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

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

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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.

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