHS England will collect and publish data on waiting time from referral to clinical triage.

12	NHS England will support local healthcare systems and specialist post COVID children and young people hubs to strengthen referral pathways to minimise unnecessary delays to assessment and treatment for children and young people.
13	Post COVID specialist children and young people hubs will offer help to young people aged 16 and 17 so they do not fall into any gap between paediatric and adult services.
Transforming the way we provide care	
14	Patients with suspected long COVID will have access to appropriate community-based diagnostic testing where clinically indicated
15	NHS England will publish updated commissioning guidance to help systems identify how best to care for people with long COVID.
Information and support for patients	
16	NHS England will continue to work with lived experience partners and other stakeholders to develop the content of the Your COVID Recovery website, so it is an accurate and trusted source of information for the public.
17	Post COVID services and rehabilitation services treating people with long COVID should use the outcome measures set out in the revised National commissioning guidance for Post COVID services to collate outcomes from assessment and discharge.
18	NHS England will support integrated care systems to develop a network of lived experience partners, who will support the development of local services.
19	NHS England will develop an information resource for post COVID services by September 2022, to use to inform people with long COVID about opportunities to participate in long COVID research.
20	NHS England will publish revised guidelines in summer 2022 for supporting our NHS people affected by long COVID.

2. Progress since the long COVID plan 2021/22

In June 2021 NHS England published [Long COVID: the NHS plan for 2021/22](#). This detailed 10 key actions for the NHS in 2021/22; it has made significant progress against these.

1. The NHS has **established 90 post COVID services, providing access to specialist diagnosis, treatment and rehabilitation**. Since October 2020 £194 million has been invested in NHS services for people with long COVID, including £90 million secured for 2022/23. Since July 2021 over 60,000 people have received specialist assessment in these services.
2. A further **£30 million has been made available for an enhanced service that helps general practice support patients and enable more consistent referrals to clinics** for specialist assessment and treatment. Over 93% of practices in England have signed up to the enhanced service: this has significantly increased the recording of people diagnosed with post COVID syndrome in general practice, from 1,540 to 3,720 clinical codes per week between June 2021 and March 2022.
3. Local service plans show widespread adoption of **care co-ordination by post COVID clinics**. Most services now use it to support patients through the care pathway, ensuring that they have the appropriate diagnostic tests, referral and treatment; and they understand what stage they are in the pathway.
4. **Fourteen post COVID specialist children and young people's hubs have been created** across England to co-ordinate complex care and provide expert advice to local paediatric services.
5. **All post COVID services now have multifaceted rehabilitation pathways in place** that provide both physical and mental health support. The updated [National commissioning guidance for post COVID services](#) describes the provision that should be available.

6. **The Your COVID Recovery website has been used by 10.8 million people and the online rehab service has been extended to over 2,200 patients.** NHS England has improved the accessibility of the website: content is written in plain English and is downloadable; there is an auto-translation function for 18 languages; and for people who have a sensory impairment, assisted technology and read aloud functionality has been introduced.
7. **Since July 2021 NHS England has published [NHS long COVID activity data](#)** on referral, assessment and waiting times for post COVID assessment clinics to give transparency and aid performance improvement. Alongside this we are now publishing results from the post COVID service [Friends and Family Test](#), which show 91% of patients who responded had a good experience of care. A national long COVID registry for patients attending post COVID services in England has been established; this integrates data from across multiple national data collections. Data has been analysed to support service delivery
8. NHS England has **implemented actions to tackle health inequalities, focusing on equity of access, outcomes and experience for patients.** Monthly activity data allows healthcare systems to monitor the sex, age, ethnicity and deprivation (based on the Index of Multiple deprivation) of those accessing the clinics. To help clinics identify and respond appropriately to local access issues, particularly for those most likely to be affected by health inequalities, we sought help from the voluntary sector to better understand the experiences of under-represented communities and to develop our approach to ensure services reach these communities. We have ensured that all elements of the long COVID programme consider how health inequalities can be reduced, from providing information for those affected to delivery of post COVID services.
9. The long COVID programme **national learning network has established a collaborative space for healthcare professionals to share service delivery challenges and develop creative and innovative solutions.** The network is open to those setting up and running post COVID clinics and has over 1,400 members.
10. In addition to making health and wellbeing support available to NHS staff with long COVID, the health and wellbeing team have published [Guidelines for supporting our NHS people affected by long COVID](#). The guidelines were developed in partnership with NHS staff with lived experience of the condition.

3. Evidence review

Long COVID is a relatively new condition. While there has been significant investment in long COVID research in the UK³ and globally, to date evidence for potential changes to the clinical case definition remains inconsistent. Furthermore, variations in the quality of some studies and different outcome measures prevent firm conclusions around phenotypes or clusters of symptoms and the trajectory of illness for all age groups.

In the UK NICE/SIGN/RCGP guidance⁴ provides the current clinical definition of “long COVID” and aligns with the WHO definition being used worldwide. If the evidence base for the definition changes then the NICE/SIGN/RCGP guidance will be updated. Healthcare professionals should ensure they are aware of future updates to this guideline.

3.1 Prevalence of and risk factors for long COVID

A consequence of the evolving definition for long COVID is variations in how prevalence is measured. The Office of National Statistics (ONS) has outlined its approach⁵ to estimating self-reported long COVID symptoms and ONS estimates are currently used to inform NHS planning.

Overall prevalence of long COVID continues to remain high: 1.6 million people in England are estimated to have self-reported long COVID symptoms lasting longer than four weeks following SARS-CoV-2 infection, with over 1.2 million reporting symptoms continuing for over 12 weeks, 685,000 for over a year and, in the UK, 403,000 for over two years.⁶ A steady decline in persistence of symptoms by 12 weeks following infection is seen in some people,⁷ however, those with ongoing symptoms beyond 12 weeks report these are severely debilitating. 1.4 million (70%) report their ability to undertake daily activities is adversely affected, with 398,000 (20%) reporting that this has been “limited a lot”.

