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## **Taking stock of the evidence base for the impact of public involvement in research<sup>1</sup>: An invoNET round table discussion**

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### **Introduction**

On 21 March 2014, [INVOLVE](#) hosted an [invoNET](#) round table discussion at the King's Fund in London, bringing together researchers, service user researchers and service users with expertise in the impact of public involvement in research. The aim of the discussion, chaired by [Patricia Wilson](#), was to take stock of how the evidence base on the impact of public involvement in research is evolving, and to consider how it should be developed in the future. This report summarises the main points of the round table discussion. Information on the people who took part and their reflections on the discussion are available at [www.involve.nihr.ac.uk/invonet/invonet-round-table/](http://www.involve.nihr.ac.uk/invonet/invonet-round-table/).

### **Evidencing the impact**

The discussion started with an assessment of the current state of the evidence base reporting the impact of public involvement. It was agreed that this is a rapidly developing area. The field has changed markedly over the past decade, with an increasing acceptance among researchers and funders of research that public involvement is both necessary and feasible.

The group explored the question of why evidence of impact is needed. It was noted that in the past some people have argued that the ethical imperative for involving the public in research negated the need to evaluate or evidence it. However, in recent years this position has shifted with a growing agreement that all aspects of the research process can and should be examined and held to account. The point was made that many people, including service users, now believe that assessing the impact of public involvement is important. Service users want to know that their involvement has made a difference to the research, its process and outcomes, as do the funders whose resources have enabled this.

The availability of evidence about impact is also important for researchers and public involvement leads within organisations, as it enables them to reflect, learn and improve their methods and approaches to involvement. However, the current level and quality of the evidence base were thought to be inconsistent. One group member suggested that it would be useful to identify the areas of health and social care where public involvement and its evidence are lacking as this might indicate resistance to change or progress.

There is an acknowledged complexity associated with the involvement of many different perspectives. Those interested in public involvement – from members of the

public looking for social justice to the funder looking for value for money – will have different views on the meaning of impact. The group agreed that researching the impact needs to reflect these different dynamics: this is about **impacts**, rather than **an impact**, and **evidence bases**, rather than **an evidence base**.

The influence of values and perspectives on the evidence was discussed at length. This was thought to be a key reason why impact should be evidenced. The evidence that matters will vary according to different stakeholders' perspectives, values and needs. It was pointed out that more information is needed about the motivations of the people interested in impact in order to develop impact assessments that generate useful, relevant evidence.

There was concern among some members of the group that some researchers may not be aware of the importance of contributing to the evidence base for public involvement impact and may miss opportunities to evaluate and report on it. It was suggested that the methodological underpinnings of research may need to shift in order for the notion of public involvement, and the benefit of capturing its impact, to be fully recognised. There is a perceived dichotomy between the longstanding respected culture of doing research and the relatively novel concept of public involvement in research. It was argued nonetheless that evidencing the impact of public involvement could be one way to demonstrate the validity of a study, and underpin the need to collect evidence about it.

Building on this, it was suggested that the assessment of the impact of public involvement often runs alongside but is separate from the research itself, possibly reflecting the stage which public involvement has reached in its development. This was felt to be problematic, reinforcing the perception that public involvement is an add-on. A comparison was drawn between the perceived status of public involvement in research with the role of statisticians and health economists. A decade ago, it was argued that such methodologists had to 'justify their existence' and would often be recruited to research teams as an afterthought. Today, their inclusion in health research studies is considered as integral. Researchers should be encouraged to regard the inclusion of the public as just as integral to health research as the inclusion of statisticians and health economists.

It was suggested that [research leaders](#) could be encouraged to present a new vision of, and statement about, the importance of evidencing the impact of public involvement in research. The [RAPPORT study](#) was given as an example of public involvement impact assessment being inseparable from the wider notion of impact assessment across the research.

The value of learning from other sectors was also highlighted. There is scope, it was thought, for looking to other areas outside health and social care where public (or stakeholder) involvement and the development of evidence about its impact are assumed and part of normal practice.

### **Assessing the impact**

The group then discussed what kinds of impact should be assessed. While the importance of assessing the impact of public involvement was supported in principle,

there were concerns that a lack of appropriate assessment approaches and methods is limiting the development and range of the evidence base.

As described above, the challenge of assessment was thought to be made more difficult by a lack of information about **who** wants to know **what**. It was suggested that opposing views and values on impact should be acknowledged, and that it was possible that they could be accommodated in assessments and evaluations of impact, and within the evidence base. The Public involvement impact Assessment Framework ([PiiAF](#)) was mentioned as one approach that builds an evaluation process based on identified priorities and values. The PiiAF leads people through a process at the start of a project that helps to identify what is important to each party and develops an evaluation plan based on these priorities. It was noted that the use of such an approach required planning, resources and effort. It was also acknowledged that the time required to carry out public involvement activities properly, including assessment, may be compromised not only by some researchers who do not see its value, but also by potential over-reliance on an existing public involvement team. Examples were given of researchers putting a bid together, then approaching the public involvement team with the expectation that they would independently take care of the planning and implementation of that aspect of the research.

