

Long Covid Briefing – January 2021

1. Despite other significant pressures on the NHS, progress has been made on the five point plan to support people experiencing long term health effects from Covid-19. The plan represents the initial rapid response to the growing challenge of long Covid. The work will evolve the more we learn about the condition, patient demand, referral patterns and best treatment.

Progress on long Covid clinics

2. Sixty-nine post Covid assessment clinics were announced on 18 December 2020 with a further 12 due to launch shortly.
3. Of the 69 already established, six have advised they have had to pause appointments as core staff have been redeployed to support acute care. These are in London, South East and the East of England. Current pressures mean the ramp up of services will be delayed although the intention is for all patients who have been referred to the post Covid clinics to be seen within the next few months. And anyone with urgent post Covid care needs is being advised to seek help through the usual routes – GP, 111 or 999.
4. By February 2021 the Long Covid clinical pathway based on NICE guidance and existing models will be developed to inform resource and workforce modelling and planning for long Covid services in 2021/22.
5. More work is being done to understand treatment needs following referral into a clinic. It is becoming clear that there will be big dependencies on diagnostic tests, rehabilitation and mental health services.

Primary care role

6. General practice plays a key part of the long Covid clinical pathway. Patients, with previously confirmed or suspected Covid-19, may present with a wide range of symptoms including breathlessness, fatigue, cognitive impairment or psychological symptoms. The initial role of the general practice clinician is to exclude other pathologies and treat appropriately. If long Covid is diagnosed (>4 weeks after infection), the patient may be:
 - Signposted to self-management including the online platform Your Covid Recovery (YCR) or
 - Offered supported self-management which may include YCR and a referral to a social prescriber and/or
 - Referred to mental health services if needed
7. Most patients will improve or recover by 12 weeks but if symptoms are severe or not improving, then a referral into a post Covid assessment service may be required. This is being built into the clinical pathway.
8. SNOMED codes will become available to General Practitioners in the next month which should support understanding of the gap for those reporting in primary care and for those with self-reported limiting illness as a result of long Covid. This will provide information on numbers of people accessing support. Further analysis by protected characteristics may also help to identify any potential inequities of access by different groups.
9. To raise awareness of the available services to practices, information has been disseminated both nationally and locally. Educational materials are also being produced to increase healthcare professionals' knowledge of the condition.
10. Methods to raise awareness of the condition and available support to patients are also being considered. These will need to be tailored in such a way that they reach all our diverse communities.
11. Of note, practices are currently being diverted to other significant priorities (i.e. Covid vaccination) which may result in less capacity than usual to focus on long Covid.

Latest information on projected potential patient cohort

12. Based on the latest Covid Infection Survey, the ONS estimates that, in the week commencing 27 December 2020, 301,000 people in England had Covid-19 symptoms that had persisted for between 5 and 12 weeks.¹ They found that:
 - Around 1 in 5 (20%) respondents testing positive for Covid-19 exhibit symptoms for a period of 5 weeks or longer.
 - Around 1 in 10 (10%) of respondents testing positive for Covid-19 exhibit symptoms for a period of 12 weeks or longer.
13. The CIS data shows all age groups, including children, are affected post 5 weeks, although more prevalent in 35-49 age group, and in women. See Appendix A.
14. The ONS will publish more data on prevalence and symptoms in the first quarter of 2021 and will link data from the Covid infection survey and GPES with the 2011 census to start to give an indication of socioeconomic breakdown of long Covid such as occupation, ethnicity and a range of other variables.
15. Based on early literature we assume 2% of infections warrant assessment in a long Covid clinic, with a gradual capacity ramp-up. This reflects existing capacity constraints and time to establish long Covid services.
16. Local data collections from a sample of trusts show the following numbers, and we are seeking to establish routine data flows as services are established:
 - UCLH and Newcastle already seen over 1,000 long Covid patients (post hospital and community incidence)
 - Barts identified 325 post hospital patients for follow up from wave 1
 - Guys & St Thomas's identified 385 post hospital patients for follow up from wave 1
 - King College Hospital identified 362 post hospital patients for follow up from wave 1

Your Covid Recovery

17. [Your Covid Recovery](#) (YCR) is one element of the five-part package of measures to boost NHS support for post-Covid syndrome patients. It's a digital, interactive and tailored recovery programme that has been developed by experts to provide rehabilitation support for post-Covid-19 patients to manage their recovery at home.
18. It is a two part virtual platform established for those affected by Covid-19. This was done in conjunction with the University Hospitals of Leicester and various stakeholders from across the rehabilitation world. Your Covid Recovery has two elements: a public facing information site and a separate virtual rehabilitation platform which provides personalised self-management tools for the post Covid19 patient.

YCR Public facing website

19. Since launching the public facing information site in July 2020, there have been over 700,000 people that have used the site, which gives people general information and advice on living with post-Covid syndrome.
20. Feedback from the site has been positive, see below for quotes, and clinical teams, particularly GP Practices, are signposting their patients to the phase one website to their patients as part of their recovery:
 - Very informative throughout and answers most questions anyone could ask.
 - Would suggest everyone who has Covid is told about this website. It is reassuring when you live on own and don't know what to expect or where to turn for help.