³ [News: £19.6 million awarded to new research studies to help diagnose and treat long COVID | NIHR](#)

⁴ [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#)

⁵ [Technical article: Updated estimates of the prevalence of post-acute symptoms among people with coronavirus \(COVID-19\) in the UK - Office for National Statistics \(ons.gov.uk\)](#)

⁶ [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK: 7 July 2022](#)

⁷ [Persistent COVID-19 symptoms in a community study of 606,434 people in England | Nature Communications](#)

The CloCk study of long COVID in children and young people⁸ found that up to one in seven (14%) children and young people who caught SARS-CoV-2 may have symptoms linked to the virus 15 weeks later.

Fatigue, shortness of breath, cough, muscle aches, loss of smell, loss of taste and difficulty concentrating (brain fog) continue to be the most frequently reported symptoms^{9,10} of the over 200 symptoms that have been associated with long COVID to date.¹¹

3.2 Risk of long COVID by SARS-CoV-2 infection variant and vaccination status

Of people with self-reported long COVID, over a third had first been infected with COVID-19 before the Alpha variant emerged, with the Delta and Omicron periods each accounting for about a quarter of long COVID cases. Current estimates of the risk reduction from vaccination vary.

After adjusting for socio-demographic factors, early findings¹² show a reduced risk (49.7% lower) of reporting long COVID symptoms four to eight weeks after a first SARS-CoV-2 infection most likely to be with Omicron BA.1 than Delta among adults who were double-vaccinated when infected. This difference in risk is not seen in those who were triple vaccinated. A lower risk of long COVID following infection with Omicron versus Delta was also noted in the ZOE App study.

In those who are triple vaccinated, there is an increased risk (21.8% higher) of long COVID with Omicron BA.2 infection compared to BA.1. However, triple vaccination appears to offer some protection against activity limiting long COVID from both variants with no difference in risk of activity limiting long COVID.

Long COVID prevalence lags four weeks behind acute infection rates. The surge in acute COVID-19 infections likely to be Omicron between December 2021 and March

⁸ [Physical and mental health 3 months after SARS-CoV-2 infection \(long COVID\) among adolescents in England \(CLOCK\): a national matched cohort study- The Lancet Child and Adolescent Health](#)

⁹ [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK - Office for National Statistics \(ons.gov.uk\)](#)

¹⁰ [COVID-19 Symptoms: Longitudinal Evolution and Persistence in Outpatient Settings - PMC \(nih.gov\)](#)

¹¹ [Characterizing long COVID in an international cohort: 7 months of symptoms and their impact - eClinicalMedicine \(thelancet.com\)](#)

¹² [Self-reported long COVID after infection with the Omicron variant in the UK - Office for National Statistics \(ons.gov.uk\)](#)

2022 can be expected to further increase long COVID prevalence over the coming months.

3.3 Treatment and management of long COVID

There is general appreciation that long COVID manifests heterogeneously and a multidisciplinary team (MDT) encompassing various specialties best serves patients.¹³ Evidence for interventions remains very limited, and most studies have been too small and underpowered to determine the relative effectiveness of treatments.¹⁴ Research currently focuses on rehabilitation programmes, including exercise-based rehabilitation (which may exacerbate symptoms for some people), or interventions to manage specific symptoms, as distinct from the whole condition.

A meta-analysis¹⁵ has shown potential for colchicine to reduce mortality. This will be further explored, alongside antihistamines and Rivaroxaban, in STIMULATE-ICP¹⁶, a National Institute for Health Research (NIHR)-funded study investigating effectiveness of colchicine in treatment of long COVID symptoms. NIHR is also funding the HEAL trial¹⁷ to evaluate apixaban and atorvastatin in the convalescence stage post acute SARS-CoV-2 infection, and the LOCOMOTION¹⁸ research project to identify best practice in providing services for those with long COVID.

A literature review of the role of primary care in management of long COVID¹⁹ identified the themes of GP uncertainty, listening and empathy, and co-ordinating access to appropriate services. Primary care's role can be optimised through better understanding of patient experiences, standardised approaches for symptom identification/treatment, and access to multidisciplinary specialist services when needed.

¹³ [A systematic review of the systematic review of post COVID-19 syndrome | The Journal of Medicine, Law & Public Health \(jmlph.net\)](#)

¹⁴ [Drug treatments for covid-19: living systematic review and network meta-analysis | The BMJ](#)

¹⁵ [Drug treatments for covid-19: living systematic review and network meta-analysis | The BMJ](#)

¹⁶ [Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathway](#)

¹⁷ [HElping Alleviate the Longer-term Consequences of COVID-19 \(HEAL-COVID\) - Full Text View - ClinicalTrials.gov](#)

¹⁸ <https://www.leeds.ac.uk/news-health/news/article/4871/creating-a-gold-standard-of-care-for-long-covid>

¹⁹ [Enhancing the management of long COVID in general practice: a scoping review | BJGP Open](#)

3.4 Preventative measures of long COVID

Corticosteroids

When administered in the acute phase of SARS-CoV-2 infection, systemic corticosteroids may attenuate the long-term symptoms of COVID-19 in patients who are hospitalised and requiring oxygen and improve patients' quality of life.²⁰

COVID-19 vaccinations

Early data shows a 41% reduction in likelihood that those infected after two doses of COVID-19 vaccine self-report long COVID,²¹ which amplifies the importance of vaccinations in addressing the long-term sequelae of COVID-19. This observed risk reduction may underestimate the positive effect of vaccinations as it does not factor in those who do not acquire COVID-19 because they are vaccinated.

