



Long covid as a long term condition

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The neglected field of long covid and post-infection conditions needs sustained research investment, increased clinical workforce training, and healthcare policy prioritisation

Long covid is a novel public health challenge with at least 200 million individuals affected by the condition worldwide.¹ The syndrome is defined as persistent symptoms beyond three months of the covid-19 infection and lasting at least two months.² The natural trajectories in the condition are not entirely well researched, but many individuals fully recover in the first 6-12 months. The chances of full recovery reduce after this period, and when the duration of symptoms are over two years, long covid is deemed to be an established long term condition in many individuals.^{3 4} However, the exact proportion of individuals who develop this long term condition is currently unknown. The condition in affected individuals typically remits and relapses and substantially compromises their quality of life.⁵ Long covid is more common in people with comorbidities and adds to the burden of multimorbidity or multiple long term conditions.⁶

In their pragmatic multicentre long covid personalised self-management support co-design and evaluation (LISTEN) trial, Busse and colleagues randomly assigned 554 people who had not been admitted to hospital with long covid to receive either a personalised supervised self-management programme or usual care.^{6 7} The intervention involved six one-to-one sessions with specialist healthcare professionals. The study observed little evidence of benefit in the Oxford participation and activities questionnaire (Ox-PAQ) but suggested significant benefits in many secondary outcomes, such as fatigue levels. This find is encouraging because an effect is suggested at a symptom level, but that did not translate to an improvement at activity and participation levels. Such a differential effect in separate aspects of health is recognised in the long covid literature.⁸

Several limitations are to be considered in the LISTEN trial, which the authors acknowledge.⁷ The study ran over a 17 month period from 2022 and 2023 when NHS routine services (usual care) were constantly changing pathways and treatments offered; long covid was a novel condition then with very little understanding and an emerging evidence base. Participants were aware of whether they received the personalised self-management intervention, and with many outcomes being necessarily subjective measures, they may have been influenced by that knowledge. Given that long covid is a syndrome of fluctuating symptoms with an episodic disability,

the primary outcome measure should ideally be a specific symptom severity scale specific to a condition rather than a generic functional measure (the authors acknowledged that many of the condition-specific scales were just being developed at the time of the trial).⁹

One of the striking findings of the LISTEN study is the small change seen in most of the outcome measures, suggesting only a partial improvement rather than a full recovery. The EQ-5D-5L utility or index scores, a measure of overall health status, improved very little during the trial. The unadjusted index score value changed in the usual care group by 0.01 (0.52 at baseline to 0.53 at follow-up) and in the intervention group by 0.04 (0.49 at baseline to 0.53 at follow-up). Such incomplete recovery has also been observed in the NHS England long covid service evaluation study and some other studies too.^{10 11} The final EQ-5D utility scores in the LISTEN trial were below the normative values in the other long-term conditions such as diabetes mellitus (0.83), chronic kidney disease (0.70), cancer (0.75) and multiple sclerosis (0.56).¹² This highlights the personal burden of long covid as a chronic condition or long term condition and reinforces the need to redouble our efforts to improve intervention.

The LISTEN trial illustrates the need and value of further research in to personalised treatments delivered by a multidisciplinary team in community settings and people's homes. Personalised medical and rehabilitation interventions must focus not only on symptom management but also on improving functional ability and return to preinfection vocational levels. The trial also indicates a need to track the condition trajectories long term and understand the personal, vocational, social, and familial impacts of the condition. Research into treatments also needs to be explored at every stage of the condition trajectory, right from prevention (vaccines) to early medical treatments (immunomodulatory agents being trialled) to rehabilitation treatments (such as LISTEN).⁶

The emergence of long covid has brought to light other post-infection conditions such as post-severe acute respiratory syndrome (known as SARS), post-Middle East respiratory syndrome (known as MERS), post-influenza syndrome, and the long term condition myalgic encephalitis/chronic fatigue syndrome. These conditions, which can manifest in a range of debilitating symptoms long after the initial infection has cleared, have drawn substantial attention due to their high prevalence and impact on the quality of life. However, despite their recognition, these conditions remain under-prioritised in clinical practice, policy making, and research agendas.⁶ Addressing

these challenges will require a multi-faceted approach involving sustained research investment, increased clinical workforce training, and health-care policy changes to improve outcomes for affected individuals.

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