Public involvement in research: assessing impact through a realist evaluation

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Scientific summary

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Background

This study was concerned with developing the evidence base for public involvement in research in health and social care. There now is significant support for public involvement within the National Institute for Health Research, and researchers applying for National Institute for Health Research grants are expected to involve the public in their projects. Despite this strong policy commitment, evidence for the benefits of public involvement in research remains limited.

Two recent literature reviews by Staley in 2009 and Brett *et al.* in 2010 on the impact of public involvement in research identified a number of gaps in the evidence, in particular the lack of primary studies and the uneven quality of published literature in this area [(Staley K. *Exploring Impact: Public Involvement in NHS, Public Health and Social Care Research*. Eastleigh: INVOLVE; 2009) (Brett J, Staniszewska S, Mockford C, Seers K, Herron-Marx S, Bayliss H. *The PIRICOM Study: A Systematic Review of the Conceptualisation, Measurement, Impact and Outcomes of Patients and Public Involvement in Health and Social Care Research*. London: UKCRC; 2010)].

The reviews both found that there was wide variation in how the evidence of the impact of involvement has been assessed and reported. Equally, they found that the impact of involvement was highly context-specific, making it difficult to judge the quality of the evidence or draw conclusions. Much of the evidence of impact was based on the retrospective views of researchers and (less commonly) the public involved. Although there has been no consistent approach to assessing impact, similar benefits and costs were consistently reported. The two reviews concluded that public involvement has had a variety of impacts, including on the research, on the public involved, on the researchers, on participants and on the wider community. Most of the identified impacts were viewed as positive, but some negative impacts were identified, such as the additional cost of involvement to research projects. In response, the Medical Research Council and National Institute for Health Research commissioned new research studies on the impact of involvement in research in 2009 and 2010 respectively, which included this study; of these, this is the first study to report.

Aim and objectives

The overarching aim of this research was to identify contextual factors and mechanisms that are regularly associated with effective and cost-effective public involvement in research. In order to achieve this aim we sought to pursue the following objectives:

1. to identify a sample of eight National Institute for Health Research and other quality-assured research projects that are diverse in terms of research methodology, participants and extent of public involvement in research
2. to identify the desired outputs and outcomes of public involvement in research in the sample from multiple stakeholder perspectives (e.g. members of the public, researchers, research managers)
3. to track the impact of public involvement in research in this sample from project inception through to completion where possible and, at a minimum, for complete stages of the research process (design, recruitment, data collection, analysis, dissemination)
4. to compare the contextual factors and mechanisms associated with public involvement in research and their impact on desired outcomes of research from stakeholder perspectives, and to make a judgement of the costs of different mechanisms for public involvement in research
5. to undertake a consensus exercise among stakeholders to assess the merit of the realist evaluation approach to assessing the impact of public involvement in research, and our logic for the measurement and valuation of economic costs of public involvement in research.

Design and methods

This project was designed by a group of academic researchers and research partners (members of the public involved in research) from the Service User and Carer Involvement in Research group at the University of the West of England.

Our research design was based on the application of realist theory of evaluation, particularly drawing on the work of Pawson, which argues that social programmes are driven by an underlying vision of change – a 'programme theory' of how the programme is supposed to work. The role of the evaluator is to compare theory and practice. Moreover, the outcomes of social programmes can be understood by identifying regularities of context, mechanism and outcome. Thus the key question for the evaluator is 'What works for whom in what circumstances . . . and why?' (Pawson R. *The Science of Evaluation.* London: Sage; 2013). We therefore planned a realist evaluation based on qualitative case studies of public involvement in health and social care research.

We generated a realist theory of public involvement in research based on the two literature reviews, which allowed us to identify contextual factors and mechanisms which we believed were intended by policy-makers and other stakeholders to enable desired outcomes of involvement to be achieved. To date there has not been a robust testing of the underlying programme theory of public involvement in research; our study was designed to allow an independent prospective testing of this programme theory for the first time. We included an economic evaluation, designed to complement the realist evaluation, to estimate the resources used for public involvement across the case studies.

The setting for this project was within organisations hosting health and social care-related research studies primarily in the south and west of England. Our aim was to recruit a diverse sample of eight case studies which had significant public involvement during the period January–December 2012. There was no existing database or other source of routinely available data that enabled upcoming studies with such involvement to be identified. To meet our aims, the studies only needed to be diverse, not representative, so we took the pragmatic decision to sample through our existing knowledge of public involvement in studies in the south and west of England and to 'snowball' through our existing networks, including the People and Research West of England consortium. Potential interviewees (researchers, research managers, third-sector partners and research partners) were identified in discussion with each principal investigator and invitations forwarded by them, with the intention of interviewing approximately five stakeholders per project on three occasions over the year of data collection. Eight case studies were conducted over the calendar year 2012 with 88 interviews with 42 participants.

Results

Case study data supported the importance of some aspects of our initial theory of public involvement in research and led us to amend other elements. Thus, this study made a contribution to building an evidence-based theory of public involvement in research. We identified the previously unrecognised importance of principal investigator leadership as a key contextual factor for the impact of public involvement. There were case studies where public involvement was still effective without direct principal investigator leadership if there was a wider culture of involvement in the research group; but in these cases there were other factors related to leadership on public involvement that acted as a proxy for principal investigator leadership: the principal investigator was open to public involvement, and willing to develop their leadership or, alternatively, to delegate it to another senior member of the team. Thus, if one had either a committed principal investigator or an established culture of public involvement, then there was likely to be an effective approach to public involvement in research, but both were not necessarily needed for effective involvement to take place.