In other studies, vaccination against COVID-19 was not associated with symptom severity, quality of life or mental wellbeing; some people reported improvement in symptoms such as brain fog and insomnia.^{22,23}

Modelling of the extension of the UK vaccination programme to young people aged 12 years and over suggested this could reduce the prevalence of long COVID by 27% as well as reduce COVID-19 morbidity and mortality, across all ages.²⁴ NHS England continues to support vaccination as a key line of defence against COVID-19.

Research in people who were hospitalised with COVID-19

Several studies continue to investigate post-hospital discharge sequelae of COVID-19. Findings from the largest UK post-hospitalisation study (PHOSP-COVID) highlight approximately three in 10 people hospitalised with COVID-19 were experiencing ongoing symptoms at five months²⁵ with limited recovery one year after hospital discharge and large decrements in health-related quality of life compared to pre-

²⁰ [Corticosteroids for COVID-19 symptoms and quality of life at 1 year from admission - PubMed \(nih.gov\)](#)

²¹ [Self-reported long COVID after two doses of a coronavirus \(COVID-19\) vaccine in the UK - Office for National Statistics \(ons.gov.uk\)](#)

²² [Are vaccines safe in patients with Long COVID? A prospective observational study | medRxiv](#)

²³ [Effect of SARS-CoV-2 Vaccination on Symptoms from Post-Acute Sequelae of COVID-19: Results from the Nationwide VAXILONG Study - PMC \(nih.gov\)](#)

²⁴ [Vaccines | Free Full-Text | Vaccinating Adolescents and Children Significantly Reduces COVID-19 Morbidity and Mortality across All Ages: A Population-Based Modeling Study Using the UK as an Example | HTML \(mdpi.com\)](#)

²⁵ [Evans RA, McAuley H, Harrison EM, et al. Physical, cognitive, and mental health impacts of COVID-19 after hospitalisation \(PHOSP-COVID\): a UK multicentre, prospective cohort study. Lancet Respir Med. 2021;9\(11\):1275-1287. doi:10.1016/S2213-2600\(21\)00383-0](#)

hospital.²⁶ A large cohort study from Wuhan, China reported 50% of patients had ongoing symptoms two years after discharge from hospital despite the population having less pre-existing disease and low numbers requiring invasive mechanical ventilation compared to PHOSP-COVID.²⁷ Female sex, obesity, and receiving invasive mechanical ventilation were associated with lower rates of recovery at one year.²⁴

Four recovery sub-groups have been described where symptoms, mental health and physical health largely tracked together supporting a holistic approach to recovery interventions.²⁶ The more severe sub-groups were associated with female sex, obesity, a higher total number of symptoms, lower exercise performance and higher levels of systemic inflammation. Based on these and other findings, clinical trials are being conducted within the PHOSP-COVID infrastructure testing interventions including an anti-inflammatory agent and rehabilitation.

A cohort of post hospital discharge patients showed significant improvement in physical, respiratory and quality of life markers with remote pulmonary rehabilitation.^{28,29} However, studies are subject to bias and imprecision due to the issues noted above.

4. Understanding patient outcomes and experience

4.1 Understanding outcomes for patients with long COVID

The complex nature of long COVID, the range of services required to support rehabilitation and treatment, and mechanisms for recording outcomes, make it challenging for services to collate longitudinal patient outcomes data.

²⁶ Huang L, Li X, Gu X, et al. Health outcomes in people 2 years after surviving hospitalisation with COVID-19: a longitudinal cohort study [published online ahead of print, 2022 May 11]. *Lancet Respir Med.* 2022;S2213-2600(22)00126-6. doi:10.1016/S2213-2600(22)00126-6

²⁷ PHOSP-COVID Collaborative Group. Clinical characteristics with inflammation profiling of long COVID and association with 1-year recovery following hospitalisation in the UK: a prospective observational study [published online ahead of print, 2022 Apr 22]. *Lancet Respir Med.* 2022;S2213-2600(22)00127-8. doi:10.1016/S2213-2600(22)00127-8

²⁸ [W3134579102 | OpenAlex Web](#)

²⁹ [Post COVID-19 – effective treatment and rehabilitation \(sbu.se\)](#)

Case study 1: Outcomes of the Leeds Community Healthcare NHS Trust post COVID service

The post COVID service at Leeds Community Healthcare NHS Trust has been operational since September 2020, and to date it has received over 1,700 referrals. The service has collected a range of outcome measures for patients at assessment and discharge. Those at discharge are shown below.

Outcome measure at discharge	Number of patients	Improved	Deteriorated	No change
EQ-5D	329	70%	26%	4%
EQ Visual Analogue Scale	310	65%	21%	14%
Modified fatigue impact scale	295	69%	26%	5%
Modified Medial Research Council (mMRC) Breathlessness	315	52%	7%	41%

In a recent survey by NHS England of post COVID services, 95% of respondents reported their services were using measures for clinical assessments and patient management, 56% that they were collecting EQ-5D-5L, 67% that follow-up data was shared with GPs and 23% had evaluated services.

Some services were able to report demonstrable improvement in outcomes; see, for example, case study 1.

4.2 Understanding patient experience of post COVID services

NHS England's engagement with people with lived experience, the voluntary sector and other patient representative bodies such as Healthwatch, together with evidence gathered by the Health and Social Care Select Committee, shows that there are inconsistencies in access to the high standard of care provided by some post COVID services.

To help providers understand the experience patients have of post COVID services, the Friends and Family Test (FFT) has been introduced. FFT data was first published for [post COVID services](#) on 9 June 2022. In April 2022, 64% of post COVID services collected FFT data and of the 446 patients providing a response about their experience of the post COVID services:

- 93% rated this as good or very good
- 95% said they were involved as much as they wanted to be in their care and treatment
- 97% felt they were treated with respect and dignity.

Work is ongoing to improve submission rates.

