

INVOLVE

Promoting public involvement
in NHS, public health and
social care research

NHS

*National Institute for
Health Research*

Summary

Exploring Impact:

Public involvement in NHS, public health
and social care research

This summary has been written for a broad audience, but with the expectation that people will have some basic understanding of research.

The summary was written by Kristina Staley of TwoCan Associates with support from the INVOLVE Coordinating Centre.

Information about INVOLVE

INVOLVE is a national advisory group which promotes and supports greater public involvement in NHS, public health and social care research. We are funded by the National Institute for Health Research (NIHR).

INVOLVE works with others towards creating the research community of the future which will be broader, more inclusive and more representative of the population as a whole.

For further information on INVOLVE please visit our website www.invo.org.uk

Information about TwoCan

TwoCan Associates carry out research and development and provide training and support to help voluntary and statutory organisations involve people who use services in their work. For further information visit www.twocanassociates.co.uk or email us at info@twocanassociates.co.uk

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For further information please read the full report:

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Summary

Introduction

Public involvement in research is founded on the core principle that people who are affected by research have a right to have a say in what and how research is undertaken. In recent years, there has been a growth of interest in public involvement as well as increasing requirements for involvement from research funders. This has led to an understandable concern to know exactly what difference involvement makes. There has been much interest in obtaining evidence to demonstrate added value and to find out where and when involvement brings the greatest benefits. This area of enquiry has come to be framed in terms of the **impact** of public involvement in research.

This is a summary of a literature review that aimed to increase our knowledge of the evidence of the impact of public involvement on health and social care research. The project was commissioned by INVOLVE. The work was carried out by Kristina Staley from TwoCan Associates with Maryrose Tarpey, Helen Hayes and Sarah

Buckland at the INVOLVE Coordinating Centre. The project was overseen by two advisory groups.

Methods used

The project involved carrying out a structured review of the literature obtained from a collection of articles at INVOLVE, a systematic search of electronic databases, and requests for 'grey' literature sent out to INVOLVE's networks.

Relevant articles were identified by applying inclusion and exclusion criteria at a number of stages. A total of 89 articles met all the criteria and were considered relevant for an in-depth review. This was carried out using a framework which helped with categorising the evidence of different types of impact and drawing out common themes.

Context to the findings

There is huge variation in how the evidence of the impact of public involvement has been assessed and reported. The impact of involvement is also highly context-specific. This makes it difficult to judge the quality of the evidence that is available or to draw any general conclusions.

The vast majority of the evidence of impact is based on the views of researchers and members of the public who have worked together on a research project. Most often these have been obtained informally. However in spite of the variation in the process, many people express similar views. So although there is not a consistent approach to assessing impact, or describing it, the same benefits and costs are being consistently reported.

Findings from the literature review

Based on the evidence from this review, public involvement in research has had a variety of impacts, including impact on the research (at all stages and levels), on the members of the public who were involved, on the researchers, on participants, on community organisations and the wider community. It has also influenced whether the results of research have been used to bring about change.

The findings from this literature review have been summarised under the following eleven themes:

1. Impact on the research agenda

Identifying topics for research

Public involvement has led to the consideration of a wider set of topics than if academics or health professionals had been working alone. It has also opened up new areas of research.

Shaping the research agenda

In some instances, public involvement has shifted the focus of research to be more in line with the public's interests and concerns. Researchers have reported that involvement added value by forcing them to be clearer about why they wanted to conduct their research and how it would be relevant to the public.

Initiating research projects

Public involvement has been reported to provide the motivation and momentum necessary for researchers to initiate and conduct research. This has helped to accelerate the whole process.

Influencing funding decisions

Some researchers have reported that public involvement made their research more fundable, either by adding credibility to their proposal or by improving its feasibility and overall design.

2. Impact on research design and delivery

Project design

In projects where the public have been involved from the earliest stages, they have helped to reshape and clarify the research question. Public involvement has also influenced what outcomes are measured, as well as how they are measured. As a direct result, research findings have been made more relevant and useful to the end-users.

Research tools

Researchers have reported that public involvement has led to improvements in the design of research tools such as questionnaires, interview schedules and questions for focus groups. Field-testing these tools with the public has also improved their reliability.

