

**P-06-1217 Open Long Covid one stop medical hubs / clinics, Correspondence –
Petitioner to Committee, 17.01.22**

In accordance with NICE guidelines, every health board in Wales has developed integrated, multidisciplinary rehabilitation services for people with Long COVID. These services provide an integrated assessment of both physical and mental health symptoms and difficulties and a treatment programme or advice as required. Local, integrated referral pathways between primary and community care and diagnostic investigations, rehabilitation services, specialist services and specialist mental health services are in place across Wales for people who require them. The integrated primary and community care services are led by general medical practitioners and secondary care services are led by a doctor or consultant with the relevant skills.

This is contrary to the experience of LongCovid patients across Wales. Many LongCovid patients in Wales have experienced being passed from pillar to post, between numerous disparate Consultants, if lucky to be referred from primary care, which is inefficient, causes delays and unnecessary distress and confusion, especially for patients who frequently suffer from brain fog, fatigue and exhaustion. A precious few have experienced the benefits of being seen by a single medical Consultant with extensive clinical experience and practice of dealing with LongCovid, through whom their diagnoses of serious complications have been made rapidly and their secondary care has been expedited by Consultant-to-Consultant referrals in a most efficient manner. In addition, this provision of satisfactory care has resulted in a significant improvement in their mental health such that support for that in the primary sector has been unnecessary, resulting in significant savings to the NHS in time and resources. In accordance with NICE guidelines there should be

medical Consultant-led services, i.e. LongCovid clinics, in Wales, as provided in England, but there are not. Welsh Government policy is that such clinics are NOT to be supported and no reasonable explanation has been forthcoming. In addition, the GPs on which this has been foist are insufficiently skilled and experienced to deal with the frequently complex, complicated, multisystem and serious complications of LongCovid, such as cardiovascular, respiratory and thromboembolic disease, as BMA Wales has pointed out to Welsh Government. This is not compatible with the basics of quality, is not patient centred and patient safety is at risk.

NICE guidelines also recommend the sharing of knowledge, skills and training between services to help practitioners in the community provide assessments and interventions. The NHS in Wales has a Long COVID Community of Practice group, which includes leads from every health board working together to standardise care and share knowledge and learning. In addition, the Institute of Clinical Science and Technology (ICST) have developed and rolled out a Long COVID digital guideline to provide education, training and summarise new research to help health professionals in Wales increase their expertise and skill in treating Long COVID.

As mentioned in my previous letter sent to you in October, over the summer I announced a £5m package to support the Adferiad (Recovery) Programme, which supports those experiencing ongoing effects from a COVID-19 infection.

The £5m is not dedicated to Long Covid, it is also intended to support individuals who have specific needs as a result of the impacts of the pandemic. Even if this amount was solely used for those affected by Long Covid it would provide approximately £86 per sufferer when divided by the 58,000 in Wales affected which is the ONS's latest estimate. Around 20% of

those seen in the only medical Consultant-led clinic that operates, under duress, in C&VUHB, require extensive and complex diagnostic procedures costing hundreds/thousands of £, so this amount does not match the need. For example, one patient has required three brain scans, full lung function and cardiovascular tests, numerous clinic appointments, plus various prescriptions for medicines over more than a year, which comes to more than £3,000 and counting.

My officials were asked to review this programme on a six monthly basis and we are expecting to receive reports from health boards on their long COVID services early in the new year. *Are they, or anyone in Government, receiving any feedback from the patients themselves, let alone e.g. PROMS from the Health Boards (which cannot be relied upon alone unless verified by the National Audit Office), regarding these services, so feedback on output not input? It is the almost universal experience of those who have availed themselves of these services that they are woefully inadequate. Many have had to source services outside of Wales and/or in the private sector, or participate in research studies in England that provide clinical reports, e.g. COVERSCAN in Oxford (see below).*

We have also asked health boards to provide their recommendations for future service delivery, as it remains key that our services can change and adapt based on learning from experience and the latest research and evaluation. *Will these recommendations be made available by the Health Boards to their patients? Patient involvement is crucial in the development of services.*

The role of research is critical in shaping new treatments and therapies, as well as improving services for those suffering from Long COVID. Through Health and Care Research Wales, Welsh Government is working closely with UK research funders, namely the National

Institute of Health Research (NIHR) and UK Research and Innovation (UKRI), who have during 2020 and 2021 funded 19 studies on Long COVID including immunological studies, evaluations of therapies and self-help tools. In November 2021, all researchers of the 19 studies met to share information of the research underway, and NIHR and devolved nations were present. The outputs will be shared with UK policy and practice colleagues over 2022/23. *Research is absolutely critical, but this fails to address the fact that such studies are not being made available to patients in Wales, precisely because Wales doesn't have the centralised Long Covid consultant led clinics to manage these, so patients in Wales are unable to contribute to studies designed (and in part funded by Wales) to help their own diagnosis and recovery.*