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/ad-hocs/12788updatedestimatesoftheprevalenceoflongcovidsymptoms>

- Thank you for the website. It is very hard still feeling unwell and not being able to see a GP for advice.
- Excellent web site and I hope as knowledge of Coronavirus increases and in particular recovery, this web site will improve even more.
- Thank you and very well done I found the site clear, informative and reassuring.
- I felt the site was very easy to navigate, written in plain English, not full of medical terms I couldn't understand. I found it very helpful indeed, it has definitely answered some of my questions that were troubling me. I felt less anxious after reading through all the sections.

Virtual rehabilitation platform

21. The virtual rehabilitation platform allows services to provide patients with access to a self-management style rehabilitation option, enabling patients to set goals for their mental and physical health, providing peer to peer support through social community forums, and offering an 'ask the expert' facility for patients to contact their local rehab service. Patients will access this where appropriate once a full assessment is carried out by local healthcare professionals, who will then continue to monitor the patients virtually and then finally completing a discharge assessment of the patient.
22. The rollout of this is currently underway with over 160 local clinical services around England having been trained to refer into the platform and with further services set up to be trained.
23. Because some patient information is stored on the platform, information governance laws require each service to enter into a data sharing agreement with UHL. Once completed, unique access codes are provided at which point services can refer patients. Subject to IG agreements, we are aiming for all trained local services to be registered to refer by the end of January.
24. The online platform is currently hosted and managed by University Hospitals Leicester and will transfer in due course to NHS Digital to enable further scaling up and expansion, and the creation of additional functionality.
25. The system UHL use has been reviewed and stress-tested by NHS Digital, with data being kept on servers within the Trust behind Secure Firewalls that are ISO27001 and DS&P toolkit compliant.
26. Whilst it is not currently possible to provide evidence of effectiveness of this particular platform for this novel disease, the approach to self-management via an online platform has been based on the successful implementation of two rehabilitation platforms also developed by University Hospitals Leicester; Activate Your Heart and SPACE for COPD, both of which have proven to be effective. The content will be reviewed and updated, based on user feedback and as the clinical evidence and guidance develops.

Latest academic research of relevance

27. A [paper based on findings from the ZOE](#) app which has 4 million users, suggests about **1.5-2 %** had Long Covid symptoms after 12 weeks
28. [A study](#) (n=4,182) using a sample from the same Covid Symptom Study (Zoe) app found **2.3%** had symptoms in the same time period.
29. Symptoms range from heart palpitations, chest pain and breathlessness, lung fibrosis and thromboembolism to anxiety and depression.
30. A recent study of over 47,000 individuals discharged from English hospitals following Covid-19, conducted by ONS analysts, found they face elevated rates of multi-organ dysfunction compared with the matched control group, and the increase in risk is neither confined to the elderly nor uniform across ethnicities. Post discharge adverse events included exacerbated diabetes, new onset diabetes, major cardiovascular events and respiratory disease.²
31. Another study of 837 patients post hospital discharge found that following SARS-CoV-2 pneumonitis, a cohort of patients are left with both radiological inflammatory lung disease and

² <https://www.medrxiv.org/content/10.1101/2021.01.15.21249885v1.full-text>

persistent physiological and functional deficit. Early treatment with corticosteroids was associated with rapid and significant improvement.³

32. The NIHR is due to announce imminently awards for their £20million call for research into longer term physical and mental effects of Covid-19 in non-hospitalised individuals.
33. The [Post-Hospitalisation Covid-19 Study \(PHOSP-Covid\)](#), led by the [NIHR Leicester Biomedical Research Centre](#), is assessing the impact of Covid-19 on patient health and recovery and is due to report initial findings within the next month.
34. REACT-GE bio markers study; CNS-Covid neurological study.
35. Between Jan-March 2021 NIHR will announce research awards for long Covid effects in non-hospitalised people.

Appendix A Long Covid prevalence five weeks after onset

Table 1. Estimated five-week prevalence of any symptom among Coronavirus Infection Survey respondents testing positive for COVID-19, stratified by sex and age group, UK: 22 April 2020 to 14 December 2020¹⁻⁵

	Percentage		
Group	Estimate	Lower 95% confidence interval limit	Upper 95% confidence interval limit
All people	22.1	21.2	23.2
Male	20.7	19.3	22.1
Female	23.6	22.2	25.0
Age 2-11 years	12.9	10.4	16.0
Age 12-16 years	14.5	11.7	17.9
Age 17-24 years	17.1	14.4	20.2
Age 25-34 years	24.9	22.0	28.2
Age 35-49 years	26.8	24.5	29.3
Age 50-69 years	26.1	24.3	28.1
Age ≥70 years	18.0	15.5	20.8

³ <https://pubmed.ncbi.nlm.nih.gov/33433263/>