Editorials

The health system response to long COVID in England — at a critical juncture

As of 2 August 2021, in England there have been over 5.9 million cases of acute COVID-19 infection, and over 130 000 deaths.[1] The Office for National Statistics (ONS) estimate that 962 000 people in England are experiencing long COVID symptoms at least 4 weeks post-infection, with almost a fifth reporting 'a lot' of day-to-day limitation[2] — although there is uncertainty about the accuracy of these estimates.[3] In addition to the health burden, there is potential for significant socioeconomic harm due to the increased prevalence among the working age population and those from deprived areas.[2] Here, we look at the English health system's response to date, and the challenges ahead.

PROGRESS TO DATE

In late 2020, a five-part package was announced by NHS England to support patients with long COVID:[4]

1. A rapid guideline was produced by a collaboration involving the National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guideline Network (SIGN), and Royal College of General Practitioners (RCGP).[5] Strengths included a clear case definition: 'ongoing symptomatic COVID-19' (signs and symptoms 4–12 weeks post-infection), 'post-COVID-19 syndrome' (beyond 12 weeks), and 'long COVID' (umbrella term); and a review of patient experiences.
2. Multidisciplinary post-COVID-19 assessment clinics were established in each Integrated Care System (ICS), supported by a national £34 million investment.[6]
3. Self-management was thought to be appropriate for 30%–50% of patients[7] leading to the launch of an interactive rehabilitation platform — 'Your COVID Recovery'.[8]
4. The National Institute for Health Research published two comprehensive themed reviews on long COVID[9] and jointly commissioned £18.5 million worth of new research to fill the identified evidence gap[10] with studies on: mechanisms, patient pathways, and treatments for long COVID; as well as characterisation of long COVID in children and young people.
5. A Long COVID Taskforce was established, bringing together clinicians from across the NHS, academics, and patient representatives.

CURRENT POLICY

On 15 June 2021, NHS England published *Long COVID: The NHS Plan*, making several further commitments for the coming year.[7] These included:

1. Moving beyond 'assessment' clinics. £100 million (for the financial year) to expand current services beyond assessment clinics, covering the whole pathway from diagnostics to treatment. Reflecting the multi-system nature of long COVID, there is an important focus on the development of new multidisciplinary, vocational rehabilitation pathways, with 'care coordinators' to ensure seamless care and the prioritisation of those most in need. There is a focus on co-designing service pathways with patients.
2. An increased emphasis on primary care. One third of the new funding is specifically allocated to primary care to provide an enhanced service. While there is an emphasis on education, reducing inequalities, and 'consistent' coding of long COVID in the patient records to progress understanding of the condition, primary care's exact role in the long-term remains unclear. We describe some possible roles for primary care in Box 1.
3. Targeted support. The plan commits to provide extra support for specific groups, including the formation of specialist hubs for children and young people, specific focus on mental health and cognitive impairment, and a health equity audit to quantify the scale of long COVID access and outcome health inequalities. The commitment to provide a package of support for NHS staff with long COVID is also much needed.

Box 1. Possible roles and responsibilities of primary care relating to long COVID

- Participation in learning activities and sharing of learning between health professionals
- Clinical examination and assessment of patients with symptoms suggestive of long COVID
- Initial investigations such as blood tests, assessment for postural hypotension, functional assessment, and radiological imaging
- Referral into post-COVID-19 assessment clinics or specialist services
- Patient education about long COVID
- Signposting to self-management resources
- Accurate coding of long COVID in the patient record
- Prescription and monitoring of medications, either independently or as a shared care arrangement with secondary care
- Follow-up of patients undergoing assessment or treatment for long COVID, as a source of support and continuity of care

KEY CHALLENGES

We have adapted the World Health Organization's (WHO's) 'building blocks' of a successful health system[11] to consider the key challenges ahead.

Service delivery. The knowledge gap remains significant, and the evidence base will take time to catch up. Symptoms like 'brain fog' are considered novel to long COVID, and little is known about how these symptoms should be optimally managed. This context necessitates pragmatic decision making and innovative models of care. Existing services, such as those for chronic fatigue syndrome or chronic obstructive pulmonary disease, may offer much of the expertise needed to support patients with long COVID. However, care will be required when applying these services to fit the long COVID cohort; evaluation and sharing good practice will be essential. There are also opportunity costs here; guidance is needed to support already stretched services in managing and prioritising their waiting lists, especially those that are supporting long COVID patients and those with other conditions, to ensure the outcomes of the WHO framework are achieved, such as equitable access.

