



# Being Inclusive in Public Involvement (PI) in Health Research:

## Things to think about: for researchers and practitioners

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*“A diverse and inclusive public involvement community is essential if research is to be relevant to population needs and provides better health outcomes for all. We have been struck by the degree to which researchers and public contributors have encountered barriers when trying to work with different communities and populations. This suggests a system-wide issue that needs considered and careful attention.” (NIHR Going the Extra Mile 2015).*

What are some of the things to think about to become more inclusive in public involvement in health 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 health research (practitioners). This document was compiled from the INVOLVE Diversity and Inclusion Group’s\* collective experience as the evidence base is at an early stage. We hope that public contributors to research will find it useful too.

### 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. Even more so 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.

#### 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

Health research, and public involvement, is 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., black and minority ethnic 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 revolve around effective relationships. Consider how you might first meet, 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 people, 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.

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