Research methods

Public involvement has ensured that research methods have worked in practice and that studies have been conducted in a way that has made it easy for people to participate.

Recruitment

Public involvement has been reported to have led to increased participation rates. In particular involvement has:

- improved the information provided to potential participants
- ensured recruitment procedures have been sensitive to the needs of the participants
- enhanced the credibility of the research project and researchers
- helped to engage seldom heard groups
- encouraged and motivated people to take part
- provided commitment, energy and enthusiasm
- improved access to potential participants.

Negative impacts of public involvement on recruitment have rarely been reported.

Data collection

Different types of involvement have been reported to have different kinds of impact on data collection and quality. By increasing a sense of ownership of a research project, it has increased participants' response rates to questionnaires and thus enhanced the quality of the data.

Involving the public as peer interviewers (or as co-facilitators of focus groups) has been reported to enhance the collection of qualitative data and increase its relevance and reliability. The evidence suggests that involving peer interviewers in research into services is especially important to obtain honest and reliable feedback.

However, there are also reports of some negative consequences of involving peer interviewers. In some cases, the 'shared experience' between the interviewer and interviewee has been found to limit discussion, so that certain issues have not

been fully explored. These problems can be addressed by providing appropriate support and training to improve the user researchers' interviewing skills.

Analysis of data

Involving the public in the analysis of qualitative data has been reported to be of great value. Researchers have found that public involvement has helped them to:

- check the validity of their conclusions
- correct their misinterpretation of data
- identify themes that they might have otherwise missed
- identify which findings would be most relevant to patients or the public
- improve the way in which results have been described in reports.

Where the public have been involved in this stage of a project, it has also had the knock-on effect of enhancing their level of commitment to a study.

This has created a greater sense of ownership of the results and thus increased the likelihood of action being taken in response to the findings.

Writing up

There have been few reports of the impact of public involvement on writing research publications. Where the public have been involved, researchers have found their involvement helped to make reports more hard-hitting, accessible and useful to the target audience.

Dissemination

Public involvement in dissemination has been reported to increase the likelihood of people acting on the findings. Collaborations between researchers and the end-users of research have encouraged both the direct use of research (i.e. changing policy and practice) as well as its more conceptual use (i.e. changing awareness, knowledge and attitudes). The effects of involvement at this stage have been to:

- help engage the target audience
- make the findings more accessible and the messages more powerful
- enhance the credibility of the findings
- help devise novel forms of feedback.

3. Impact on research ethics

Improving the consent process

Public involvement in the development of patient information sheets has made the information clearer and more accessible for people considering whether to take part in a research project.

Improving the ethical acceptability of research

Public involvement at an early stage of project development has helped to identify potential ethical concerns as well as solutions to these ethical problems.

4. Impact on the public involved

By being involved in research, people have reported gaining new knowledge and skills and benefiting personally from involvement, most often through a general increase in their self-confidence and self-esteem. Other reported benefits include gaining peer support and friendship.

People who have been paid for their involvement have reported that they valued an opportunity to earn money and felt it appropriate that they received a regular (and fair) payment for their contribution.

There are fewer reports of involvement having had a negative impact on the people involved. Examples of bad experiences include people being overloaded with work, exposed through the media or frustrated at the limitations of involvement.

5. Impact on researchers

Researchers have positively commented on how much they have learnt from working with the public. Public involvement has helped them develop a greater understanding of a health condition, or of a particular local area or culture. Some have also experienced career benefits. Researchers have also reported that their beliefs and attitudes have been challenged by public involvement. It has sometimes made them rethink their views of service users and changed their attitude towards involvement itself.

There are few reports of involvement having had a negative impact on researchers. Researchers have commented that working with the public has required a lot of time, energy and money. This has led to some frustration and the need to renegotiate timescales and deadlines with funders. Other difficulties have included the loss of power, forced changes in working practice and challenges to researchers' values and assumptions.

6. Impact on research participants

Public involvement during the early stages of a project has been reported to improve the way research is carried out and made it easier for people to take part in research.

The involvement of peer interviewers (or user researchers running focus groups) has been reported to have had a positive impact on the participants. It has helped them to be more honest and open in their responses.

