Long Covid SOS submission to NHS England 10 Year Plan Consultation

Q1. What does your organisation want to see included in the 10-Year Health Plan and why?

Long Covid affects 2 million people in England and Scotland, of whom 1.5 million are adversely impacted, and 381,000 disabled by the condition[1] . The number of people living with Long Covid shows no signs of reducing, and almost 5 years since the start of the pandemic, in the absence of mitigations against Covid infections, many continue to develop Long Covid. Long Covid can develop after reinfections and it is accepted that with each infection the cumulative risk of persistent symptoms increases[2]. Reinfection for people already impacted can result in significantly worse symptoms[3].

The cost to the NHS is and will continue to be considerable[4]. Recent research commissioned by NHS England suggests that patients attending Long Covid clinics are still suffering significant burden and disability at 6 months after an initial assessment and "the burden and disability in this cohort of LC patients were worse than in Diabetes Mellitus, COPD, Heart Failure, and Multiple Sclerosis"[5]. The same study reports that only 21% were able to work in their roles as they did pre-infection, with 62% stating that they were on sick leave, had to reduce hours, change roles, or leave their jobs. Long Covid predominantly impacts working age adults.

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[1] Office for National Statistics (ONS), released 25 April 2024, ONS website, article, Self-reported coronavirus (COVID-19) infections and associated symptoms, England and Scotland: November 2023 to March 2024

[2] Letícia Soares, Gina Assaf, Lisa McCorkell et al. Long COVID and associated outcomes following COVID-19 reinfections: Insights from an International Patient-Led Survey, 24 September 2024, PREPRINT (Version 1) available at Research Square [https://doi.org/10.21203/rs.3.rs-4909082/v1]

[3] Boufidou F, Medić S, Lampropoulou V, Siafakas N, Tsakris A, Anastassopoulou C. SARS-CoV-2 Reinfections and Long COVID in the Post-Omicron Phase of the Pandemic. Int J Mol Sci. 2023 Aug 19;24(16):12962. doi: 10.3390/ijms241612962. PMID: 37629143; PMCID: PMC10454552.

[4] Mu Y, Dashtban A, Mizani MA, et al. Healthcare utilisation of 282,080 individuals with long COVID over two years: a multiple matched control, longitudinal cohort analysis. Journal of the Royal Society of Medicine. 2024;0(0). doi:10.1177/01410768241288345

[5] Sivan M, Greenwood D, et al. A National Evaluation of Outcomes in Long COVID Services using Digital PROM Data from the ELAROS Platform University of Leeds. 2023

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Our organisation advocates for urgent and sustained attention to Long Covid within the 10-Year Health Plan in order to improve the health and outcomes for the millions impacted, many of whom are in the prime of their working lives.

We believe that our **Bill of Rights** for people with Long Covid should inform NHS England's strategy for the next 10 years:

- **The Right to be believed**
  People with Long Covid symptoms have the right to be believed and treated with respect when they seek medical care and other forms of support.

- **The Right to a diagnosis**
  People presenting with Long Covid symptoms have the right to be fully assessed with relevant medical investigations, and to be given a diagnosis of Long Covid where appropriate.

- **The Right to support**
  People with Long Covid have the right to claim benefits, reasonable adjustments and flexibility at work, and access to full social support, without risking symptom exacerbation.

- **The Right to safe healthcare**
  People with Long Covid have the right to safe evidence-based treatments and require a multidisciplinary approach. Patients should not have to self-advocate for care or clean air.

- **The Right to funded research**
  Funding for ALL types of Long Covid research must be accelerated. Patient and public involvement is a necessity in the design and conduct of Long Covid research.

We call for:

1. **Increased public health messaging** to raise awareness of Long Covid as a significant, relatively common long-term condition, that can impact anyone of any age. More education for the general public is needed so that they can assess their own risk and to combat stigma. This should include improved sign-posting to relevant services.

2. **Prevention:** Long Covid and other conditions (such as diabetes, CVD and autoimmune diseases) which have increased prevalence after Covid can be prevented by a) avoidance of infection and b) access to covid vaccines. This should be an important part of NHS England's prevention strategy and has the potential to significantly reduce expenditure

3. **Long-term care planning** to support individuals with Long Covid, which should include funding, maintaining and improving specialist clinics, developing pathways for multidisciplinary care, continuing education and training of primary and secondary care staff, allied health professionals and pharmacists and better physical and mental health support. This would put the NHS in a better position to support people developing other potential new infection-associated chronic conditions in the future

4. **Proactive pandemic preparedness** to put in place adequate workforce resources, sleeping research studies, and policies in order to prepare services and minimise the impact of post-viral illnesses in future epidemics / pandemics.

Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

Challenges:

- **Lack of specialist knowledge**: Many community healthcare professionals lack training in Long Covid management, leading to inconsistent care. Knowledge is not shared adequately across regions/ICBs resulting in a lack of expertise and familiarity with best practice

- The need for **multiple specialist input** for many Long Covid patients - leading to patients needing to visit many different medical sites

- **Funding limitations**: Resources for community care are insufficient to meet growing demand.

- **Fragmented services**: Disjointed care pathways make it hard for patients to access appropriate support.

- Prejudice, there are sadly still many health care professionals and NHS organisations who treat long covid and similar conditions as being "in the head" and not as the physical conditions they are. Resulting suboptimal and even harmful care.

Enablers:

- **Multidisciplinary care models**: Creating hubs where GPs, physiotherapists, OTs, mental health professionals, and Long Covid and other specialists can collaborate and see patients

- **Increased training**: Upskilling community healthcare providers in recognising and managing Long Covid, and providing appropriate and consistent treatment

- More focus on **recent research findings** in Long Covid, both UK-based and abroad, the outcomes of which could help inform treatment

- Enabling the **sharing of best practice**, novel interventions and research developments across all regions

- **Patient involvement**: Involving people with lived experience of Long Covid in care planning and service delivery, bringing humanity to the condition.

Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

Challenges:

- **Digital poverty**: Limited access to technology among vulnerable populations can exacerbate inequalities.

- **Poor data gathering**: Inconsistent digital health records hinder holistic care. Data is not adequately shared between secondary care centres and primary care. Data on Long Covid prevalence is no longer being collected by the ONS. GP record SnoMed codes for Post covid syndrome potentially expire automatically after just 3 months. Omitting vast numbers of patients who have long covid/post covid syndrome from the data pulls from GP records.

- **Privacy concerns**: Ensuring patient data is secure and used ethically.

- **Poor integration of existing and new communications channels**: The NHS app, SMS, letters in the post, digital letters, telephone - it all feels poorly integrated and confusing to patients

Enablers:

- **Virtual Consultations**: Expanding virtual consultations for those with mobility or energy limitations while ensuring that those with symptoms which demand face to face appointments are provided for.

- **Wearable technology**: Monitoring symptoms in real-time to inform personalised care and to help patients to manage their symptoms, share data and seek care when necessary.

- **Research databases**: Establishing an improved national Long Covid registry to improve understanding and treatment development. Research into this

was carried out by LSE with involvement from members of our team. Their recommendations should be followed.

- **Coding:** making the SnoMed code behave in a similar way to an asthma code, so there is a 'diagnosed with post covid syndrome' code and a resolved code.

Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Challenges:

- **Recognition:** Many healthcare professionals still struggle to diagnose Long Covid and other post-viral syndromes. Many patients, due to poor public messaging and cost implications, are not testing when unwell. They therefore are unaware they have had Covid and so do not connect their symptoms to a prior infection.

- **Health inequalities:** Marginalised communities face barriers to early diagnosis and care.

- **Stigma:** Long Covid is still often dismissed as psychological by, the public, GPs and other health care professionals, delaying diagnosis and treatment.

- Inaccuracy of rapid tests and general public apathy about airborne infection

Enablers:

- **Public awareness:** Educating the public about the risks of Covid and Long Covid, including encouragement and strategies to avoid infection and information about the early signs of Long Covid and the importance of seeking help.

- The NHS should lead by example when it comes to **prevention:** we understand that much of the estate is old where good levels of ventilation are difficult to achieve, however investment needs to be made in air filtration and ventilation improvements. Routine testing of staff showing signs of sickness should be reintroduced. Staff should be required to wear FFP2/3 masks if they are at work with symptoms which could be related to Covid or other infections. Patients with symptoms of Covid or other infectious diseases transmitted via the respiratory route should be required to mask.

- **Vaccination**: it is well established that Covid vaccines reduce the incidence of Long Covid. At present, most people of working age are not able to access vaccines on the NHS. It is possible that up to half of Long Covid cases could be avoided if vaccines were available to all.

- **High-quality testing technology is affordable now**: We'd like to see PCR testing available in the community, at an affordable price, to reduce the spread of Covid and to help patients understand why they have unexplained symptoms

- **Routine screening post-infection**: Encouraging GPs to ask questions about lingering symptoms post-infection. The leaflet for GPs we produced in partnership with the Clinical Post Covid Society and RCGPs should be available through every NHSE ICB/trust.

- **Better guidance for patients** should be available on the NHS website so that people seek care

- **Community outreach**: Engaging underserved populations to ensure access to early intervention.

- **The Reasonable Adjustments Digital Flag** to be used for all patients in primary and secondary care. This will prevent patients with Long Covid wasting time and energy in appointments repeating their health history.

- **NHS staff** the NHS should also lead by example on integrating and supporting its staff who suffer with Long Covid - adapting to reduced hours, reduced duties and encouraging/supporting use of aids such as wheelchairs. These staff, who have personally experienced Long Covid, will bring a level of insight, care and true empathy that would greatly improve the care of patients, as well as preserving the knowledge and experience that is being lost when those with Long Covid are forced to leave the NHS.

Q5. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example:

• **Quick to do, that is in the next year or so**

1. Please see our Bill of Rights

2. **Launch public health campaigns** to raise awareness of Long Covid, the continuing risk of Covid, the importance of rest and recovery after a Covid infection, and to reduce stigma.

3. **Expand ring-fenced funding** for existing Long Covid clinics, (which should be doctor-led and of a minimum standard), and training for GPs.

4. Advocate for funding of comprehensive Long Covid research to improve diagnostics, treatments, and develop prevention strategies.

5. Invest in prevention of infections of HCWs and patients on the NHS estate. Set high indoor air quality standards and provide funding for it. The investment will pay itself off quickly in fewer staff absences and less infection in the community, helping reduce waiting times.

• **In the middle, that is in the next 2 to 5 years**

1. Create regional Long Covid care hubs with integrated services for **ON GOING** multidisciplinary support.

2. Implement a **national database** for tracking Long Covid cases and outcomes.

3. **Improve medical school training** so that doctors graduate with a knowledge of post viral illness and specifically Long Covid. Ensure that CPD encompasses updates on the treatment of post viral illness in all age groups

• **Long term change, that will take more than 5 years**

1. **Long-Term Health**: Address and minimise chronic conditions or disabilities arising from pandemics, like post-viral syndromes or mental health effects, by investing in research, rehabilitation, and supportive care systems. Ensure that regional Long Covid care hubs can evolve into lasting institutions that address infection associated chronic conditions.

2. Invest in **community infrastructure** to ensure equitable access to high-quality, localised care.

3. Expand **technological innovations** like wearable devices and telemedicine to revolutionise long-term condition management.

4. Continuing ongoing funding for research and the development of treatments