

Sir Simon Stevens
Chief Executive Officer of the NHS
Sent by email

Friday 11 September 2020

Dear Sir Simon,

I am writing to you regarding the support available for people with confirmed or suspected COVID-19 who are continuing to struggle with prolonged, debilitating and sometimes severe symptoms months later. These patients are sometimes referred to as 'long-haulers' or described as having 'post-acute', 'chronic' or 'long-term' COVID-19. Here, we will use the term 'Long COVID'.

Patient Safety Learning

By way of a quick introduction, I am the Chief Executive of [Patient Safety Learning](#), an independent charity and voice for improving patient safety. We believe patient safety is not just another priority; it is a core part of the purpose of health and social care. Patient safety should not be negotiable. Our aim is to reduce harm to patients from unsafe care.

Long COVID and patient safety

In July, we highlighted [patient safety concerns around care and support for Long COVID patients](#) with a number of key stakeholders and decision-makers in health and social care, along with a proposed set of actions to address these issues. We drew on patient experiences in this respect, two of which were shared on our patient safety shared learning platform, [the hub](#), and which you may find of particular interest:

- [My experience of suspected 'Long COVID'](#)
- [Dismissed, unsupported and misdiagnosed: Interview with a COVID-19 'long-hauler'](#)

Subsequently, the NHS launched the 'Your COVID Recovery' online portal, which we welcomed as a positive step in recognising the need to increase the support for those recovering from COVID-19. From our conversations with patients and community support groups, we are aware that concerns remain about the availability of support for those who have been managing their symptoms at home. Patients have highlighted that much of the 'Your COVID Recovery' site focuses only on those patients who have been in hospital.

Post-COVID clinics

On 8 September 2020, speaking at the Health and Social Care Select Committee, the Secretary of State Matt Hancock MP stated:

"The NHS set up Long COVID clinics and announced them in July. I am concerned by reports this morning from the Royal College of GPs that not all GPs know how to ensure

that people can get into those services. That is something I will take up with the NHS and that I am sure we will be able to resolve.”¹

We have found that there is significant confusion as to where these clinics are, what services they offer and who is eligible for support. As far as we are aware, there is no published list of post-COVID clinics. We have been inviting patients to share with us where these clinics are. Most responses are ‘we don’t know’. From our conversations with patients on social media and [the hub](#) we believe that the following information would provide greater clarity for Long COVID patients:

Location of these services

- Publish a list of all existing post-COVID clinics and contact details.
- Where there are regional disparities, set out plans to address these and avoid a postcode lottery. We note that a recent report from the BBC stated that less than 12% of the 86 Clinical Commissioning Groups asked were running such services and that the Royal College of GPs had called “for a national network of ‘post-COVID’ clinics”.²

Referral process

- Confirm whether Long COVID patients who have not been hospitalised can access these clinics by referral from a GP or self-referral.
- If by GP referral, confirm that these now been added to the e-Referrals System and publish the guidance issued to GPs on this process.

Eligibility and services available

- Clarify whether services at these clinics are restricted to those who have been hospitalised or also open to those who are managing their symptoms at home.
- Clarify whether these services are available to all patients or only those who have had a confirmed positive test for COVID-19. We are aware of a significant number of Long COVID patients who have not received a positive test and have expressed concerns about the lack of clinical recognition for their illness and access to appropriate medical support
- Confirm what services are available at these clinics. Will they help patients access a range of clinical investigations, as well as treatment and rehabilitation?

Second phase of ‘Your COVID Recovery’

- Publish the timeframe for the implementation of Phase 2 of the ‘Your COVID Recovery’ portal, described as a virtual rehabilitation platform offering patients interactive and tailored support. Initially, it was stated that the portal would launch “later in the summer”, therefore we ask for transparency about the cause of delay.³

I welcome your comments on these issues and look forward to your response in due course.

Yours sincerely,



Helen Hughes
Chief Executive, Patient Safety Learning

¹ Health and Social Care Committee, Oral evidence: Social care: funding and workforce, HC 206, 8 September 2020. <https://committees.parliament.uk/oralevidence/817/pdf/>

² BBC News, Coronavirus: ‘Long Covid’ patients need treatment programme, doctors say, 8 September 2020. <https://www.bbc.co.uk/news/health-54031587>

³ NHS England and NHS Improvement, NHS to launch ground breaking online COVID-19 rehab service, 5 July 2020. <https://www.england.nhs.uk/2020/07/nhs-to-launch-ground-breaking-online-covid-19-rehab-service/>