NHS England has also reviewed its own long COVID or post COVID service-related queries addressed to the NHS England Customer Contact team. Key themes identified were:

- difficulty accessing a GP appointment
- uncertainty regarding the long COVID pathway
- not being listened to by healthcare professionals
- delays in access to diagnostics
- access to information and advice.

This NHS plan for improving long COVID services and the revised [national commissioning guidance for post COVID services](#) seek to address these key areas for improvement.

4.3 Understanding outcomes of post COVID services

For post COVID services to understand the change in an individual's symptoms over time and plan for wider future demand, they need to record outcomes data using consistent measures.

The use of PROMs to analyse the effectiveness of care is standard practice in healthcare. Best practice is to use measures that are specific to the condition, but such measures have not yet been developed for long COVID.

The revised National commissioning guidance for post COVID services recommends the EQ-5D-5L, and the Health Related Quality of Life (HRQOL) measure, including the EQ Visual Analogue Scale (EQ VAS), to measure outcome in adults. For children and young people, the EQ-5D-Y and shortened International Severe Acute Respiratory and emerging Infection Consortium (ISARIC) symptom form are recommended. The minimum recommended time points for collection of patient reported outcome measures (PROMs) by post COVID services are first assessment, three months from assessment and discharge.

NHS England is working with NHS Digital to enable the reporting of EQ-5D-5L in the Community Services Data Set (CSDS). This will enable outcome data to flow through the long COVID registry and help assess the impact of post COVID services and pathways.

In 2022/23 all services discharging long COVID patients from rehabilitation and treatment should share discharge information and recorded outcomes with the patient's primary care provider and the referring post COVID service. This will enable the post COVID service to audit patient outcomes from assessment to discharge. Services providing assessment and/or treatment as part of the long COVID pathway should consider how they capture outcomes to enable evaluation of their service and the interventions provided. This could include capture of EQ-5D-5L through the CSDS or the use of digital enablers such as EPIC, or the use of apps such as the online rehab element of Your COVID Recovery and Living With COVID Recovery™ or outcome tools such as Elaros™.

Other tools are emerging for gathering symptom data and, potentially, to facilitate shared decision-making for assessment and management. However, these tools, such as the SBQ™-LC comprehensive measure of long COVID symptom burden, still require validation in the post COVID service setting.

5. Increasing capacity

5.1 Current demand for NHS services

We have seen significant demand for NHS post COVID services over the last 18 months. Since July 2021, over 50,000 people have been recorded as receiving a

specialist assessment in a post COVID clinic and 100,000 follow-up appointments have taken place. Although the actual number of people who have received care since December 2020 is much higher.

On average 1,500 people are referred to post COVID services each week.

Demographic data collected by specialist services shows:

- 62% of people assessed were women
- 69% of people were aged 35 to 64
- 64% of people were white
- 7% of people were Asian or Asian British
- 3% of people were Black
- 3% of people were mixed or other ethnic groups
- 19% were people classified as living in areas of greatest socio-economic deprivation; that is, among the 20% of people in groups 1 and 2 on the Index of Multiple Deprivation (IMD).

Services are disproportionately used by white females and those aged 45 to 54. NHS England is working to understand how to ensure that the under-represented groups, such as men, ethnic minorities and people with learning disabilities, are aware of and able to access post COVID services.

5.2 Modelling future demand

Given the ongoing incidence of SARS-CoV-2 infection rates and emergence of new variants, demand for post COVID services is anticipated to continue.

Not all people who report long COVID symptoms will require assessment in a post COVID assessment service. The ONS estimates that 19% of those who self-report long COVID have symptoms that limit their daily activities 'a lot'. Based on their experience of delivering care for people with long COVID, clinicians delivering post COVID services advise the assumption that this is the maximum proportion of people with long COVID (2.2% of people infected with COVID) who potentially require an assessment in a post COVID service.

There are however a range of reasons why this may be an overestimate of those requiring post COVID services; for example, some of the most common symptoms may still not warrant a specialist assessment as people can benefit from online advice such

as from Your COVID Recovery to manage them, and some people may be seen in other disease-specific pathways.

The NHS is investing a further £90 million in post COVID care in 2022/23 to ensure dedicated support continues to be provided where it is needed.

Case study 2: Role of GP leadership in post COVID pathways in North Central London

North Central London (NCL) ICS is using some of the money for post COVID services to fund long COVID GP leads in each borough. These GPs attend community long COVID multidisciplinary (MDT) meetings to ensure there is a strong primary care voice in care planning and access to primary care clinical records for the team treating the individual.

Public health teams have analysed primary care coding and referral rates in NCL to enable GP leads to identify the practices requiring most support to deliver the post COVID pathway and encourage referral to the post COVID service when appropriate.

5.3 Widening access to post COVID services to reduce health inequalities

NHS England is committed to reducing disparities in access to post COVID services. Given the unwarranted variation in access to and waiting times for post COVID services, NHS England will continue to work with providers to implement actions to address access for specific groups. This will include:

- improving service-level data to help identify inequalities in access, experience and outcomes
- all services having a robust inequalities plan in place which are reviewed as required in the national commissioning guidance for post COVID services
- public health colleagues in regional teams working with local healthcare systems will monitor new diagnoses recorded in primary care and referral rates to post COVID services, which will help to identify unwarranted variation
- making every contact count by using opportunities in other healthcare settings to signpost people to post COVID services

- using social prescribers to support people with the socio-economic impacts of COVID, as set out in the national commissioning guidance for post COVID services
- ensuring the long COVID programme aligns to the [Core20plus5](#) approach.

We are focused on understanding why there may be differences in access for those with protected characteristics, initially race, age and sex, in each geography. We will commission work to further understand unwarranted variation in access for specific groups as identified by the data, and the under-representation of some groups in the data for post COVID services, to help support improvements in equity of access.

