

NIHR Greater Manchester PSTRC

Plain English Publication Summary

Publication: [Challenges and adaptations to public involvement with marginalised groups during the COVID-19 pandemic: commentary with illustrative case studies in the context of patient safety research](#)

Publication details (Vancouver format)

Adeyemi I, Sanders C, Ong BN, Howells K, Quinlivan L, Gorman L, Giles S, Amp M, Monaghan E, Naseem S, Pearson A. Challenges and adaptations to public involvement with marginalised groups during the COVID-19 pandemic: commentary with illustrative case studies in the context of patient safety research. Research Involvement and Engagement. 2022 Dec;8(1):1-2.

What are the most important findings/conclusions in this paper? Why are they important?

The conclusions of this paper provide guidance to other researchers and patient and public involvement (PPI) practitioners. The authors reflect on how to work remotely with people who have experience of being excluded or overlooked in society, and in research. The most important conclusions from the paper are:

- Researchers need to work flexibly and provide different methods of engaging in PPI.
- Working in partnership with specialist organisations and charities is essential for inclusivity. This is particularly important for remote working which can present more challenges for engagement.
- Research costs should include the extra time and resources that providing flexible involvement options require. The time and resources of organisations and charities that enable PPI also needs to be recognised.

What did you do?

Researchers in the NIHR Greater Manchester Patient Safety Translational Research Centre (GM PSTRC) work in partnership with patients and members of the public to plan, manage, design, and carry out the research. This is referred to as patient and public involvement (PPI). In this paper, the authors are researchers and public contributors in the NIHR GM PSTRC. Together, they reflect on the more creative and less traditional methods of PPI used during COVID-19, especially with groups of people who are not traditionally used to working with researchers. The paper gives examples of how researchers and PPI practitioners can be more inclusive when encouraging PPI. The paper uses examples of working with people with vision impairments, people with lived experience of self harm and/or suicide or their carers, and people with lived experience of homelessness to show challenges and ways of working.

Why did you conduct this research?

COVID-19 has had an indirect impact on ways of working in patient and public involvement (PPI) in research. For example, video conferencing has been used as an alternative to face-to-face meetings. In writing this paper, the authors wanted to share their learning on how to carry out PPI work remotely.

What was known before your paper was published?

The promotion of a diverse and inclusive public involvement community is at the core of the UK government's vision for a patient-centred NHS, and the National Institute for Health Research (NIHR) vision of public involvement for 2025.

However, we know that there are many groups of people that are unlikely to be represented in research studies, because of poor access and/or communication. We also know that the COVID-19 pandemic has affected certain groups of people more than others. So, it is really important to continually reflect on how patient and public involvement is done in research to ensure that people from marginalised groups, who may have been more affected by the pandemic, are included in research studies.

What is next? What is the potential impact of the work in this paper? What will change as a result of this paper (or the study it describes)?

In sharing their learning and adaptations of patient and public involvement (PPI) during the COVID-19 pandemic, the authors hope to benefit others carrying out remote PPI work. We hope it will increase the opportunities and accessibility of PPI for people who have been marginalised in the past and may continue to be excluded the future.

The paper calls for a shift in our understanding of funding PPI in research and suggests ways that will increase involvement from marginalised groups, as well as recognising the value of specialist organisations and charities who work with researchers in promoting inclusive PPI.

Does this paper link in to a particular study / project? If so, please summarise the study and explain how this paper has improved understanding, or will move the study forward.

N/A