It was mentioned that impact case studies from the [Research Excellence Framework 2014](#) could provide valuable evidence. However, it was also noted that impact research is often led by researchers and therefore reflects researchers' agendas. The concept of co-production was raised, and the degree to which service users are currently involved in shaping the notion of impact was discussed. If this involvement can be identified, it can be assessed. It was also suggested that researchers should develop quantitative as well as qualitative approaches to assessing impact. A further point was made that research can and has been carried out into the impact of involving the public, conducted as a collaborative effort between researchers and service users. Knowledge may be co-produced by a research team working together, and this may be captured through observation and reflection. Other members of the group felt that, in many instances, public involvement impact assessment should be patient-led or designed, in order not to risk losing the evidence that really matters to the public.

Patient Reported Outcome Measures were given as an example of a type of research impact generated from a patient perspective, aiming to capture what matters specifically to patients. However, assessing the impact of public involvement in methodological research can be challenging, as it is more difficult to assess or evaluate the potential longer-term benefits and value.

The group questioned the elements of research which could be evaluated for impact of public involvement, from the research findings to the people involved, through to the services delivered and the change effected. It was felt that some impacts are relatively easy to identify and to assess. For example, in the case of the impact of public involvement in research question generation: the clear impact is the identification of questions which would not otherwise have been raised. However, other impacts, such as culture change and the results of collaboration and synergy that would not have happened without public input, are much harder to capture.

There were also concerns about why some aspects of a research project should be assessed and not others. Some people felt that assessing the impact of public involvement should be a standard part of a wider assessment of the research, rather than a singling out of the impact of one particular perspective of the research team.

### **Capturing the evidence of impact**

Building on the discussions about why impact is being evidenced and what is being assessed, the group also explored the challenges and gaps in capturing impacts.

One major challenge for evidencing impact is thought to be limited knowledge among researchers about the tools available for assessing impact. It was suggested that one barrier to undertaking impact assessment has been the necessary emphasis on qualitative data capture and a lack of confidence around working with experiential knowledge. Ensuring people have the skills to carry out an effective assessment is important, as is the need to develop methods that different stakeholder groups find manageable. It was noted by some that there is very little sharing of methodological approaches and models to measure impact. Work may be happening, but the lessons and the tools are not necessarily being communicated. Linked to this is an inconsistent understanding of how to implement and then evidence the impact of public involvement. The community is still learning and there is a need to collaborate and learn together.

The group believed the terms [‘public involvement’](#), [‘engagement’](#) and [‘participation’](#), as well as the concepts relating to them, are often used interchangeably. There were concerns that this is causing confusion and potentially making future impact evaluation difficult. The existing evidence base is mainly focused on involvement. It was suggested that the research community has responsibility to make these concepts and their differences clearer, and to ensure they understand what they are asking people to do.

It was emphasised that work must be done to identify the impacts of importance to different stakeholders, developing them into evidence bases that are relevant and applicable to the many groups involved. These could include public contributors, researchers, funders, commissioners and journal editors. It was suggested by some members of the group that there is currently patchy evidence on what these groups think public involvement is going to deliver for them, and whether or not it is meeting their expectations.

A number of gaps in the evidence were highlighted. For example, as previously mentioned, the tracking of cultural change within research and health and social care settings, as an impact of public involvement, remains elusive. Some felt that while public involvement may be embedded into the pre-commissioning phase for some research, it is rarely identified, and is therefore lost and not included should an impact assessment be carried out at the end of the research.

In addition, the collection of evidence of public involvement which has not worked or met expectations could be vital for future learning, but is rarely reported. There is also a lack of longitudinal data, starting with pre-commissioning, relating to the

impact of public involvement. It was suggested that longitudinal data collection needs to go beyond the immediate impact of public involvement on the delivery of the research itself and its dissemination.

Researchers have reported on the impact of public involvement on relationships within a research team, as noted in the [PIRICOM](#) and [INVOLVE](#) literature reviews. As researchers become more skilled at involving the public in meaningful ways, it is important to continue to capture how this affects working relationships. Research environments can be hierarchical, influencing how the public may be involved or may perceive their involvement. Again, it was felt that opportunities to learn from other sectors are being missed.

It was reiterated strongly that the concept of public involvement continues to grow within the health and social care research community. This development needs to be accompanied by the imperative to report on impacts and to describe the methods used for assessing those impacts.

### **Concluding comments – the future of the evidence of impact**

The round table discussion brought together a group of knowledgeable experts from the field of public involvement in research. Together they took stock of the evidence base on the impact of public involvement in research and considered its future development. From this some future directions for underpinning the evidence base for public involvement were identified, for both the research community and for INVOLVE and its development of invoNET. These are summarised below:

- Researchers and those working specifically in public involvement should think strategically about what different stakeholders want from public involvement, so the evaluation of those values and potential impacts can be built into research projects from their inception.
- Longitudinal research is needed to follow the research stages and the impacts of public involvement from priority setting and question development through to reporting the findings and beyond.
- It is important that recording and reporting of unsuccessful public involvement activities and of negligible impacts be encouraged, to help create a more open culture of learning among researchers.
- In order to achieve more consistent and coordinated development of the evidence base for the impact of public involvement, there should be greater collaboration, development of capturing impact methods and measurement approaches and active sharing of approaches and methods for public involvement impact assessment.
- INVOLVE should continue to develop its online [evidence library](#) and support the collective responsibility of the research community to assess, report, learn and improve public involvement in research.

### **Endnote**

1. INVOLVE defines public involvement in research as research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them. This includes, for example, working with research funders to prioritise

research, offering advice as members of a project steering group, commenting on and developing research materials, or undertaking interviews with research participants.

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.

For a more detailed explanation of public involvement, how it links to and differs from engagement and participation in research see <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>

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