7. Impact on the wider community

Public involvement in research has also been reported to have had a positive impact on the wider community (i.e. community members beyond those actively involved in a project or those actually taking part in research). It has helped by:

- creating trust and acceptance of the research
- keeping projects grounded and focused on benefits for the community

- improving relationships between the community and professionals.

8. Impact on community organisations

In many community-based participatory research projects, staff and/or members of community organisations have been involved as representatives of the local community. These organisations have reported benefiting from involvement through gaining knowledge, raising their profile, making links with other community members and making a positive contribution to the research.

However, some report that their involvement has had some disadvantages, including financial costs and being criticised for not being able to meet an increased demand for services.

9. Impact on implementation and change

Public involvement has been reported to make a difference to the way research findings have been used to bring about change, particularly in developing new services or improving existing ones.

This has often involved directly influencing organisations or changing professional practice. It has also increased the capacity of individuals to bring about change and helped to establish long-term partnerships with capacity to take action.

10. Factors that influence the impact of involvement

Involvement throughout a research project

The evidence suggests that public involvement has had the greatest impact when people have been involved throughout an entire research project, rather than just at discrete stages.

Long-term involvement

Over a longer term, involvement is reported to have more impact because:

- members of the public gain more insight into research
- members of the public and researchers develop more constructive, ongoing dialogue

- a general ethos of learning from each other is established.

Training and support for the people involved

Public involvement has been reported to be more likely to have a positive impact if members of the public receive appropriate training and continued support.

Linking involvement to decision-making

Some research projects have established advisory groups. Integrating these groups into the management structure of a project has helped to ensure that the public's views have actually influenced decisions.

11. Reflections on assessing the impact of involvement

Some researchers have reflected on the impact of involvement. Their main conclusions are that:

It is difficult to assess the impact of involvement.

This is because:

- it is often too difficult or too costly to set up a comparison project without involvement to assess the links between involvement and outcomes.
- the most valuable contributions often result from informal, personal interactions, which are hard to capture and evaluate.
- the public are often involved in a committee or steering group. The complexity of decision-making in groups makes it very difficult to assess the impact of any individual.
- involvement activities are interconnected and link to several stages of the research process. This makes it difficult to pinpoint the precise impact of any particular aspect of the involvement.
- it may take many years for any detectable outcomes to emerge from a study.

It is difficult to predict where involvement will have the greatest impact

Public involvement in research is a complex, social process that is undertaken for many different reasons and in many different contexts. Some researchers have therefore concluded that it is not possible to say that public involvement should always be undertaken in the same way to achieve the same benefits.

More work is needed to clarify the added value of involvement in different research contexts

Professionals and the public bring different knowledge and skills to the process of partnership working in research. These contributions need to be explored in more depth to be clear about where public involvement brings added value.

Discussion

Challenges in undertaking this review

The main challenges for this review lay in:

- identifying relevant articles, because of inconsistencies in the use of terms such as 'involvement', as well as inconsistencies in describing and reporting on impact.
- the limited amount of evidence of impact. This partly reflects both the inherent problem of assessing impact and the lack of structure and guidance on reporting on involvement in peer-reviewed journals. The current research culture also encourages researchers to report on positive results, rather than describe the 'lessons learnt' as part of the process.
- the gaps in the evidence. The most notable being the lack of articles on the impact of public involvement on research funding and commissioning. Other gaps, may reflect a lack of involvement, rather than a lack of evidence.

Main themes identified in the review

In spite of the limitations, some strong and consistent themes emerged from the review. Based on an assessment of where there appears to be the most evidence, some of the strongest themes were:

- public involvement was reported to help increase recruitment to all types of research
- public involvement was reported to be of particular value in qualitative research where participants are asked to share their views and experiences
- public involvement was reported to be of particular value in clinical trials where it helped to improve trial design and ensured the use of relevant outcome measures
- public involvement was most frequently reported to benefit the people involved as well as the research participants.

Strengthening the evidence base

Based on this review the strength of the evidence base around the impact of involvement could be improved by:

- producing guidance on how to report on the impact of involvement in journal articles and reports
- finding more consistent and robust ways of assessing impact
- helping researchers and the public to find the most useful ways of telling the 'story of involvement'.

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For further information please read the full report:

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INVOLVE

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