Report of the invoNET sponsored workshop: What's the evidence for? A critical reflection on the evidence base for public involvement in research

Introduction

invoNET is facilitated by INVOLVE. It is a network of people interested in developing the evidence base on the nature, extent and impact of public involvement in research to increase the awareness of current research and findings, and also to promote shared learning and discussion. It is currently reviewing how best to support those interested in the evidence base and how to broaden awareness of invoNET and the Evidence library.

Following discussions by the invoNET Task and Finish Group at the Summer 2012 INVOLVE Advisory Group meeting and symposium, a workshop was held at the INVOLVE 2012 Conference to debate the evidence base of public involvement in research as well as help inform the shape of future invoNET events and further work.

The workshop was organised to consider:
1. What do we mean by the 'evidence base' on the nature, extent and impact of public involvement in research?
2. Who we are trying to influence with this evidence?
3. What are the purposes of the evidence base on public involvement in research?
4. What is lacking in the existing evidence base in order to fulfil the purposes identified?
5. How can invoNET help build the evidence base?

The workshop was facilitated by Tina Coldham, Louca-Mai Brady and Rosemary Barber with support from other invoNET Task and Finish members -   Jonathan Boote, Jim Elliott, Tara Mistry, Mark Petticrew and Patricia Wilson. Hugh McLaughlin also contributed to the initial development of the workshop outline.

The workshop was well attended and delegates were in the main very enthusiastic about the discussion topics although there was limited awareness of invoNET and what it could offer.

Issues discussed at the workshop

The key questions posed by the workshop facilitators covered:

1. What do we mean by the 'evidence base' on the nature, extent and impact of public involvement in research?

The nature of the evidence about the impact of public involvement was contested, with different stakeholders valuing different types of evidence. Delegates felt that it was important to clarify the evidence requirements of different stakeholders in order to avoid misunderstandings and confusion about the type of evidence that is acceptable. People felt that not all categories of evidence will be understood or accepted by all researchers. In general, there was felt to be a need for greater specificity about what we mean by an evidence base and for more rigorous evidence.

2. Who are we trying to influence with this evidence?

Delegates thought that there were many different types of people who could be influenced by evidence of the positive benefits of public involvement in research. They included: commissioners of research; NHS providers; influential peers who can provide leadership on public involvement, and sceptical researchers as well as researchers in training at the

beginning of their career. People thought that research participants and potential research participants should also have access to this information.

3. What are the purposes of the evidence base on public involvement in research?

Delegates thought that evidence can be useful to convince sceptics, and provide useful information for people new to public involvement, offering examples and sharing good practice. We can also learn about any deleterious effects of patient and public involvement (PPI). By using particular evaluation methods, for example realist evaluation, we could begin to find out more about what works for whom and how. We can also investigate the importance of the context within which public involvement takes place. It is likely that a wide range of people will be interested in the evidence base, including: the public, clinicians, researchers, research funders, service managers and industry. Different stakeholders are likely to value different aspects of the evidence in different ways.

4. What is lacking in the existing evidence base in order to fulfil the purposes identified?

For example, are we looking for evidence of impact on the research, evidence of what does and does not work, or information in relation to particular groups and types of research including social care and health research?

Delegates felt that we are lacking theoretical frameworks that can help to explain how public involvement can work best and guide evaluations. Information about the impact of public involvement should move from descriptions to testing theories using a strategic approach. Key domains on impact might include: the relevance of the research question, research questions generated by the public, where public involvement made a difference to research, impact on the quality of research, and the quality of the participant experience. Aspirations are to move towards implementing good practice underpinned by evidence and to build capacity. The links between research findings and the benefits for users of services need to be strengthened. We need to know if the research made a tangible benefit to services. Little information is available about cost effectiveness and there may be scope to learn from other services about this. If monitoring were to be set up by research commissioning programmes it could provide detailed information about how public involvement, promised in research funding applications, was implemented in research projects and programmes. It would be important to consider how this monitoring data would be appraised and reported, and how any identified issues would be addressed. Delegates stressed the need to ensure accountability to the public by informing them of the difference public involvement in research has made.

5. How can invoNET help build the evidence base?

Discussions during the workshop confirmed the need to raise awareness and increase the use of invoNET. There were also a number of further questions which delegates suggested invoNET now needed to address. These included:

- What type of evidence(s) should invoNET provide access to, and for whom?
- How can - and should - invoNET support the development of theoretical frameworks and a more strategic approach to PPI?
- How can invoNET help to develop approaches to assessing tangible benefits and cost effectiveness of public involvement in research through monitoring and evaluation?

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