In addition, a new and important contextual factor of ‘field of research’ was identified. Although not part of our original theory, this concept reflected an important aspect of the context for public involvement in research which we needed to incorporate into our theory. As well as research design, studies differed in the extent to which research partners had an ongoing relationship with researchers and in the degree of diversity among their ‘publics’. The field of research is defined by complex and often taken-for-granted assumptions, procedures and practices that make one field or discipline distinct from another. One of the clearest ways that the field of research manifested itself in our data was the way the pattern of involvement in clinical trials differed from that in other studies. In all of our trial case studies, there was a lengthy period of data collection when little or no involvement activity took place. This was very different from other studies, where involvement was much more ongoing. Thus, the field of research structured the opportunities and boundaries for public involvement and the mechanisms of involvement that were appropriate for those studies.

A history of public involvement in the institution was another hypothesised key contextual factor, but this did not appear as directly important in our case studies as leadership. All of our case studies had some history of wider institutional support for public involvement, and often this was drawn upon within case studies, but it appeared useful rather than essential. In some cases such support had been available for some time, but had not been drawn upon by the principal investigator prior to the research project under study.

Bringing the different contextual factors together, leadership and culture are the key contextual factors for ensuring public involvement happens, but the field of research is equally crucial in a more underlying way in determining the opportunities and constraints of what is possible. A history of institutional support for involvement is helpful but not essential.

The question of how these contextual factors collectively shaped the mechanisms for involvement returns us to the key role of researcher leadership: the importance of someone senior in the team taking a lead on public involvement, and crucially, allocating resources for involvement. This was not necessarily about a formal allocation of budgetary resources, as another important new finding was that many research projects significantly underestimated the real costs of public involvement. Substantial resources in terms of research team time were allocated to involvement without being formally budgeted for.

What was crucial was that, as well as a senior team member leading on involvement, a member of the team with good interpersonal skills took on a facilitation role. That is, they were the first point of contact, ensured good communication with research partners and dealt with such practical aspects as organising meetings and sorting expenses. Nurturing good interpersonal relationships was crucial to effective involvement.

The other key resource issue we explored related to how research partners were rewarded for their involvement. Monetary payments were made in only two of our eight case studies, and in one of these it did not appear a significant factor in the research partners’ motivation. However, most of our case studies did not require extensive time commitments or extended skills from research partners, for which payment may be more necessary and expected. Much more important in all our case studies were other types of reward, notably feeling valued, being listened to and receiving feedback that demonstrated that the contribution research partners were making was having an impact. Thus payment for research partner time appeared more significant for some types of public involvement than others.

Training has been identified in previous research as an important resource to support the public in getting involved in research, but it did not feature very significantly in our data. Some of the research partners played an effective role in case studies without requiring any training. Training appeared most relevant where research partners were taking on more extended or technical roles such as data analysis. More commonly in our case studies research partners were sharing their lived experience and responding as informed users to draft materials, roles for which they did not require training but needed facilitation and informal support. Thus our theory was amended to emphasise informal support over formal training, and the need for formal training to be linked to the development of appropriate skills for more complex tasks.

Another area of debate which emerged through our data was whether or not defined roles were as useful a mechanism as we initially hypothesised. Although in one case study there was an initial tension over the lack of clear agreement on the research partners' roles, most participants (including both researchers and research partners) were content to let the research partner role develop organically without clear definition. Overall it appeared helpful for researchers to make clear their practical expectations of what they would ask research partners to do at each stage of the research project, but this did not necessarily require a formal role definition.

The crucial factor that did appear to influence outcomes, which many discussions with informants came back to, was the importance of building good interpersonal relationships between the research team and research partners. This clearly links back to the need for principal investigator or senior leadership, the importance of facilitation and the non-monetary rewards that motivate and build the confidence of research partners. All of these aspects are mediated through the development of relationships of trust between researchers and research partners, where the research partners feel valued and included.

Public involvement contributed to at least some of the intended outcomes for involvement in all of our case studies. It was associated with improvements in research design and delivery, particularly recruitment strategies and materials and data collection methods. All the research teams reported that they had valued and acted upon some of the contributions of research partners, despite the diverse types and scale of research projects and the diverse mechanisms of public involvement. Research partners' reports of their experiences of observing changes following their contributions and our own observations validated the researchers' claims. This did not necessarily mean that the research partner-inspired changes achieved project objectives; for example, in some cases, research partner contributions led to improvements in the quality of recruitment strategy and materials, but did not always improve recruitment of study participants, as other factors were also involved. There was some degree of proportionality, as some case studies had little or no public involvement during our data collection period, and so little opportunity to benefit from public input during this period, while other case studies had consistent public input across the year. Nonetheless, the overall message from across the case studies was that, when the public were involved as research partners, this improved research design and delivery. A secondary but also important message was that research partners found their involvement rewarding in a number of ways, principally because they felt they were making a positive contribution and felt valued.

Conclusions

Testing our initial theory against the case study data enabled us to develop a revised theory identifying key contextual factors (principal investigator leadership, culture, field of research) and mechanisms (senior lead, resource allocation, facilitation) for public involvement in research that lead to desired outcomes. Ours is the first realist theory of public involvement in research and, unlike many previous theories and conceptual frameworks, is built on prospective empirical research. While we acknowledge some methodological limitations, our identification of principal investigator leadership as a key contextual factor raises important new questions for future research, including how principal investigators come to commit to public involvement and how one might influence sceptical or agnostic PIs. Other implications for future research include the need for more methodological work on capturing impact, including further economic analysis, and qualitative work on the negative or mixed experiences of research partners, and on the values researchers and research partners place on payment and its perceived effectiveness.

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