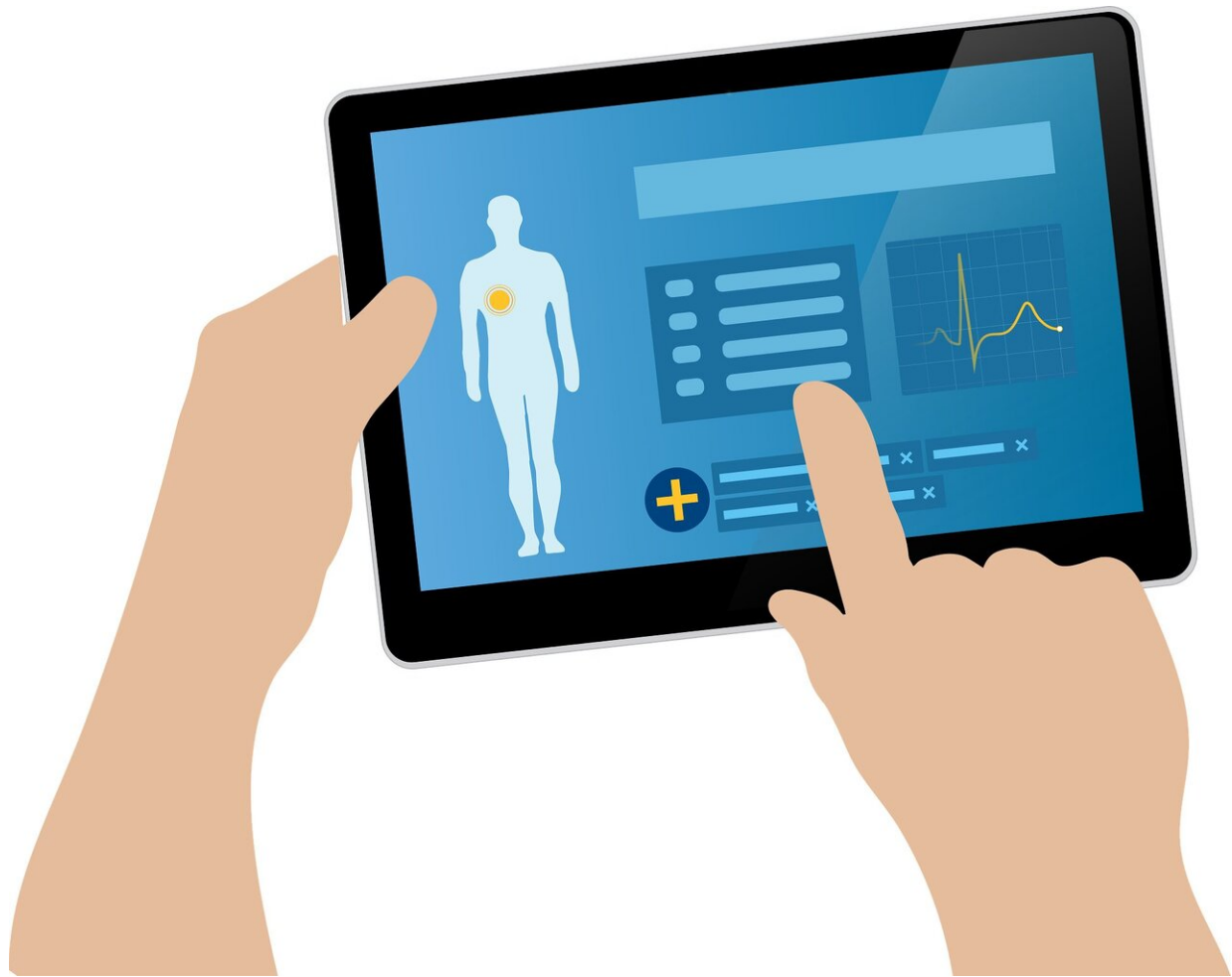


New recommendations make it easier for patients to give feedback on their health

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Patients providing feedback on their health during research or in clinical practice could now find it less onerous, thanks to a set of recommendations developed by an international group of experts.

The study, led by researchers from the Center for Patient Reported Outcomes Research (CPROR), NIHR Birmingham Biomedical Research Center and Applied Research Collaboration at the University of Birmingham and [published](#) today (Feb. 29) in *Nature Medicine*, produced a list of 19 recommendations that researchers or clinicians can follow when planning and delivering the collection of patient-reported outcomes (PROs).

Dr. Lee Aiyegbusi, study lead and associate professor at CPROR, University of Birmingham, says, "It is vital to understand the impact of disease and treatment from a patient perspective using PROs. However, we need to be mindful of the burden this may place on patients and research participants. Research and clinical teams are encouraged to seek input from PRO experts and utilize these recommendations when considering the implementation of PROs for health care research or [clinical practice](#)."

PROs are increasingly used in health care research to provide evidence of the benefits and risks of interventions from the patient perspective, and to inform regulatory decisions and health policy.

Although important, the completion of PROs may be potential burden on respondents—the patients—especially if responses are requested regularly. Patients can find this task difficult, time consuming, or emotionally stressful, leading to poor completion rates and missing data.

Produced in collaboration with patient partners and advocates, the 19 recommendations aim to address these issues and cover three categories:

- Rationale and schedule for PRO assessment—for example, involving patients in determining the frequency and timing of PRO collection and considering respondent burden when deciding the PRO research questions
- Measure selection—for example, considering the format complexity of PRO measures, and if they are relevant for the target population
- Measure delivery—for example, ensuring respondents understand the purpose and importance of the task, and providing clear instructions and training

Mr. Roger Wilson CBE, a patient research partner involved in the study, says, "PROs are a crucially important development for [clinical research](#)—the patient voice being heard alongside scientific data. Research such as this paper which clarifies the understanding of 'how' to include PROs in a study alongside the 'what' to include is valuable. This study also emphasizes the value created by involving [patients](#) in study development."

More information: Olalekan Lee Aiyegbusi et al, Recommendations to address respondent burden associated with patient-reported outcome assessment, *Nature Medicine* (2024). [DOI: 10.1038/s41591-024-02827-9](https://doi.org/10.1038/s41591-024-02827-9)

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