Health inequalities often develop or worsen if people do not have appropriate housing, good education and employment, a stable income, peer support and are vulnerable to being victims of crime. We will publish the multiagency framework for long COVID in autumn 2022. This tool for integrated care systems (ICSs) brings into one place examples of how non-healthcare organisations are helping to improve the quality of life for those experiencing long COVID, providing ideas that ICSs can build on in accordance with the needs of their populations.

Case study 3 highlights the work in London to address disparity in access and the value of the NHS working with local voluntary and community groups.

Case study 3: Proactive case finding principles developed in London

Feedback from stakeholders has identified that referral to a post COVID service can be severely impacted by difficulties in accessing a GP appointment. Other information points to barriers in age. The post COVID service data points to age as another barrier: only 5% of people accessing services are over the age of 75. Anecdotally, services also report seeing very few people with learning disabilities or a severe mental health illness.

NHS England's London regional team has noted that the demographic of people seeking support for long COVID does not reflect the areas and populations most affected by acute COVID-19. In response, service providers are using four principles to proactively identify and support people to seek medical support – and in turn they are making service users feel comfortable and confident in how they will be supported.

1. **Integration with local community organisations.** Staff from NHS services have worked alongside community members and leaders to build support groups, raise awareness in community-based gatherings and provide basic signposting for those who are struggling. Through creating these relationships between the NHS and

community organisations, people from more diverse groups have started to come forward to seek medical support.

2. **Making every contact count.** The consequences of long COVID are leading people to seek support, such as financial and employment support, or practical help with daily activities. The NHS is working with local authorities, public health and the Department for Work and Pensions, among others, to raise the profile of long COVID, so those who may come into contact with people with long COVID can make those contacts count, by recognising the common symptoms of long COVID and advising people what to do next.

A good example of this has been getting COVID vaccine champions to talk about long COVID at the same time as discussing vaccination with individuals.

3. **Targeting groups considered to be more vulnerable, such as the homeless and asylum seekers.** It has been important to recognise that social factors often adversely impact the health of populations that have traditionally been underserved. Buddying with other services already supporting these groups can help identify those among them with long COVID.
4. **Culturally competent education.** Staff recognise that to educate and support people effectively, the local culture needs to be understood, as this enables culturally competent conversations, translations and alternative approaches (thinking about who is giving the message as well as how the message is delivered).

NHS England will support the principles of making every contact count by maximising opportunities to raise awareness of long COVID across healthcare settings and to signpost individuals to post COVID services at healthcare interventions, such as when someone is vaccinated, has an annual health check or has a chronic disease review.

If healthcare professionals in any setting suspects post COVID syndrome, such as community pharmacists undertaking medication reviews, specialty nurses who work with people with learning disabilities, they should convey this to the persons primary care team and support referral to the post COVID service if appropriate.

Case study 4: The NHS in mid and south Essex reach deep into communities to offer a proactive and preventative model of long COVID care

Building on the success of the Essex Vax Van, the Mid and South Essex Community Collaborative have pioneered a successful outreach model to give residents in hard-to-reach areas access to high quality proactive and preventative care for post COVID syndrome and its symptoms.

An outreach van goes to communities to offer health checks and diagnostic tests in this mobile clinic for adults, children and young people, including blood pressure, heart rate, oxygen saturation, spirometry and other tests for breathlessness, 6-lead electrocardiography. The team is also working with local teams to provide information on smoking cessation, social prescribing and local facilities.

Patients already referred to the long COVID team can be booked into appointments at the van, as well as being able to 'walk-in' to the mobile clinic. People can talk to the team about how to recognise the symptoms of long COVID. What the mobile clinic offers is not a replacement for a full assessment for long COVID, but it does start a conversation that may be followed by a referral to a GP.

5.4 Discharge from post COVID services

It is becoming evident that some people experience a return of their symptoms after they have been discharged from a post COVID service. All services will be advised to provide patients they are discharging 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 help to reduce any potential further burden being placed on general practices by patients contacting them about any outstanding concerns and will mitigate against unnecessary re-referral.

5.5 Training the healthcare team

NHS England is providing a range of materials that support the education and training of healthcare professionals to ensure those who support patients with long COVID can recognise the condition, carry out appropriate diagnostic tests, and refer, treat or rehabilitate those affected.

NHS England has co-developed [long COVID: advice and resources for healthcare professionals in primary care](#) with the Royal College of General Practitioners (RCGP). These resources recognise the key role of primary care in supporting patients, both adults and children, with long-term symptoms of COVID-19: in assessing, diagnosing, referring where necessary and providing longer-term holistic support to ensure services meet the needs of our people and communities. The RCGP also have e learning resources for [long term effects of post COVID-19 syndrome](#) which can be accessed free by any healthcare professional.

In addition, building on Health Education England's suite of [online resources](#) on long COVID, a live training course will be available from autumn 2022 for at least one member of each post COVID service clinical team. This is aimed primarily at healthcare professionals. The training programme will aim to:

- increase knowledge and awareness on how to identify, investigate and diagnose long COVID
- increase knowledge and understanding of possible diagnostic tests, treatments and rehabilitation interventions
- strengthen multidisciplinary team working with patients and communities across integrated care services.

The nursing and midwifery workforce is intrinsic to the support of people with long COVID, eg community nurses who care for people at home. In summer 2022 NHS England will publish a long COVID framework for nursing, midwifery and care staff which showcases good practice across England to help them care for people with long COVID.

5.6 Future design of post COVID services

There is likely to be an ongoing requirement for the assessment and treatment of patients with long COVID in the longer term, although the future demand for post COVID services is difficult to predict. As described above, vaccination has been shown to reduce the likelihood of developing long COVID, but the impact on long COVID of the very high numbers likely to have been infected this year with the Omicron variant is unknown; also new variants may emerge.

