Dear Editor,

The Association of Coloproctology of Great Britain and Ireland and the Bowel Disease Research Foundation led the way on patient and public involvement (PPI) in colorectal research with the 2013–2016 Delphi Games, which led to the integration of patients as key partners in research studies, as well as studies such as CIPHER and PREPARE ABC. With the COVID-19 pandemic, we have seen the majority of colorectal research studies suspended, given the need for routine work to be reduced to focus resources on critical care. When we look to return to a new normal, these studies and others in the pipeline will resume.

It is likely that social distancing will continue for many months, which may have unintended consequences for PPI. Much of our existing work has been done on a face to face basis, allowing the flattening of hierarchy between clinicians, researchers and patients. It also allows patients to meet others who have been through similar experiences. While not the aim of PPI, this is an added incentive for patients who give up their time freely to help design future research studies.

We do not know if our PPI work will be able to continue in the same format if social distancing continues. Travel may well be restricted, which would pose an additional barrier. During COVID-19 we have seen a rise in the use of the online videoconference, and it has been suggested that this may be an option for carrying out future PPI. While we must do all that we can to ensure that patients remain an integrated part of research, the National Institute for Health Research have published their set of eight commitments on this [https://www.nihr.ac.uk/documents/shared-nihr-commitments-to-public-involvement-participation-and-engagement-during-the-covid-19-pandemic/24640 (accessed 28 April 2020)], we must be cognisant that not all patients are comfortable with online meetings, or have access to the necessary equipment, or indeed have the technological knowledge to be able to use it. PPI must remain open and accessible to all ages, and all socioeconomic groups; to not do so would risk the years of work that have got us to the current point where patients are an integral part of colorectal research.

Doing PPI effectively can be challenging, and there are a number of issues that may not be immediately apparent:

1. Reaching the right patients: those with first-hand experience, who may not be easy to reach via media such as social media.
2. Distress to participants: participating in PPI events can bring up distressing memories and strong emotions for some patients.
3. Marginalization: excluding participation of certain cohorts of patients, due to either use of technology, location of meeting or lack of funding for expenses.

While we recognize that there may be a new normal that we may find ourselves living in once this pandemic is over, we must ensure that PPI remains inclusive and does not exclude those who have the lived experience of the conditions that we are researching. We encourage the colorectal surgery community to use the tools produced by the National Institute for Health Research and the National Coordinating Centre for Public Engagement [https://www.nihr.ac.uk/documents/shared-nihr-commitments-to-public-involvement-participation-and-engagement-during-the-covid-19-pandemic/24640 (accessed 28 April 2020)] when considering changes to PPI engagement to ensure that the patient voice remains strong in research.

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