

Being Inclusive in Public Involvement in Health and Care Research

Things to think about for researchers and practitioners

April 2021

What are some of the things to think about to become more inclusive in public involvement in health and care research? How do we develop inclusive research communities?

This document has evolved from an original piece created by Bella Starling and is intended to be a helpful series of prompts for researchers and for those whose job it is to support public involvement in research (practitioners). This document was compiled from the NIHR INVOLVE Diversity and Inclusion Group's¹ collective experience as the evidence base is at an early stage. We hope that public contributors to research will find it useful too.

What is public involvement?

Patient and public involvement in research is often defined as doing research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, and undertaking interviews with research participants. When using the term 'public' we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.

Things to think about:

1. Check your power

Working with members of the public in research operates in a context of imbalanced power relationships between people, researchers and institutions. This is especially true if your aim is to work with those who may be considered as vulnerable, discriminated against, marginalised or lacking power. Try to understand power relationships within your context, your role and how to operate to promote inclusion.

¹ Include public contributors, charity public involvement leads, researchers and INVOLVE staff.

Please note - INVOLVE was the NIHR's national advisory group to support active public involvement in NHS, public health and social care research. INVOLVE was superseded by the NIHR Centre for Engagement and Dissemination in April 2020, and as such does not exist anymore.

2. Value the people you work with

Recognise and nurture the people who become involved in research. Many will have existing and emerging passions, assets and talents, not to mention different perspectives and opinions. Diversity is the engine of innovation.

3. Use language carefully

Research, and public involvement, are littered with jargon. Avoid it. Guides and glossaries exist to help you. Also, consider the language you use to communicate beyond simple translation: to avoid potential for misunderstanding, confusion and/or offence. Be mindful of how to describe each other in research partnerships. Some don't like certain terms (e.g. service user). Others do. Some researchers prefer the use of titles. Others don't. Agree together.

4. Consider inclusive locations

Think about where, when and how public involvement can be most inclusive. Universities, hospitals, science centres, libraries, community centres, arts venues, the street, online, radio, social media - the list of places is limited only by your imagination. What might work for one group of people working together, might not for another. Decide together.

5. Listen and seek agreement

Dialogue simply does not happen without active listening. Listen carefully. Then act on what you have heard. Or give good reasons why you might not be able to.

6. Get from A to B, perhaps via Z

At the beginning of working in partnership with members of the public, starting points might be different for different partners. In finding your clear purpose and planning for involvement be prepared not to start where you think is the beginning, be flexible and allow time to find the route together. Consider structural constraints as well as value the commonalities and differences in your partnership. Be prepared to have some discussions about sensitive subjects.

7. Collaborate

As well as individual people, many community organisations have a huge amount of knowledge and expertise about public involvement. Some specialise in working with specific communities e.g. ethnic minority groups, asylum seekers, etc. Understand and work with organisations to enable communities to lead and own their involvement in research.

8. Invest in the workforce

Effective public involvement requires investment in personnel, whether these are researchers or in defined practitioner roles:

- support the workforce to recognise and be conscious of the wider, multi-layered processes that exclude and subordinate particular groups (e.g. through training approaches)
- support people from diverse backgrounds to enter into the research and involvement workforce
- avoid the disincentive of short-term contracts or 'add-on' involvement responsibilities to existing research and involvement posts; partnerships need continuity and time
- think creatively and differently about where your next involvement talent could come from and the skills and relationships they bring

9. Commit to a relationship

Inclusive research often revolves around effective relationships. Consider how you might first meet and nurture the first flush of friendship. Acknowledge that things might not always go smoothly, that long term relationships can flourish, and that sometimes, things come to a natural – or planned – end.

10. Evidence, evaluate, share, reflect

Capture and evaluate your public involvement, publish it if you can. [Theory of Change](#) approaches can work well to evaluate involvement, and help with establishing partnerships and common purpose.

11. Act small, think big

A small social change can make a big difference. Supporting researchers and members of the public to develop confidence, learning and skills is valuable for further change and growth.

12. Be values based, socially innovate

Avoid diversity and inclusion becoming a box-ticking exercise by adopting a values- and outcomes-based approach. Support the ideas of the diverse and the many, not the few.

For more information, you can read the companion document to this guidance [A practical guide to being inclusive in public involvement in health research - Lessons learnt from the Reaching Out programme](#). You can also find out more on the topic by referring to the [‘inclusive opportunities’ Standard for public involvement](#).

Acknowledgements

This resource was reviewed by the NIHR Centre for Engagement and Dissemination in March 2021 for accuracy and currency. The NIHR endorses this resource.

This guidance is due for review in March 2023.

The previous version was referenced as: [Being Inclusive in Public Involvement in Health Research](#) (2019).