During 2022/23, NHS England will work with integrated care systems (ICSs), post COVID service providers, people with lived experience and others to review the service

model for the care of people with long COVID and determine requirements for the future.

Feedback from both clinicians and patients shows that a holistic approach to assessing and treating patients with complex symptoms (as those with long COVID often have) delivered by a blend of specialist physical and mental healthcare professionals helps ensure they receive good NHS care. Stabilisation of the new long COVID pathway and further evaluation of outcomes is now required to maximise benefits for patients with long COVID and to identify transferable learning for the management of other long-term or multisystem disease.

The current multidisciplinary service model capitalises on the clinical expertise built up over the last year, but the evidence base is still light for how best to manage long COVID. Over the next 12 months, research studies such as STIMULATE-ICP and LOCOMOTION are expected to begin to yield evidence of what treatments or care models work for long COVID.

5.7 Key actions: increasing capacity

- NHS England will invest a further £90 million in post COVID services in 2022/23.
- NHS England will publish the multiagency framework for long COVID in autumn 2022.
- NHS England will work to further understand unwarranted variation in access for those groups that appear less likely to access post COVID services, to improve equality of access, focusing on age, race sex and deprivation based on the IMD.
- NHS England will work with the RCGP to publish [long COVID: resources for healthcare professionals in primary care](#).
- NHS England and Health Education England will roll out a long COVID training programme for healthcare professionals from autumn 2022
- Post COVID services should enrol at least one clinician in the long COVID training programme by March 2023.
- NHS England will publish a long COVID framework for nursing, midwifery and care staff in summer 2022.
- NHS England will review the future model for long COVID services, informed by latest evidence.

6. Prioritising treatment

6.1 Clinical prioritisation

Clinical prioritisation is fundamental to ensure that those with the most clinically urgent needs are diagnosed and treated rapidly, the revised [National commissioning guidance for post COVID services](#) provides criteria for referral of adults and of children and young people into post COVID services. The criteria consider the impact long COVID is having on the individual, including on their ability to undertake normal activities of daily living, including going to work or school; and prioritise those with the greatest clinical need (people who are not improving or who require further assessment).

6.2 Reducing health inequalities and unwarranted variation in access to post COVID services

We know there is currently significant unwarranted variation in waiting times for particular people referred to post COVID services across different geographies. To address this, NHS England will support post COVID services to ensure that all patients referred to them have an initial assessment by a registered healthcare professional within six weeks, through either a clinician-led triage or specialist assessment. The clinician-led triage will include a standardised process for identification of symptoms. It is not a substitute for specialist assessment but at this point the clinician will:

- determine the most appropriate clinical pathway for the patient, eg full MDT specialist assessment, post COVID rehabilitation or psychological support
- prioritise the patient based on clinical need considering any health inequalities that may make them more vulnerable.

Following this the service will:

- ensure the patient is advised of likely waiting times for the next stage of their care
- signpost to/provide self-management advice for the management of long COVID taking into account the person's symptoms and access needs.

We will support this process by offering specific training, as detailed in section 5.5, to help standardise the clinician-led triage across post COVID services and publishing

data on waiting times for this initial assessment as well as time to specialist assessment from autumn 2022.

To monitor service-level improvements in waiting times for post COVID services, we have included an indicator in the [NHS Oversight Framework](#) detailing the proportion of patients who have a first consultation in a post COVID service within six weeks of referral.

Case study 5 illustrates the benefits of triage at the start of the care pathway.

Case study 5: Role of the nurse specialist in North West London post COVID services

Imperial College Healthcare NHS Trust introduced a nurse specialist role in response to growing waiting times and an identified need for patients to have some interventions, including self-management advice, earlier in the patient pathway.

Following an initial triage to check the post COVID service is suitable, a nurse specialist contacts the patient to determine the most appropriate care pathway for them. This may include a more urgent review at a post COVID clinic, referral to the community rehabilitation team for ongoing therapy support or self-management advice. This approach has reduced unnecessary referrals and 95% of patients who received a call from the nurse specialist stated they felt a lot better after the consultation as they had been able to speak to someone who understood what they were going through and addressed their immediate concerns.

6.3 Effective multidisciplinary team working

The array of long COVID symptoms can require the expertise of a wide range of specialists and professions. Long COVID services have been developed around a multidisciplinary team (MDT) to enable a holistic review of the patient's physical, psychological and cognitive symptoms. The role of the MDT is to identify the appropriate diagnostic and management plan for each patient assessed. MDT meetings often take place virtually following assessment of the patient by a smaller number of team members. These meetings are an opportunity to discuss complex case presentations and for team members to share learning about patient management. All post COVID services should regularly hold such meetings, and as a minimum they should have access to respiratory and cardiology expertise.

Case study 6: The multidisciplinary team at University College London Hospitals NHS Foundation Trust

Post COVID services at University College London Hospitals NHS Foundation Trust (UCLH) have evolved significantly from the first clinics run from a mobile unit by a respiratory consultant and a physiotherapist. The multidisciplinary team (MDT) at UCLH now consists of a range of professionals, including an integrated care respiratory consultant, general physicians, physiotherapists, occupational therapists and psychologists. The team also has support from cardiology and neurology colleagues and can involve dermatology, immunology and rheumatology when required.

MDT meetings are held weekly with the purpose of gaining specialist input regarding patients who have been referred. Community providers attend when they have specific questions they would like to raise. Cardiology and neurology specialists are always present, and these specialists also have a clinic each a week for post COVID patients. Through this joint working, referrals to these specialties have reduced by 80%, freeing time for high quality specialist assessment of those who need it.

In addition, community MDT meetings are held in each borough with post COVID rehab partners. These provide an opportunity for skill transference from those who have seen a large number of post COVID patients to those who have been involved with the pathway for a shorter time.

