

P-06-1217 Open Long Covid one stop medical hubs / clinics, Correspondence – Petitioner to Committee, 23.11.21

Long COVID

Long COVID is a new condition which despite National Institute for Health and Care Excellence (NICE) guidelines describing the services required for this condition, the services provided in Wales are inadequate, inequitable in comparison to England and highly variable across Wales.

Long COVID is a commonly used term to describe the long term effects following an acute COVID-19 infection, clinically defined as “ongoing symptomatic COVID-19” between 4-12 weeks and “post-COVID-19 syndrome” beyond 12 weeks (1). Long COVID is a complex, multisystem condition caused by infection with COVID-19 infection, irrespective of the severity of the initial acute infection(2). Long COVID can be continuous or relapsing and remitting in nature(3). There is increasing evidence of significant long term medical complications including cardiac, respiratory and renal disease, new-onset diabetes and excess deaths(2). A report issued by the Office of National Statistics (ONS) in September 2021 estimated that 970,000 British people are affected by long COVID(4), in March 2021 the ONS reported that 56,000 people in Wales were living with the condition (5).

Long COVID negatively impacts an individual’s ability to perform daily activities and to work normally. The ONS have stated that 66% of long COVID patients report that their symptoms adversely affect their day-to-day activities and 19% report that their ability to undertake day-to-day activities is “limited a lot” (4). Given the increased prevalence of the condition in working age people, and the impact on daily living and ability to work, individuals are at increased risk of financial hardship.

NICE guidelines published in December 2020 advised the provision of "access to multidisciplinary services (these could be 'onestop' clinics) for assessing physical and mental health symptoms and carrying out further tests and investigations. They should be led by a doctor with relevant skills and experience and appropriate specialist support, taking into account the variety of presenting symptoms” (1). Similarly, a Delphi study published in June 2021 stated that "Medically-led multi-disciplinary clinics are required as serious cardiovascular, neurocognitive, respiratory and immune sequelae can present with non-specific symptoms” (2). Despite the NICE guideline, there are currently no recognised Long COVID clinics in Wales that meet this description. England, however, has invested over £100million into long COVID services, setting up 89 clinics (6) and 15 paediatric hubs(7), creating a stark inequality between the two nations.

Research regarding the pathogenesis of long COVID is ongoing therefore a curative treatment has not yet been identified. Despite this, medical assessment of long COVID patients is required as a number of serious complications have been identified, these include conditions such as pericarditis, myocarditis, autonomic dysfunction, postural orthostatic tachycardia syndrome, blood clotting disorders (such as central venous thrombosis and pulmonary embolism), thyroid dysfunction and

new-onset diabetes(2). Given the increasing evidence of serious long term medical complications, patients should not be assumed to have a self limiting post-viral fatigue syndrome and provision of solely rehabilitation services should not be considered adequate for this patient group. So far, Health Boards across Wales have been tasked with developing Long COVID services. In some regions of Wales, long COVID services have been made available however these are therapies led, concentrating on rehabilitation and self management of the condition only. Some health boards in Wales are still in the development stages of creating long COVID services, resulting in an unfair postcode lottery. Everyone with long COVID in Wales is equally deserving of medically-led multi-disciplinary services as their English counterparts and Wales must therefore invest in the provision of effective, safe and equitable medically-led services across all regions of Wales.

