

INCLUSIVE PRACTICE IN LONG COVID TREATMENT AND SUPPORT

Sophie Evans

Dr Jordan Mullard

Professor Ghazala Mir



Long COVID multidisciplinary consortium
Optimising treatments and services across the NHS



- ❖ Patient experience – LOCOMOTION Patient Advisory Group
- ❖ Findings on patient experience from WP 1.3
- ❖ Q&A
- ❖ Findings on clinical practice and ways forward
- ❖ Q&A



- First contracted COVID-19 in April 2020 as a result of my NHS frontline duties
- 27 years old, young, fit and healthy with no previous past medical history
- There were no risk factors other than ethnicity that would have suggested the difficult trajectory of my COVID-19 & Long Covid experience
- First symptom of COVID-19 was a thunderclap headache
- Self – presented to ED 4 times within first 6 weeks of COVID-19 infection
- The headache alongside other COVID-19 symptoms persist to the present day
- Days turned into months and months turned into years, which eventually led to the realisation of a Long Covid diagnosis



- This Locomotion study and the research in all work packages has been developed with patients who live with Long Covid as we are equal partners.
- Active research participant – supported development of interview tools
- We played an active role in supporting and helping with the recruitment process for work package 1.3 particularly with signposting to diverse, marginalised communities
- Opportunity to become a patient author by reviewing and contributing to the paper “You’re just a guinea pig”: Exploring the barriers and impacts of living with long covid: A view from the undiagnosed.

Coproduction of clinical best practice needs to involve those with currently limited access to/poorer outcomes from LC clinics

Focus on people from **deprived/ethnic minority/homeless/Traveller groups or people with a disability.**

Sample – geographic spread (North/South England; Wales; Scotland)

Data - qualitative interviews, survey and primary care data from other work packages, PPI input:

- 18 Key Informants – experts with relevant experience
- 23 People not accessing LC clinics from excluded/high risk groups
- Feedback from 10 LC clinics on Quality improvement initiatives
- Analysis of primary care data from WP 3.1
- Input from LOCOMOTION Patient Advisory Group members

Key barriers to treatment and support



UNIVERSITY OF LEEDS

Most respondents cited they did not feel heard by healthcare professionals: *And the GP said, “oh, yes, we've heard the symptoms. Everybody has them and I think you will”. I don't really care if everybody has them. I'm talking to you about me! And I want you to listen to what my symptoms are!* [LC 22-Black British Female].

Many mentioned a fear of discrimination: *I think about my ethnicity and whether or not that played any sort of role in this whole experience?* [LC02 Black British Female] *'I think as, as an ethnic minority we're all, I am always aware of what's coming out of my mouth. There's a lot of editing and censoring that goes on. Especially in those sorts of professional environments'* [LC10 South Asian Male]

Failure to refer: *You know it took me a long time to even ask for a referral! I kept on, my friend kept saying like 'get referred'. And I was like 'meh what's point?' I don't really trust that actually it would do anything anyway. You just, are almost like a guinea pig* [LC13 Black British Female]

Some cited a lack of trust: *There's been a lot of, you know, mistakes...things that have been done! People have been treated in not great ways! I just think, you know, that's what's brought the mistrust really* [LC12 Black British Female].

A majority felt they'd received inadequate advice: *You speak to different GPs every time you call the surgery! I had one who used to say 'it doesn't really matter what it is! You just need to rest and work less!'*[laughs] *I'm like 'I can't! Can you tell my boss?'* [LC06 Southern European Female].

Key Impacts



UNIVERSITY OF LEEDS



A majority of respondents cited LC impacts ability to work, experience of work, fear of losing their job (11 were still working):



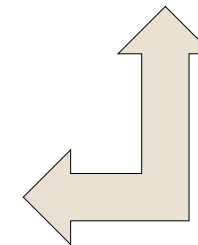
Most cited physical impacts or unknown symptoms



Many cited psychological and emotional impacts



Some cited impacts on family life and social roles



Leading to avoidance and loneliness



Diagnosis, Knowledge and Validation

The diagnostic odyssey (Blaxter 1978), embodiment and biographic disruption (Engman, 2019) came up as key themes amongst LC cohort: *Like I just worked and lived and socialised and went on lovely holidays and just enjoyed my life. And in one day, it was taken away from me very abruptly! And then nothing has ever been the same again [LC02]. It's been a complete shift in sort of who I am as a person? Who I am as a personality? [LC10]*

Lack of LC knowledge, frustration, not knowing where to go for support & being undiagnosed but living with LC symptoms a liminal space, 'not a patient yet' generates emotional distress coupled with multiple intersecting inequalities compounding anxiety and frustration of the unknown (Adorno, 2015; Jordan et al., 2015)

Context of 1st wave infection and early experiences of LC and the lack of knowledge on behalf of healthcare workers makes some patients sympathetic [LC01, LC12, LC21]. However, others who have a clearer sense of LC themselves feel frustrated and angry at not having their symptoms recognised by healthcare professionals (LC02, LC06, LC10) or employers, (LC06, LC23)

Validation, invalidation, authenticity, and legitimacy as key concepts at play in people's experiences of the diagnostic journey (c.f. Kool et al., 2009)



Questions on patient experience

Finding solutions without support



UNIVERSITY OF LEEDS

Own research about LC/care pathway/ support groups

NHS staff/contacts most able to obtain and pass on knowledge about LC/ treatment or support available *“it wasn’t difficult for me to ask a colleague to ask a doctor who may know someone else in infectious diseases to give me the referral criteria and the phone number. If I didn’t work at the hospital, I would have just been in limbo*

Persistent self-advocacy

- *“you have to ring in at 8 o’clock. And that is a nonstarter because you’ve got, you’re competing with about 20 other people. [...] By the time we get to number one, they’ve cut you off!” [LC04]*
- *“there’s a lot of knowledge that’s missing. I think that is probably one of the big drivers about who is self-reporting [...] and who can advocate for it” [KI10]*

Changing work patterns

“I stopped volunteering at a couple of charities that I was doing stuff for and if it’s not home based then, to be honest with you, I’m not interested. I’ve just signed off a lot of things” [LC10].

Suggestions for healthcare change

- Overview of care rather than referral to multiple clinics
- Treatment as well as monitoring
- GP liaison with employers to support return to work
- Employer support networks (consistency across NHS staff)



Make inequities visible

- Identify and prioritise/tailor services for excluded groups

GP as barrier

- GP symptoms training/targeting; 3rd sector involvement in LC referrals/navigating support

Low awareness

- Community/OH/HR outreach/influencers

Waiting times

- Information/education/ signposting to peer/other support while waiting for specialist care

Geography

- Diverse clinic sites

Finance/capacity

- Choice of virtual/ face-to-face/home visits
- IT support and equipment
- Signposting - benefits/support grants/food bank/housing

Beyond
monitoring

Referral for specialist care if symptoms fit profile for long Covid
Flexibility - adapt care as research develops and needs are recognised
Evolving service – establishing new pathways through trial and error
GP liaison with employers to support return to work
Employer support networks (more consistency across NHS organisations)

Reduce
fragmented
care

Multidisciplinary/multisector teams; tailored care pathways/holistic support
Reduce adverse impact of referral to clinics with long waiting lists for groups with high level of existing ill health
Help with uncertainties about comorbidity and self-management of changing needs



Questions on good practice recommendations

Further information



UNIVERSITY OF LEEDS

Website:

<https://Locomotion.Leeds.ac.uk/>

Emails:

G.Mir@Leeds.ac.uk

J.Mullard@Leeds.ac.uk