A guide to working effectively with public contributors

This document has been developed by ARC West public contributors. They have created this guide to help you engage with public contributors during all stages of your research project. Involving public contributors helps ensure that your project is ethical, democratic and practical. It requires a thoughtful and structured approach.

Introduction

We at the National Institute for Health and Care Research Applied Research Collaboration West (NIHR ARC West) are very proud to have a diverse and experienced group of public contributors who are available to support and inform research projects throughout the region. This includes a young people's advisory group (YPAG) and local groups involving people from ethnically diverse communities. We would welcome more contributors from <u>under-served</u> <u>groups</u>.

It is important that public contributors are drawn from all quarters of our society. Age, disability, ethnicity, gender, language and cultural considerations or lack of access to digital platforms should not inhibit engagement. However, we know that many people face barriers to involvement in health and care research, and we must work together to remove these.

Many public contributors have a varied and extensive lived experience as citizens, patients, carers and some have also worked within the NHS as healthcare professionals or managers, so they bring with them knowledge and insight which should be very useful.

One of the main advantages of engaging with public contributors is that they are not entirely focussed on the academic research process, so they have a complementary perspective that helps improve the quality of health and social care research. They want to understand how such research might benefit patients and society at large, as well as represent value for money. They are particularly keen to see good research outcomes implemented and this should form part of your early discussions with them.

When you invite a public contributor to work with you on a research project it is helpful to decide together what their contribution should be – how much or how little involvement is required, when it starts and when it concludes. It is important not to see this as a "tick box exercise" but a real opportunity to gain another perspective. To enable people to contribute effectively, ensure you ask them about any individual needs they may have which will enable them to participate fully.

Let public contributors know what you want them to review or feedback on and invite them to identify areas where they can support the research. Let them know if they have made a difference or informed your research in a new way. In a 2021 NIHR survey of public contributors, while most contributors welcomed the opportunity to be involved and 79% stated that they were satisfied or very satisfied with their involvement, some "stated that they did not receive feedback, (or) rarely got opportunities to give feedback."

Find out more about NIHR's work on embedding public involvement:

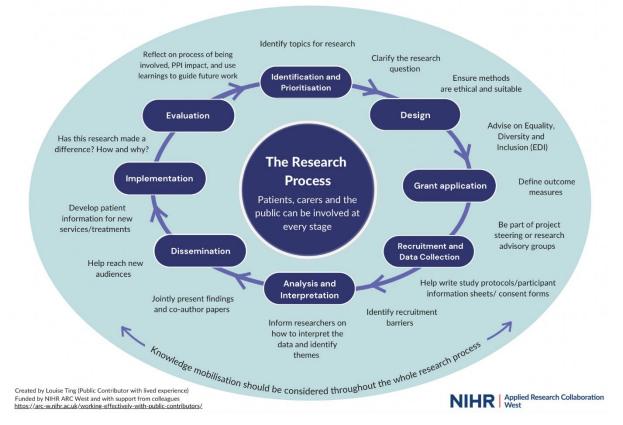
• NIHR's shared commitment to public involvement (2022)

- NIHR launches Centre for Engagement and Dissemination (2020)
- Taking stock NIHR public involvement and engagement (2019)

To support you with your public involvement practices, there are various resources and guidance available, including:

- NIHR ARC West's patient and public involvement resources (scroll down to 'for researchers and PPI professionals')
- Why reaching out to communities is key to putting people first in research
- <u>Going the extra mile: Improving the nation's health and wellbeing through public</u> <u>involvement in research</u>
- UK standards on public involvement
- <u>NIHR resources for partnering with the public</u>
- Improving how we work with patients, carers and the public
- Shared commitment to public involvement
- NIHR learning for involvement training and resources for public involvement in research
- NIHR race equality framework
- Briefing notes for researchers public involvement in NHS, health and social care research
- Public co-applicants in research guidance on roles and responsibilities

How can public contributors help you with your project?



- 1. Review early draft research proposals from a public, patient or service user perspective. Is it ethical? Will it make a difference to patients, carers or society? Is it good value for money? Is the research inclusive? How will it be conducted? Can it be implemented?
- 2. Support project funding applications
- 3. Attend early scoping or steering group sessions. As a critical friend they may challenge some areas of the approach or objectives. Are there any circumstances where the research project may not be able to proceed due to staff or funding or unforeseen issues?
- 4. Consider ethical issues and attend ethics committee meetings
- 5. Check plain English documents. Are they clear and not too lengthy?
- 6. Co-author reports and publications
- 7. Help disseminate findings
- 8. Help generate and deliver publicity for the research outcomes
- 9. Help change practice based on your research (knowledge mobilisation)

In some cases, it may be advantageous to coproduce your research with appropriate contributors. There is more information about this on the <u>our resources for co-producing</u> <u>research page</u>.

Public contributors will give your project another viewpoint and may well bring up issues that might not necessarily arise without their input. They can also help with knowledge mobilisation.

An agreed protocol at the outset will be helpful to all. A proposed timeline for application submissions and further involvement of your public contributor is helpful. As a courtesy, let your public contributors know whether an application has been successful or not.

Nearly all research funding bodies are keen to know about the extent of public involvement throughout a project. Increasingly, this is an important factor when considering the merits of the application.

Factors to consider when engaging with public contributors

A meeting in person or through a computer platform where many attendees are academics, doctors or professors may intimidate some public contributors. This might make them reticent about airing their views, particularly when unprepared.

Let them know beforehand that they may be asked to introduce themselves and outline any topics they may be asked to consider or discuss. Ensure that they have an opportunity to ask questions or give their thoughts. A debrief after meetings may help ensure they have understood the issues and address any concerns. It's also a chance to answer questions or issues arising from the meeting.

If a public contributor is unfamiliar with using Zoom or Teams, take time in advance to explain some of the features such as raising a hand or switching off video and audio. Avoid jargon and acronyms where possible. Most people involved haven't got a research background and so it's important to communicate in accessible language.

As noted above, people from <u>under-served groups</u> experience barriers to being involved in research. Please consider these and make reasonable adjustments.

Public contributors should be paid for their time in line with <u>local or national guidance</u>, which is one way of recognising their contribution (skills, knowledge and time) and helps them feel valued. Whilst not everyone may accept remuneration, it is often still important to offer the opportunity. It can help address perceived power imbalances and barriers to participation. Let them know how payment will be made and provide any forms they need to complete for this to happen.

Checklist: Have you, the researcher, provided public contributors with:

- Timely information about the proposed project, ahead of the first meeting
- An agreed reasonable time frame for them to review documentation
- Dates, times and venues or electronic platforms for meetings
- A point of contact in the research team
- Clarity about actions required as a result of each meeting
- A <u>role descriptor</u> outlining your shared expectations and responsibilities
- Minutes, actions and timelines throughout the project
- Feedback on the impact that their contribution is having
- An opportunity for discussion about their experience of being involved and improvements that could be made
- Feedback about progress or whether an application has failed
- An opportunity for ongoing review of their contribution using the <u>Cube evaluation</u> <u>framework</u> (information included within the guidance document) or <u>public involvement</u> <u>impact log</u>