

HRA COVID-19 Public Involvement workshop

Key points

- **Involvement is important, expected, and possible**; there is support available for researchers
- **We need clear, consistent leadership and communication**, with high level ownership and UK-wide messaging across the research system
- **Our solutions need to be streamlined and flexible**
- **System-wide collaboration is crucial** from the whole public involvement in health and social care community

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Background

On 27 April 2020 the Health Research Authority (HRA) hosted a workshop to discuss how best to facilitate meaningful public involvement in COVID-19 research.

Jim Elliott, HRA Public Involvement Lead, explained that although there is no change to the ethical review and governance requirements for COVID-19 research being set up, research teams and sponsors are acting on much shorter timelines than usual. HRA Research Ethics Committees and staff are also reviewing these studies much faster than usual.

However, the proportion of research teams involving patients and the public has reduced dramatically, down from nearly 80% of the research HRA reviews to just 20% of COVID-19 research.

The HRA thinks that meaningful public involvement is more important now than ever before. We want to help high quality research get set up rapidly. Good public involvement can help that to happen by addressing barriers to recruiting and retaining research participants – which can be difficult in a public health emergency.

The aims of the workshop were to analyse this problem and discuss possible solutions. Below is a list of the organisations which were represented at the workshop, and an overview of the main challenges and potential solutions we discussed.

Why is it difficult to get meaningful public involvement in COVID-19 research?

Below is a summary of some of the main challenges identified during the workshop.

Time pressures

COVID-19 research has a much narrower window for public involvement at the design phase than usual. It can take time to identify people with relevant lived experience to be involved in a specific research project. Good practice guidance about public involvement emphasises that it's important to allow public contributors plenty of time to contribute, so some researchers assume that there isn't enough time to involve people well in COVID-19 research.

Communication barriers

Public involvement coordinators are hearing about new studies too late in the process or aren't being asked at all because researchers are assuming that there isn't enough time to involve people or that public contributors will not want to get involved in COVID-19 research. Because of this, public contributors are missing out on opportunities to offer to get involved.

Needing to meet virtually is also a communication barrier; some public contributors may not have the equipment or the training they need to meet virtually, or don't want to. This could also be the case for involvement coordinators and researchers.

Lack of system-wide collaboration

At the workshop there was concern that there hasn't been clear national leadership on what is expected in relation to public involvement. This allows researchers to conclude that involvement is an optional add-on for COVID-19 studies. There are also differences in infrastructure and oversight for public involvement around the UK.

People are dealing with additional pressures

Public contributors, public involvement coordinators, and researchers alike are facing additional demands on their time and energy during the COVID-19 pandemic. Many people have additional caring responsibilities, have been ill or bereaved, redeployed or furloughed, and may also be volunteering in their local communities.

During lockdown some public contributors and their networks have less time to get involved in research because they have limited income or resources. The pandemic has already been reported to have badly affected people's physical and mental health, potentially making people with relevant experience less available to get involved with research.

Additionally, public involvement teams are often small and don't usually receive a large volume of requests for support at any one time. Some people in these teams are taking on responsibilities at the moment which would usually fall to the research team.

Processes for paying public contributors often rely on infrastructure which is under pressure during the pandemic, such as the postal service. Delays to payment are a barrier to some people being able to get involved.

Involvement doesn't include everyone

Empowering a more diverse range of people to get involved in designing and conducting research is already a system-wide challenge. For example, COVID-19 is having a disproportionate impact on Black, Asian, and Minority Ethnic (BAME) people; people who are less included in research more generally.

COVID-19 research is varied

A broad range of studies are being set up. Some types of research, such as data-only studies and early phase clinical trials, traditionally have less of a culture of involving patients and the public in their design. The researchers involved in these studies may have little awareness or previous experience of public involvement, and public contributors may feel less confident about commenting on COVID-19 research. Because a number of nationally prioritised studies have been expedited and signed off at a senior level there may be a perception that there is no opportunity now to involve patients and the public in those studies.

What can we do to address these barriers?