Inequitable healthcare for long COVID sufferers has been enhanced secondary to lack of knowledge and understanding by healthcare professionals. For example, there have been many reports on the Long COVID Wales Facebook group of patients being gas lighted by their GP including dismissing their symptoms as anxiety, being told nothing is wrong when standard tests return as 'normal', not believing that they have long COVID or not recognising long COVID in absence of a positive COVID test despite this not being a requirement for the diagnosis. Long COVID patients have also reported that GPs have been unaware of which long COVID services are available and unwilling or resistant to refer to secondary care. Additionally, given the delay in Wales developing medically-led long COVID clinics we have lost over a year of potential time to learn about long COVID patients and contribute such knowledge to the wider stage. Given the difficulty of some patients in receiving referrals to secondary care, secondary care consultants are not gaining sufficient exposure to this new disease to develop expertise here in Wales. It is essential therefore that, in the hope that medically-led clinics will be created, that such clinics should communicate with medical leaders of long COVID clinics in England and further afield, as well as taking an active interest in keeping up to date with the quickly emerging research, in order to fast track the development of long COVID expertise amongst doctors and allied health care professionals practising in Wales.

A proportion of long COVID patients have been referred to secondary care services, however, due to long waiting lists, in some cases greater than a year, many long COVID patients have sought private healthcare. Given that long COVID is a multisystem disorder, some patients report paying in to the thousands for consultations and investigations by various specialists. This of course is not financially viable for many patients especially those whose incomes have been severely affected due to the illness and this widens the divide between those who are able to access healthcare and those that aren't. Many patients with long COVID, particularly those from the first and second waves, are key workers, often working for our health and social services. These patients had to leave the safety of their homes to work for the benefit of others, it seems unjust therefore that these patients cannot access the healthcare that they deserve, even worse that they are having to pay to receive it.

Solutions

We offer the following recommendations for solutions to the issues discussed above.

- Investment by the Welsh government is needed to establish medically-led long COVID clinics in Wales. Such clinics should provide:

- o A medically- led service by doctors with long COVID expertise
- o Holistic care pathways
- o Physical assessment
- o Cognitive assessment to assess any potential memory, attention or concentration problems
- o Direct access to diagnostic testing with investigation of specific complications
- o Management of symptoms clusters
- o Tailored rehabilitation.

Following such recommendations would enable safe, equitable, effective and patient centred care.

- Clinics as described above should be accessible by patients across Wales in a timely manner, this will enable more efficient and timely healthcare and provide economic savings when contrasted with the short and longer term impacts of long COVID on high prevalence occupations such as in the education, health and social care sectors.
- NHS leaders of such clinics should communicate with successful long COVID clinics in NHS England and further afield to learn from the knowledge and experience developed in such clinics over the last year. This will expedite the development of equitable, effective, efficient, timely, safe and patient centred services.
- All Wales training, developed and provided perhaps by Health Education and Improvement Wales, about long COVID should be given to health care professionals to improve knowledge of this complex condition and its associated complications. This will enable safe, equitable and timely care for these patients.
- Health care professionals should be aware of the locally and distanced available services for long COVID patients to provide safe, efficient and timely for the patients effected.

1. COVID-19 rapid guideline: managing the long-term effects of COVID-19. NICE guideline [NG188]. Published: 18 December 2020. <https://www.nice.org.uk/guidance/ng188/chapter/Context>

2. Recommendations for the recognition, diagnosis, and management of long covid: A Delphi study. Nurek M, Rayner C, Freyer A, Taylor S, Järte L, MacDermott N and Delaney B. British Journal of General Practice 2 August 2021; BJGP.2021.0265. DOI:10.3399/BJGP.2021.0265 <https://bjgp.org/content/early/2021/07/27/BJGP.2021.0265>

3. Long COVID: An overview. Raveendran AV, Jayadevan R, Sashidharand S. Diabetes MetabSyndr. 2021 May-June; 15(3): 869–875. doi: 10.1016/j.dsx.2021.04.007 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8056514/>

4. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 2 September 2021. Office of National Statistics. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics (ons.gov.uk)

5. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 1 April 2021. Office of National Statistics. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics (ons.gov.uk)

6. Long COVID: the NHS plan for 2021/22. Document first published:15 June 2021.

7. NHS sets up specialist young people's services in £100 million long COVID care expansion. NHS England. 15 June 2021. NHS England » NHS sets up specialist young people's services in £100 million long COVID care expansion