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Aiyegbusi, Olalekan Lee; Calvert, Melanie

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Patient reported outcomes: central to the management of Covid-19

Olalekan Lee Aiyegbusi, PhD^{1, 2*} and Melanie J. Calvert, PhD^{1, 2}

¹Centre for Patient Reported Outcomes Research, Institute of Applied Health Research and Birmingham Health Partners Centre for Regulatory Science and Innovation, University of Birmingham B15 2TT, UK

²National Institute for Health Research (NIHR) Birmingham Biomedical Research Centre, University of Birmingham B15 2TT UK

*Corresponding author: Olalekan Lee Aiyegbusi, O.L.Aiyegbusi@bham.ac.uk

Centre for Patient Reported Outcomes Research, Institute of Applied Health Research, University of Birmingham B15 2TT, UK

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Patient-reported outcomes (PROs); self-assessments of patients' health status are central to Covid-19 response, recovery and resilience. Symptom reporting using PROs can facilitate diagnosis of the disease, identify those who require tests and initiate track and trace procedures. Remote monitoring of symptoms using electronic PROs (ePROs) can help identify those with severe Covid-19 in need of urgent care and those with mild-to-moderate symptoms which may be managed at home. The use of ePRO systems are especially important as rapid deterioration may occur in patients with mild symptoms. Remote monitoring could also facilitate the triage of patients with chronic conditions ensuring that in-person hospital appointments are reserved for those with potentially life-threatening issues. Individuals with lower risk could be supported virtually and monitored for signs of deterioration. This approach can relieve the strain on healthcare systems and prevent unnecessary exposures to SARS-CoV-2 virus.¹

We are just beginning to understand the long-term effects of SARS-CoV-2 infection. The symptoms have returned in some patients a few months post-recovery while others have developed serious conditions such as Kawasaki-like disease. PROs may be used for long-term follow up to assess impact on patients' quality of life and alert physicians to the development of potentially life-threatening complications.

Work has begun in earnest to develop effective drugs and vaccines to stem the spread and prevent future outbreaks. Nevertheless, there are a number of unknowns such as potency, side effects and adverse events which may only come to light during human trials. The first in-human Covid-19 vaccine trial utilised 'diary cards' completed by trial participants to monitor adverse events.² While it was encouraging that participant views were sought, we recommend using validated PRO instruments such as the patient-reported outcomes version of the National Cancer Institute Common Terminology Criteria for Adverse Events (PRO-CTCAE™).³ Its use in Covid-19 trials may complement the clinical CTCAE and facilitate cross-trial comparisons of results. Evidence suggests that PROs may detect adverse events in patients even before clinical parameters.⁴ PRO data may alert clinical teams to the occurrence of adverse events during Covid-19 trials and provide valuable evidence of safety and tolerability from the patient perspective.

There are suggestions that vaccine hesitancy could derail vaccination initiatives.⁵ Publication of PRO data from vaccine trials may combat hesitancy. Responding to the crisis and building a resilient healthcare system allowing efficient and effective response to future pandemics is crucial. PROs can provide a key tool in our defence system.

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Competing interests

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Both authors are involved in the development of ePRO systems.