

**P-06-1217 Open Long Covid one stop medical hubs / clinics, Correspondence –
Petitioner to Committee, 15.03.22**

Dear Jack,

Thank you for your reply. There are a number of outstanding points I would like to address:

There are thousands of people in Wales who have been left so unwell after Covid that we are unable to take part in rehab services. We need more thorough investigations and medical treatments. Where these have not been made available on the NHS many of us have been forced to go private, often having to travel to England to access the healthcare we need. This isn't hearsay it's the experience of many people who have had their lives torn apart by debilitating long Covid.

Two years on, people are losing their jobs, their homes and their livelihoods due to illness which has now become chronic and are therefore suffering extreme financial hardship.

The rehab services in place are not suitable for people suffering from post-exertional symptom exacerbation and so many are unable to use them. In addition many of us have Mast Cell Activation and /or Postural Tachycardia Syndrome which in England's long Covid clinics are increasingly being recognised as typical Post Covid issues and which can be treated with a regime of diet and lifestyle changes as well as medications. However these are not being offered by the long Covid services in Wales. Does the minister recognise that a postcode lottery is the reality here and that long Covid sufferers who live in Wales are disadvantaged compared to their English counterparts?

Furthermore I am concerned that the survey referred to in the Minister's letter was not an anonymised survey nor was it carried out after people had stopped engaging with the long Covid service. This means that people will have felt an obligation to give favourable feedback to the services they are still accessing as any less than favourable feedback would surely lead to awkwardness in future encounters with those running the service. Survey data should be gathered after individuals have ceased to access services and should be anonymous so that people can give their views frankly without worry of consequence.

I remain deeply concerned at the lack of patient input into the formation of services in Wales. With a new illness such as long Covid, patient experience should be at the centre of shaping services and we urge the minister to speak to us directly so that we can voice our concerns about the status quo and put forward some suggestions on how the current gaps in services could be rectified.

Please consider meeting with long Covid sufferers like myself, I'd be happy to arrange a group of people with a range of long Covid presentations to meet with you.

Kindest Regards