# We must recognise the collective wisdom of those with lived experience of long covid

Fiona Jones, Professor, City St George’s University of London

Monica Busse, Professor, Centre for Trials Research, School of Medicine, Cardiff University, Cardiff, Wales, UK

Carole Rowe, Patient and Public representative, UK

Anne Domeney, Patient and Public representative, UK

Ian Patel, Patient and Public representative, UK

Standfirst: People with long covid helped to shape research during the pandemic and researchers must continue to recognise their important contribution

Provenance: commissioned, not externally peer reviewed

Competing Interest Statement: Fiona Jones is the founder and CEO of the non-profit community interest company Bridges Self-Management and Monica Busse is a trustee (from 2024). Bridges Self-Management supported the co-design activities and intervention training in the LISTEN trial.

The LISTEN trial [Long Covid Personalised Self-managemenT support- co-design and EvaluatioN (LISTEN), COV-LT2-0009] is independent research funded by the National Institute for Health and Care Research (NIHR). The views expressed in this publication are those of the author(s) and not necessarily those of NIHR or The Department of Health and Social Care.

AI use: We have not used any AI technology to prepare this manuscript

The covid-19 pandemic was fraught and complicated, and understandably we want to consign it to history. But scientific work on covid and long covid is far from over. Scientific and medical advances since 2020 have shown us that long covid encompasses a broad constellation of symptoms and disease [1,2] and while we can treat or mitigate some of these, effective cures remain elusive. Research must consider the experiences and collective expertise of patients to understand how to better manage long covid symptoms.

The stark reality facing many people across the globe is that some will soon be entering a sixth year with the episodic and debilitating symptoms of long covid. The irreversible harm of long covid on social roles is dramatic. A survey of patients attending long covid specialist clinics showed that 52% were working fewer hours relative to pre-infection and 32% needed support from an informal carer [3]. The socioeconomic ramifications and inequalities of long covid in terms of ethnicity, economic deprivation, sex, and occupation are now clear [4]. But despite this, public consciousness and interest in long covid is waning.

The extraordinary way in which people with long covid mobilised and helped shape research in the early stages of the pandemic must be valued and utilised [5]. They made strides despite instances of being disbelieved or treated inappropriately. It is to their credit that many advances have been made in the understanding of long covid clinical phenotypes, disease clusters, and biomarkers [2,6]. With clinical trials of drug targets on the horizon, we should however recognise the critical role of well-evaluated supportive non drug interventions[7].

In the LISTEN trial, we integrated robust qualitative and participatory methodologies to co-design a self-management support intervention that people with long covid wanted and needed [8]. We learned about the importance of introducing interventions as supportive and collaborative. Without this they risk healthcare professionals undermining the knowledge and confidence of patients to manage symptom uncertainty every day. In taking this approach, we captured the range and creativity of self-generated strategies from the long covid community in the absence of any treatment options. These included individually curated strategies to reduce stressors and understand symptom triggers, as well as gaining support from their trusted personal community [9]. With this learning we were able to build knowledge about what good self-management support should be for people living with long covid

This understanding of what “good self-management support” for long covid looks like and the importance of personalising care should be an essential component of service provision, particularly given variations in symptoms and the impact on everyday life [10]. Not losing sight of this learning is critical given the decommissioning of some long covid services and the potential loss of long covid as a specialty if merged with other conditions referred to as post-acute infection syndrome [11]. It is important to recognise for impending drug and non-drug trials that while we now have clear recommendations for core outcomes that should be assessed [12], there remains little consensus on which outcome measures should be used and how much change is meaningful.

The generosity of people taking part in long covid research has shown us the scale of burden on individuals, health systems and national economies. It’s highly unlikely we will ever have a “one-size fits all” approach to treating long covid. But the therapeutic benefit of feeling believed and validated when uncertain and isolated should not be lost. Authentic Public and Patient Involvement and Engagement (PPIE) in long covid research needs to continue at pace and as we have seen can amplify the impact of research. We strongly advocate for greater use of participatory methods such as those used in the LISTEN trial to ensure meaningful contributions of those who will ultimately benefit from new interventions and research.

Medicine and science still have much work to do, but while we wait for cures and better treatments, we also should acknowledge and use the valuable tool of patient experience and their collective expertise in understanding what matters to them.

References

1 Davis HE, McCorkell L, Vogel JM, et al. Long COVID: major findings, mechanisms and recommendations. Nat Rev Microbiol. 2023;21:133-146. doi:10.1038/s41579-022-00846-2.

2. Greenhalgh T, et al. Long COVID: a clinical update. Lancet. 2023;404(10453):707-724. doi:10.1016/S2589-7500(23)00056-0.

3. Kwon J, Milne R, Rayner C, et al. Impact of Long COVID on productivity and informal caregiving. Eur J Health Econ. 2024;25:1095-1115. doi:10.1007/s10198-023-01653-z.

4. Shabnam S, Razieh C, Dambha-Miller H, et al. Socioeconomic inequalities of Long COVID: a retrospective population-based cohort study in the United Kingdom. J R Soc Med. 2023;116(8):263-273. doi:10.1177/01410768231168377.

5. Callard F, Perego E. How and why patients made Long Covid. Soc Sci Med. 2021;268:113426. doi:10.1016/j.socscimed.2020.113426.

6. Canas LS, Molteni E, Deng J, Sudre CH, Murray B, Kerfoot E, et al. Profiling post-COVID-19 condition across different variants of SARS-CoV-2: a prospective longitudinal study in unvaccinated wild-type, unvaccinated alpha-variant, and vaccinated delta-variant populations. Lancet Digit Health. 2023;5(7):e421-e434. doi:10.1016/S2589-7500(23)00056-0.

7. Busse et al. Effectiveness of a personalised self-management intervention for people living with Long Covid: the LISTEN randomised controlled trial. BMJ Med. 2024. doi:10.1136/bmjmed-2024-001068.

8. Jones F, Domeny A, Fish J, et al. Using co-design methods to develop new personalised support for people living with Long Covid: The 'LISTEN' intervention. Health Expect. 2024;27(3):e14093. doi:10.1111/hex.14093.

9. Leggat FJ, Heaton-Shrestha C, Fish J, et al. An exploration of the experiences and self-generated strategies used when navigating everyday life with Long Covid. BMC Public Health. 2024;24:789. doi:10.1186/s12889-024-18267-6.

10. Greenhalgh T, Darbyshire JL, Lee C, et al. What is quality in long COVID care? Lessons from a national quality improvement collaborative and multi-site ethnography. BMC Med. 2024;22:159. doi:10.1186/s12916-024-03371-6.

11. Choutka J, Jansari V, Hornig M, et al. Unexplained post-acute infection syndromes. Nat Med. 2022;28:911-923. doi:10.1038/s41591-022-01810-6.

12. Gorst SL, Aiyegbusi OL, et al. Core outcome measurement instruments for use in clinical and research settings for adults with post-COVID-19 condition: an international Delphi consensus study. Lancet Respir Med. 2023;11(12):1101-1114.