6.4 Delivering multifaceted post COVID rehabilitation

People with post COVID syndrome can require multifaceted rehabilitation to support recovery. Post COVID services should be able to access:

- support for breathing pattern disorders
- fatigue management advice
- physical rehabilitation
- vocational rehabilitation
- pain management
- integrated psychological support
- support with taking medicines.

6.5 Digital approaches to patient management

Recovery from long COVID can take time. For some people, attending regular appointments can be difficult. There are also circumstances where patients can remain

in contact with their healthcare professional but continue their rehabilitation programme at home. Websites and apps such as Your COVID Recovery and Living With COVID Recovery are tools for supported self-management rehabilitation that health and care professionals can signpost patients to following a full clinical assessment of the person's symptoms. Clinicians tell us that patients using these apps tend to need fewer face-to-face appointments, with regular contact maintained through the messaging features and telephone or remote consultation to review progress.

6.6 Children and young people

NHS England has established 14 post COVID specialist hubs for children and young people. These services are receiving an increasing number of referrals and are providing assessment, support and advice to children and young people and their families regarding the management of post COVID symptoms.

NHS England will work with local healthcare systems to agree the most efficient and effective referral pathways to these specialist hubs. Young people aged 16 and 17 should be referred directly to specialist hubs for children and young people where local post COVID specialist services do not accept referrals for people under 18.

The revised [National commissioning guidance for post COVID services](#) details this change to the children and young people pathway.

6.7 Key actions: prioritising treatment

- The Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) will publish quarterly reviews of evidence to help people navigate the growing range and number of research studies on long COVID. The reports will be available in the list of [Evidence Reviews Facility: Published reviews](#) and on the [COVID-19: Living systematic map of the evidence](#) from summer 2022.
- Post COVID service providers will review their service models and, where average waiting times are above six weeks for first appointment, include a triage call in the care pathway to ensure no patients waits for over six weeks. Services should also work to eradicate waits of more than 15 weeks for clinical assessment. To support this, from autumn 2022, NHS England will collect and publish data on waiting time from referral to clinical triage in addition to waiting time for first assessment.

- NHS England will support local healthcare systems and specialist post COVID children and young people hubs to strengthen their referral pathways to minimise unnecessary delays to the assessment and treatment of children and young people.
- Post COVID specialist children and young people hubs will offer help to young people aged 16 and 17 so that they do not fall into any gap between adult and CYP services.

7. Transforming the way we provide care

7.1 Access to diagnostics

Diagnostic testing is a critical part of the care pathway, particularly because of the wide range of symptoms those with long COVID can experience such as breathlessness or to exclude other diagnoses such as cancer or heart disease.

To boost access to diagnostic tests, patients with suspected long COVID will have access to appropriate community-based diagnostic testing, where this is clinically advised.

7.2 Building on the GP enhanced service for long COVID

The purpose of the [general practice enhanced service](#) launched in 2021/22 was to help general practice teams put in place the foundations to support people with long COVID. Key areas of focus were education of staff to give them a greater understanding of long COVID and the associated pathway of care, supporting use of coding in clinical information systems and improving equity of access.

Primary care will continue to be a core element of the patient pathway, often being the patient's point of entry into long COVID care. It will be for ICSs to determine the best way of distributing funding across the pathway of care locally including how to support general practice.

7.3 Offering a personalised approach to ongoing care

Community care co-ordinators, health and wellbeing coaches (HWBC) and social prescribers can also support people with long COVID to navigate the pathway, provide education and be a point of contact. They can play an important role after discharge in helping patients with the self-management of their symptoms.

ICSs should consider the benefit of personalised, non-clinical intervention as part of the long COVID pathway; for example, by recruiting social prescribers or HWBCs directly into their service or through primary care networks.

Case study 7: Embedding personalised care in Derbyshire's community health services

Derbyshire Community Health Services NHS Foundation Trust has ensured a personalised approach to the management of long COVID. Using personalised care funding it has employed a health and wellbeing coach (HWBC) in the post COVID service team to offer follow-up support to people assessed by the post COVID service, such as specialist advice on sleep hygiene and fatigue management. Given the success of this role, a second coach will be recruited in 2022/23.

Case study 8: A personalised approach to supporting people who are concerned about the socio-economic impact of long COVID

Long COVID can affect a person's ability to work and therefore their income. One post COVID service identified that clinicians were spending considerable time helping with these concerns. To provide practical help and support, the service run by Derbyshire Community Health Services NHS Foundation Trust has involved the Citizens Advice Bureau to help people with long COVID with financial management. This has received positive patient feedback.

Some systems are implementing other forms of peer support, such as the [HOPE programme](#) that empowers people to self-manage a long-term health condition.

Case study 9: Implementing the HOPE programme as part of the long COVID pathway

In Devon the HOPE (Helping Overcome Problems Effectively) programme is being used to support people with long COVID. This comprises six two-hour weekly sessions. It was developed by Coventry University and then adapted by The Self-management Partnership for people experiencing a variety of long-term physical or mental health conditions such as long COVID. The course is facilitated by two people, one with lived experience and one a health or care background. The use of a person with lived experience engenders participant trust.

7.4 Evidence-based service delivery and care

Since July 2021, NHS England has maintained a national registry for patients attending post COVID services. This includes data linkage across multiple NHS data sources, including demographic, inpatient and outpatient activity, diagnostic imaging, COVID testing and vaccination data. It has enabled insight into the natural history of long COVID and the journey for patients with long COVID, supporting equitable service. NHS England will further develop the long COVID registry and harness registry data, including by working with NIHR research programmes, to generate insights that add to the evidence base on long COVID and inform future service planning, treatment and care for people with long COVID.

7.5 Key actions: transforming the way we provide care

- In addition to GP testing and post COVID clinic testing, patients with suspected long COVID will have access to appropriate community-based diagnostic testing where clinically indicated.
- NHS England will publish updated commissioning guidance to help systems identify how best to care for people with long COVID.

