



LOCOMOTION Webinar 2 – Inclusive Practice in Long COVID Treatment and Support (21st March 2024) Q&A

Below are questions posted by attendees at LOCOMOTION Webinar 2 'Inclusive Practice in Long COVID Treatment and Support' (21st March 2024), which were answered during or after the session by members of the webinar panel.

Q. What is Locomotion's view of the media recently labelling Covid/Long Covid "Just treat it like the Flu"?

A. From Long Covid, we now have a better understanding of post-viral syndromes (chronic fatigue and widespread pain). These syndromes have for long been neglected and disbelieved. Hopefully Long Covid will validate those other post-viral syndromes too.

Q. I think it's a key issue that most GPs actually do not know what to suggest or know of the KEY platforms like Locomotion and LC clinics out there more than any other barriers - just my view - white Caucasian

A. Agree, see the two Q&As below

Q. At the end of this year PCAS funding ends, and we will be sent back to our GPs. Are our GPs getting the education from PCAS and studies like yours to enable them to cope with the nearly 2 million people with no PCAS support?

A. Hopefully the professional post-covid society will play the role of advocacy for the condition. GPs are well equipped to deal with the condition but need the support of integrated pathways that are currently there (NHSE LC pathways). I personally think there has been a huge progress made compared to previous pandemics. But clearly more needs to be done

Q. What education and training do you think GPs and practice nurses need about Long Covid?

A. Basic awareness about how many people are affected and how as well as research evidence on how to support people would be helpful. Where care pathways exist, GPs need to know how to make appropriate referrals. Importantly they need to understand how they can address reasons for under-referral and under diagnosis in groups that face social disadvantage.

Q. Is there a way to get an "official" diagnosis? I have a very supportive GP, but I haven't had confirmation that this really is LC.

A. Request a referral to LC clinic.

Q. As people are not generally testing for COVID but may present with symptoms, is this impacting diagnosis, or delaying acceptance into LC clinics?

A. Agree this is an issue but NICE definition still does not insist on a positive test.

Q. How many GPs know about this study? I live in Harrogate and my GP seems to be completely unknowledgeable about what they can do with Long Covid patients. I was referred to LC clinic, but I haven't seen someone since June last year.

A. Most of our interviewees agreed that GPs do not know enough. We are currently working on a paper for the British Journal of General Practice about our findings.

Q. Did patients tell you about accommodations they had adopted to continue working? Were employers supportive?

A. People we interviewed were from socially excluded groups and most did not get support from employers either because they were in insecure employment, self-employed or faced discrimination at work. We did identify some good practice with NHS support groups for people with long Covid and communication between long Covid clinics and employers.

Q. Would it not be better to have a doctor led MDT team, then we don't waste our time and energy seeing doctors who don't believe or know how to treat us?

A. Agree, this will be helpful.

Q. I think health care professionals need to be made aware of all the information on pathophysiology and possible management/treatments. Thank goodness I have an excellent Neurologist and Cardiologist who are interested and involved in Long Covid research as well as a GP who is happy to follow me and my clinicians. I personally do not want Long Covid to be thought of as post viral syndrome at this point- even though clearly we know that Long Covid is caused by virus as well as ME is post viral.

A. Agreed. But we only have to look at SARS and MERS, all caused by coronavirus and similar residual syndrome. Keeping Long Covid separate will not help advance this field and weaken the argument for more clinical work and research and validation (most crucial)

Q. Should LC clinics have direct access to specialist investigations like spirometry, Halter studies, etc?

A. Agree, that would be good. Some clinics have Cardiologists and Respiratory physicians coming to MDT, so they arrange these investigations.

Q. Who do you think is best placed to provide oversight of care?

A. Our findings suggest multidisciplinary teams are needed to avoid care being fragmented over different clinical disciplines.

Q. Any more recommendations to support employers? Any specific types of supports employers could implement to assist in return to work? Were employers interested in accommodating workers with LC?

A. In relation to inequalities, our recommendations were for liaison between GPs and employers on the long covid diagnosis to enable targeted support from employers and use of fit notes to support work modifications and a Graded Return to Work.

Q. I wonder what peoples experience has been around exercise are people with long covid forced to exercise from the clinics?

A. No definitely not, there has been adequate knowledge sharing in this area and the standard practice in most clinics is to pace (rather than exercise).

Q. What is the plan of action from the Covid clinics? I visited a covid clinic yesterday, but I left without knowing what will happen now. They took my blood and confirmed my heart goes up when I stand etc... but I am not sure what happens now.

A. If you are referring to funding, it has been extended for another 12 months, so clinic should continue routine work until March 2025

Q. Where can we access good news, whilst there is no cure / silver bullet - maybe a central reference centre that can share news of stories of success and how that success has been made, be it therapy, psychological, physical or supplementary - just some happy cases?

A. We are aiming to publish examples of good practice by long Covid clinics, which will hopefully inspire others to take positive steps too. Long Covid support groups can also help with learning about good practice.

Q. Does the research link in publications like the recently updated BMJ Best Practice guide to Long Covid, the work done on the role of Primary Care in Long Covid by Trisha Greenhalgh et al (2021 I think)?

A. The BMJ best practice guides are from Locomotion.

Q. Does this information go to the government? How do we all get our voices heard? We just want to get better.

A. Yes, it does via NIHR channels as this is a NIHR study.

Q. Have you identified good practice from psychology services that support the Long COVID teams? Our local service has had its funding cut which adds pressure to other mental health support services and their waiting lists.

A. Worth clarifying this as NHSE have released same funding for this year as last year. ICBs are adjusting the funding based on referral numbers etc.