Public contributors, public involvement coordinators, and researchers around the UK are already working incredibly hard to involve patients and the public in COVID-19 research. To address the barriers identified above we need to work together as a community to link existing networks and individuals. Our solutions will need to be agile, proportionate, and responsive, so that they are sustainable and can be improved over time.

Provide leadership

There needs to be clear, high level leadership and ownership to reinforce that public involvement is an expected, core part of high-quality research. The expectation needs setting that public involvement is just as (if not more) important during a public health emergency. The Clinical Trials Unit Network and NIHR Research Design Service have crucial roles in supporting research in the UK, but they don't cover all research. Cross-system communication and collaboration across the health and social care sector will be critical to make it more possible to involve patients and the public in COVID-19 research.

Develop clear and consistent messaging

Workshop attendees agreed that clear and consistent, high-level, UK-wide messaging is needed across the research system that involvement is important, expected, possible and that there is support available for researchers.

This includes sharing the message with the public that one of the best ways to help research right now is through involvement, and signposting existing involvement networks. It also means making sure that there's an alignment of expectations between funders and regulators about public involvement in COVID-19 research.

Take a streamlined approach

HRA currently has an opportunity to work with researchers earlier than usual in the research process, and could coordinate matching them with both public contributors and resources. It would help to have a central repository for involvement opportunities, with a single point of contact.

Link local and national networks

Many public contributors are part of multiple networks; people could make use of their local groups to help mitigate the limitations of remote working. Virtual panel members will need to link with their communities to make the involvement more representative, such as by finding recovered COVID-19 patients. Each network will need to know which of its members want to be involved in COVID-19 research, to evaluate the capacity in the system. It's also important to make sure that people who aren't part of existing networks or groups are included.

Using existing infrastructure efficiently

It is vital to avoid duplication. Involvement coordinators are still in contact with their existing networks - some are running weekly meetings to keep their members informed and well prepared for getting involved in COVID-19 research. Support and additional capacity are needed for the coordinators supporting involvement. Many public contributors are available, able to work to tight timescales, and motivated to support research by getting involved. It may be helpful to promote tools that help connect researchers and public contributors, such as the [People In Research](#) website.

Provide training and support

Training and support need to be made available for public contributors and researchers new to involvement work, including signposting them to relevant resources. Peer support networks could be vital for both groups. Research teams who don't think they have time to involve people might need support finding people with relevant lived experience quickly. It's important to make it clear to public contributors what they're being asked to do, to facilitate high quality involvement.

Take opportunities to do things differently

- To find new ways of involving people, such as by using virtual community links which have greatly improved during the pandemic. Many COVID-19 volunteer initiatives have waiting lists of people who who might also be interested in public involvement opportunities.
- To gather feedback on public involvement in research from public contributors and researchers, and to learn from it
- To increase public trust in COVID-19 research by improving transparency about how patients and the public have been involved in designing it. Health and social care research has never been so much in the public eye.

Attendees

Representatives from the following organisations attended the workshop, as well as independent public contributors and public involvement experts. The workshop was arranged at short notice; there are many other organisations and individuals whose input will be crucial in taking this work forwards.

Health Research Authority
Chief Scientist Office, Scotland
Health and Care Research Wales

Department of Health and Social Care,
Northern Ireland
NIHR Centre for Engagement and
Dissemination

NIHR Clinical Research Network Coordinating
Centre
NIHR Research Design Services
NIHR Biomedical Research Centres
The Association of the British Pharmaceutical
Industry
Academy of Medical Sciences
Charities Research Involvement Group
James Lind Alliance
Cochrane Consumer Network
GenerationR Alliance
National Cancer Research Institute Consumer
Forum
Cystic Fibrosis Trust
Bowel and Cancer Research UK

Cicely Saunders Institute, Kings College
London
University of Edinburgh Clinical Research
Facility
Imperial School of Public Health, Imperial
College London
Patient Experience Research Centre, Imperial
College London
Nottinghamshire Healthcare NHS Foundation
Trust
Addenbrooke's NHS Foundation Trust
Royal Marsden NHS Trust
Parkinson's UK
Personal Social Services Research Unit