8. Information and support for patients

8.1 Your COVID Recovery

The Your COVID Recovery website provides support, advice and information on COVID-19 and long COVID, to help individuals recover from COVID-19 and manage the effects on their body and mind effectively and to reduce the impact on their day-to-day life. Launched in summer 2020, it has now been used by 10.8 million people. For people who cannot access the online resource the information can be printed off in the language required.

Your COVID Recovery also provides an online rehabilitation platform for those referred by a post COVID service. This element offers a bespoke package of support personalised to the individual's healthcare needs and online support from their healthcare professional.

Since its launch the platform has continued to evolve in response to feedback and emerging evidence. We have listened to our lived experience partners and clinicians to better understand what is needed from this digital resource. For example, by September 2022 Your COVID Recovery will include resources for children, young people and their parents and carers, such as general information on long COVID in children and young people, as well as more specialised topics such as returning to education, undertaking activity and resuming a social life, which are all important steps on the journey to recovery.

8.2 Patient insight and feedback to shape care

Understanding patient experience and outcomes is key to the development of these relatively new services, particularly given we are still learning about this condition. While treating the traits of long COVID is the clinically sensible way to help patients, especially in the absence of definitive evidence on effective treatment, a common and consistent way of measuring outcomes and experience will help drive improvements in service delivery and the quality of care individuals receive.

In addition to the data discussed in section 4, NHS England is analysing qualitative data sources that capture patients' experiences and has commissioned primary research to further build the evidence base.

Service user research is underway to explore experiences of access (barriers and enablers), attitudes and awareness, and experiences of care and treatment. This will survey those with pre-existing long-term conditions; adults, children and young people living in areas of deprivation; and the wider public.

The national GP Patient Survey includes a specific question to capture patient experience of long COVID. This will enable comparative analysis to explore if and how patient experience varies. The [GP Patient Survey data for 2022 can be found here](#).

The new International Survey of Healthcare Experience, a field trial for 2022 focusing experiences of GP care for those with long-term conditions aged over 45, also includes a question to capture patient experience of long COVID.

The outcomes of these surveys will be used, alongside Friends and Family Test results, to further shape services and inform the approach to engaging with and support patients.

8.3 Working with people with lived experience

By working with our lived experience partners patient and public voice partners and other stakeholders NHS England will improve the provision of post COVID service and enhance Your COVID Recovery to better reflect the patient pathways, and link to these pathways.

We will work with regions and ICSs to support the development of a network of lived experience partners that provides a vital forum to inform the development of services at local and regional level. ICBs and provider collaboratives should seek to engage people with lived experience of long COVID from underserved communities to address potential inequalities.

8.4 Enabling people with long COVID to be involved in research

NIHR has invested over £50 million in long COVID research. Our lived experience partners have told us they would like more information about how NHS patients can participate in these studies.

NHS England has developed a research page as part of Your COVID Recovery to help connect people with NIHR-funded studies into long COVID. This will be available for post COVID services to use.

People can also go to the NIHR's [Be Part of Research](#) website to find out more about getting involved in long COVID studies.

Local clinical research network (LCRN) staff can directly support the recruitment of participants into long COVID research and provide training for long COVID clinic staff to enable them to support studies themselves. We recommend that post COVID services, whether based in primary, secondary or community care, engage with their LCRN ([Clinical Research Network | NIHR](#)).

NHS England is working with NIHR to develop toolkits to help researchers engage more effectively with under-represented communities for long COVID and other conditions.

8.5 Supporting our NHS people

The long COVID plan for 2021/22 set out the support offers and services available to NHS colleagues to support their health and wellbeing, including where they have long COVID symptoms. These include:

- Access to occupational health and wellbeing services and local employee assistance programmes through the employing organisation. It is likely that referral into occupational health and wellbeing services will need to be via a line manager, but access to Employee Assistance Programmes can often be direct.
- Access to a range of health and wellbeing offers through the [national support programme](#), including free access to a range of mental health and wellbeing apps, talking therapies through the Samaritans helpline and a range of coaching and counselling offers.

- As for all other patients with long COVID, access across the country to support via online rehab services at [Your COVID Recovery | Supporting your recovery after COVID-19](#).

NHS England has updated the [Guidelines for supporting our NHS people affected by long COVID](#) to help NHS managers understand what long COVID is and how they can support colleagues who are experiencing its symptoms. These guidelines, which were co-developed with a range of stakeholders, include advice on HR functions such as sick pay and how to record long COVID-related absence, as well as practical tips on the benefits of having regular health and wellbeing conversations to understand any reasonable adjustments that colleagues might need to support their return to work.

Colleagues can also seek support from their registered GP, or through one of the 90 NHS post COVID services available nationwide. They can seek a referral to their local post COVID clinic via their GP or a relevant clinical service.

8.6 Key actions: information and support for patients

- NHS England will continue to work with lived experience partners and other stakeholders to develop the content of the Your COVID Recovery website, so it is an accurate and trusted source of information for the public.
- Post COVID services and rehabilitation services treating people with long COVID should use the outcome measures set out in the [National guidance for post COVID services](#) to collate outcomes from assessment and discharge.
- NHS England will publish Friends and Family Test data for post COVID services from June 2022 to chart people's experience of using long COVID services.
- NHS England will support integrated care systems to develop a network of lived experience partners, who will support the development of local services.
- NHS England will develop an information resource by September 2022 for post COVID services to use, to inform people with long COVID about opportunities to participate in Long COVID research.
- NHS England will publish revised guidelines in summer 2022 for supporting our NHS people affected by long COVID.

Contact us:

enquiries@england.nhs.uk

NHS England

Wellington House
133-155 Waterloo Road
London
SE1 8UG

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