

Different experiences:

A framework for considering who might be involved in research

Key Points to Consider

- Be clear about the purpose of involving people in research and what experiences and knowledge they can provide
- Include a diversity of relevant views and perspectives
- Take a common sense approach to who you involve
- People can wear several hats, and their contributions may be broader because of those range of experiences
- The type of lived experience required will vary depending on the focus of the research

Introduction

The inclusion of public voices across the whole research cycle has provided a range of benefits to the research process and its outcomes. Over time, public involvement in research has included a breadth of valuable and influential perspectives, and has seen the rise of co-produced and service user-led studies. Increasingly, some parts of the public involvement community have tried to define or differentiate between various 'types' of public perspectives that are offered, based on previous experiences. Also, NIHR has received some criticism regarding consistency of approach when considering the involvement of members of the public with various experiences.

Rather than a set of rules, the intention is for this guidance to be used as a framework to help make decisions about who might be involved and why. This guidance does not address the question of 'how' best to involve these different perspectives.

Why do we need clarification?

INVOLVE defines the term 'public' (when clarifying the difference between public involvement and engagement, or participation) as:

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. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the

public and the perspectives of people who have a professional role in health and social care services.

Inevitably public involvement evolves, and although INVOLVE's definition still stands, it now needs further clarification and explanation.

For example, INVOLVE has received reports of its definition being used to justify the rejection of research funding applications, or the questioning of involvement plans on the basis that the members of the public involved, whilst having lived experience of a condition or service being researched, also have (or have had) a career or worked in health and social care services, research or academia. As such, these individuals have been 'classified' as 'professionals' rather than 'public', and the value of including their lived experience has been questioned. Similarly, those people with lived experience who, because of their vast experience of public involvement in research, are sometimes referred to as 'PPIE professionals'. INVOLVE's view is that members of the public with lived experience who have worked in health or social care and/or who gain research knowledge and expertise do not lose their lived experience. There are benefits from including a variety of perspectives.

While the intention of the second sentence of the definition above is important and justifiable, it may be narrowly interpreted resulting in the exclusion of people with relevant lived experiences who could benefit research. Rather, the second sentence intends to discourage professionals from simply involving their peers (for example, fellow researchers or professionals they know) or those people whom it is relatively easy to involve, rather than reaching out to the wider public.

INVOLVE is therefore exploring these issues to encourage further thought and clarity about who might be involved in research.

So what issues should we be taking into account when deciding who should be involved in the research?

The starting point should always be **clarity about the purpose** of involving specific individuals or groups. It is important to be clear why their perspective would be helpful to the research. What experiences and knowledge do we want or need in this project? Which individuals or groups are most likely to bring these experiences and knowledge to the project?

Rather than relying on one 'type' of member of the public to cover the whole public experience we think that **including a diversity of views and perspectives** often helps to improve the research. So, people should ask, if I only include people from 'this' type of background with 'this' experience what perspectives might I miss and how can I address this?

A **common-sense approach** is required. For example, if you are researching a rare condition and the only individual who comes forward as a public contributor also happens to be a professional in health care or research, it would seem counterproductive not to include them. However, it is important to consider whether they can provide the perspective needed for the specific project and to support them in setting relevant boundaries between their professional and personal experiences when contributing to the group. And it is of course important to review the way the involvement role and opportunity has been structured to ensure there are not unintended barriers stopping other public contributors from engaging.

There are other examples where including the perspective of professionals would be of benefit to the study¹. This is especially true when the end users of the research are the health or care professionals who may directly benefit from the study outcomes and may have the lived experience required. For example, research investigating the mental health of midwives may consider the midwives as their end users (for involvement purposes, the end users can be regarded as the equivalent of members of the public with lived experience). **This does not replace the need for the involvement of other members of the public or communities.** In the example above, members of the public who have or are receiving the services of a midwife may be able to contribute a valuable perspective on what they want from a midwife, or what it is like to work with a midwife with mental health issues. Again, it is about considering why particular individuals or groups might be involved. The inclusion of several different perspectives is likely to benefit a research study or an organisation's involvement programme.

People can wear several hats and their contributions may be broader because of the range of their expertise. Whilst it is important to be clear about what perspectives people bring to research, it is important that we don't forget that people will likely bring other valuable skills and experiences. Someone with lived experience of a condition, for instance, may also have had experience of research - their lived experience does not operate in isolation from other aspects of their lives. A clinical researcher with Type 1 diabetes still wakes everyday as a diabetic and has to deal with the challenges that come with the condition.

Having lived experience of a condition or service, as a patient or carer, is often crucial when determining who should be involved in research. Indeed, some would argue that a key rationale for involving people with lived experience is to empower people and communities. Whether or not individuals have lived experience of the condition or service that the research is concerned with is one of the criteria that will need to be considered when planning who to engage in involvement activities. **The type of lived experience needed will vary depending on the focus of the research.** For example, in a study about views on the NHS, social care or public health in general, contributors with

¹ It is worth noting that in adult social care, in addition to involving the public in research, there is also an emphasis on involving practitioners

experience of a range of services and conditions will be needed to give as broad a view as possible on the topic rather than individuals with one specific area of lived experience.

There is no 'one size fits all' answer to who might be involved in research. It will depend upon the needs of the individual, the study or organisation. And the reason for the inclusion of certain individuals or groups should always be clear and transparent.

It is clear that a common-sense approach is needed when considering who might be involved in any research activity. The purpose of involving specific individuals or groups should be clearly expressed. And if there is a need to involve professionals as end users, it would be worth considering whether additional value might be achieved by the involvement of members of the public too.

This guidance should not be considered in isolation. The guidance should be used in conjunction with other guidance that addresses a range of important public involvement issues such as what type of involvement is appropriate, what support should be offered to those involved, how to overcome power imbalances and how to ensure that our approaches to involving people are inclusive.

This is not a definitive framework but rather a 'living document' as we perceive that as involvement and co-production in research evolves, understandings and perspectives will also develop.

31/03/2020 G. Hickey

Useful references

[Briefing Notes for Researchers](#)

[UK Standards for Public Involvement](#)