Health workforce. The long COVID plan requires local systems to provide 'fully staffed' service plans,[7] which is challenging in the context of the NHS workforce crisis.[12]

Aspirations of seamless, multidisciplinary, novel rehabilitation pathways, delivered across community, primary, and secondary care sectors, are therefore ambitious. However, as part of the planned reforms to the healthcare system, various sectors of the NHS, local authorities, and other partners have been brought together to establish ICSs as statutory entities with responsibility to lead on integrated planning of healthcare services. This provides an opportunity for collaborative working, which may go some way to mitigating this workforce challenge.

Information. Codes for recording long COVID in primary care were introduced in November 2020.[13] However, a recent study found that these were only present in 0.04% of patient records, there was significant geographical variation in usage, and over a quarter of GP practices in England had never used them.[13]

There is a commitment to establishing a data-linked, individual patient-level dataset for the post-COVID-19 clinics to replace the existing manual, patchy, aggregate data reporting that has hindered evaluation to date. This will be vital to understanding typical patient trajectories, completing health equity audits, and ultimately determining whether the response has improved health outcomes[7] — and is required as a matter of urgency.

Financing. Significant funding has been provided to support the initial health system response. There has been a welcome move to weighted regional distribution of funding, with relatively more funding going to areas that have been harder hit during the pandemic. Though an inevitable consequence of the fast-moving situation, the year-long funding agreements, agreed close to the start of the financial year, don't assist in integrating long COVID services into sustainable rehabilitation pathways. As knowledge improves and the situation stabilises, longer-term funding commitments in line with a population health management approach will be required.

Desirable attributes. There is a high degree of flexibility for local design of long COVID rehabilitation service pathways. This is to be commended, allowing areas to tailor service design to local populations, potentially targeting local access needs more efficiently and responsively. However, when establishing new services at scale and at pace, flexibility will result in local variation. For example, the NICE guideline states shared decision making should be used to determine whether consultations occur virtually or in-person, with additional steps taken to avoid digital exclusion,[5] but in reality, many assessment clinics are not yet offering face-to-face appointments.

Leadership/governance. NHS England has produced an ambitious plan, accompanied by appropriate funding. Local clinical leadership, such as from regional NHS Respiratory Clinical Networks, is now required to support ICSs in its delivery. Progress and monitoring of implementation and impact will be delivered at regional level feeding into the national COVID programme board using a common reporting template. It is critical that areas struggling to deliver on the plan are identified and supported early to avoid unwarranted variation in services.

Long COVID could represent a catalyst to enable transformative work within the emerging ICSs, with the potential to shape how systems learn to respond in a coordinated way to population need.

LONG-TERM SUSTAINABILITY

COVID-19 is an unprecedented challenge for the NHS, and long COVID continues to place a significant demand on services. As the country 'learns to live' with COVID-19, the health system faces a shared challenge to develop sustainable, integrated rehabilitation pathways that improve outcomes and reduce health inequalities. Just as the NICE guidance is a 'living review' (it will be reviewed and updated as new evidence emerges),[5] the health system response to long COVID must be flexible and responsive.

The NHS plan is as ambitious as it is necessary and lays the platform for translation into patient care. Significant steps are required across the system to turn its words into outcomes.

Tess Marshall-Andon,
GP Registrar, Healthcare Public Health Team, Public Health England East of England, Cambridge.

Sebastian Walsh,
Public Health Specialty Registrar, Healthcare Public Health Team, Public Health England East of England, Cambridge.

Jonathan Fuld,
Consultant Physician, Department of Respiratory Medicine, Cambridge University Hospitals NHS Foundation Trust, Cambridge; Clinical Lead, East of England Respiratory Programme Network.

Anees Ahmed Abdul Pari,
Consultant Public Health Medicine and Deputy Director, Healthcare Public Health Team (Interim), Public Health England East of England, Cambridge.

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ADDRESS FOR CORRESPONDENCE

Anees Ahmed Abdul Pari
Public Health England East of England, West Wing, Victoria House, Capital Park, Fulbourn, Cambridge CB21 5XA, UK.

Email: anees.pari@phe.gov.uk

Competing interests
Jonathan Fuld is Clinical Lead for the East of England Respiratory Network and has responsibility for assurance of long COVID services in the East of England.

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