

## **Healthcare workers must be included in long covid research in the UK**

**Healthcare workers should be involved in research into long covid for more inclusive patient and public involvement, writes Manish Pareek and colleagues**

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Patient and public involvement in long covid research is key to understanding the impact of the condition on people's lives, identifying research priorities, and ensuring that study design and methods are applicable to those most affected by it (1). It is particularly important to involve diverse groups of the population, including people from ethnic minority backgrounds and people with disabilities, to ensure that the research is representative and relevant. Examples are available of the various ways in which patient and public involvement has been integrated into long covid studies in the UK. For example, the active involvement of people with long covid in generating content for the Symptom Burden Questionnaire for long covid. (1).

Researchers conducting national long covid studies have made a commendable effort to include a diverse range of patient and public members in their studies. By involving people from different backgrounds, ages, and ethnicities, these studies can have a greater impact on the lives of those affected by long covid. But healthcare workers remain notably absent from studies of long covid, despite being at the frontline of the pandemic, with higher risks of infection and potentially higher risk of long covid (2).

Our research collaborated with frontline healthcare workers to study the longer term impacts of covid-19 and long covid on the NHS workforce (3). Healthcare workers, particularly those from ethnic minorities, are at increased risk of covid-19 infection and adverse outcomes (2, 4). Yet NHS staff experiencing long covid are also facing considerable challenges beyond the physical symptoms of the condition (5). They are grappling with a lack of clear workplace policies on sick leave and support, on top of the pressures the NHS is facing, including strikes and problems with staff retention.

The stress of working in a high pressure environment during the pandemic, combined with the uncertainty and unpredictability of long covid, is taking a toll on the mental health and wellbeing of healthcare workers (5). These factors have created a perfect storm that is driving many to leave their jobs, exacerbating the already severe staffing shortages in the NHS. Healthcare workers provide care to long covid patients but they are also often patients themselves. This means that they have unique insights into living with long covid, which would be valuable to research (6).

We've seen first hand how the input of healthcare workers has helped us to achieve the aims of our research. We involved our "Professional Expert Panel" group that includes health workers from clinical and non-clinical roles. This group was created to enable health workers from diverse roles and backgrounds to inform and support our study by bringing in their unique perspectives and lived experience with long covid and how covid-19 has affected their lives in the long term. They also provided feedback on our study materials, sampling methods, recruitment strategies, and research outputs—ultimately influencing the design and scope of our research study

Long covid is clearly affecting healthcare workers. A recent anonymously published account from a doctor experiencing long covid highlighted the need to recognise healthcare workers as humans who are capable of falling ill and who should receive the same standard of care and support as other long covid patients, without feeling abandoned or neglected (7). The exclusion of healthcare workers from patient and public involvement groups risks omitting the perspectives and experiences of some of the people most affected by the pandemic, which could limit the relevance and effectiveness of long covid studies.

Policy makers and healthcare organisations must recognise the unique challenges faced by healthcare workers with long covid and support their recovery and wellbeing to prevent burnout and staff shortages. But it is also important for future long covid research to make efforts to engage with healthcare workers so that we can better understand the condition and its impacts on this population. We strongly encourage researchers and policy makers to prioritise the inclusion of healthcare workers in patient and public involvement activities related to long covid research. This will ensure that the perspectives and experiences of this population are considered and that long covid research is designed and conducted in a way that is sensitive to their needs. Involving the perspectives and experiences of healthcare workers can in turn help to improve patient outcomes by increasing representation in long covid research and promoting better care for long covid patients.

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### **Declaration of interests**

We declare no competing interests.

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