

## **The impact of public involvement on research**

### **A discussion paper from the INVOLVE Evidence, Knowledge and Learning working group**

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#### **What difference does public involvement in research make?**

This is the question that faces all of us who are engaged in promoting and encouraging public involvement in NHS, public health and social care research. In this paper, we wish to explore the different ways in which this question may be answered.

INVOLVE was established to promote public involvement in research in order to improve the way that research is prioritised, commissioned, undertaken, communicated and used. INVOLVE believes that the active involvement of the public in the research process leads to research that is more relevant to people and is more likely to be used. Research which reflects the needs and views of the public, is more likely to produce results that can be used to improve practice in health and social care.

Do we have the evidence to demonstrate that public involvement is making a difference or the collective knowledge to communicate to others, that it improves research in these ways?

Public involvement in research is founded on the core ethical principle that people who are affected by research should have a right to have a say in what and how research is undertaken. However, we need to develop an evidence / knowledge base to:

- demonstrate the benefits and value of public involvement in research
- understand the best approaches to public involvement in research
- reflect and learn from the evidence

## How can public involvement in research be assessed or evaluated

There are a number of ways in which we can begin to assess or evaluate the impact that involvement makes to research. The question 'What difference does public involvement in research make?' leads us to look at many different aspects of research. It includes both the process and outcomes of research, and includes consideration of the different people involved in commissioning, carrying out, receiving and responding to the results of research. Identifying whether involvement 'works' is not straightforward. It is not simply a matter of comparing similar research carried out **with** and **without** public involvement in order to see how the outcomes are different. One way of assessing it might be to ask a number of questions of the research, its outcomes and its stakeholders. The following are areas in which we think it is useful to ask those questions.

### 1. The quality of the research

Many researchers are primarily concerned with the quality and rigour of research, and whether public involvement might improve or, conversely, compromise this. We believe that there are a number of ways in which the research quality may be positively influenced by public involvement. They are all aspects of how the research may be potentially improved by bringing to it a new perspective – that of the people most closely affected by that research:

- a. **The nature of the research questions:** both the broad research question and the more specific questions asked may become more relevant to those most directly influenced by the research.
- b. **The choice of research tools – questionnaires, outcome measures:** the tools chosen may measure outcomes, ask questions or seek understanding about what is of concern or relevance to service users
- c. **The research outcomes:** as a result of the above, the outcomes of the research may be more meaningful, not just to service users or carers, but also to the practitioners or people expected to implement the research results.
- d. **Data collection, analysis and interpretation:** Where service users or carers are involved in data collection and analysis and interpretation eg. from interviews with peers, the quality of these processes can be improved. There is some evidence that more open and honest responses are given where interviewees perceive their interviewer to be a peer<sup>1</sup>.
- e. **Commissioning process:** Involvement in the generation of research topics for funding, shortlisting/selection of successful applications, candidate interviewing and subsequent research management are all processes that can benefit from a service user perspective.

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<sup>1</sup> With the caveat that adequate training in interviewing skills has been given.

- f. **The experience of being a research participant:** Active public involvement in the planning, design and data collection of research can help to improve the experience of those taking part in research and facilitate recruitment. It can influence the way the research is carried out, how participants are treated and the quality of the information that is provided.
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## 2. Research ethics

The perspective of involving people directly affected by the issues under investigation may significantly improve ethical practice. For example, the information sheet given to potential participants may be written in more accessible language. Public involvement can also inform practical aspects of the approach to participants such as timing and location for interviewing and recruitment.

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## 3. The people involved in the research process

Public involvement in research can have significant benefits for those involved. Both service users and researchers who have been involved in research have highlighted a number of personal and professional benefits relevant to any assessment of the success of public involvement.

For example both service users and researchers may experience benefits around:

- enrichment of their own understanding of the issues under investigation and the topic area being investigated
- improvement in the research quality
- confidence, skills and personal development (involvement in other projects, training, employment)

Researchers have acknowledged that:

- funding is often more likely to be achieved where high quality involvement is demonstrated
- findings may be viewed as more credible when grounded in a user perspective

Service users have reported the benefits of:

- inclusivity – a feeling of belonging in a traditionally exclusive area
  - empowerment
  - social contact
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#### **4. Implementation and change**

One test for the usefulness of research is whether or not it has practical application and if it has led to change. There is emerging evidence in some fields that public involvement in research improves the relevance of research.

In stating the above, the INVOLVE Evidence, Learning and Knowledge working group acknowledges that there are different types of evidence which have differing value for different people. We value **all** forms of evidence including peoples' reflections on their experiences of involvement. What works, when, for whom and in what context cannot be predicted with any certainty. Yet evidence, knowledge and learning in support of a positive impact on research through involvement are accumulating. A greater understanding of the conditions needed for beneficial involvement is required if we are to foster learning and improvement.

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## **INVOLVE**

INVOLVE is a national advisory group, funded by the National Institute for Health Research, which aims to promote and support active public involvement in NHS, public health and social care research.

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