

INVOLVE

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

The NHS logo consists of the letters 'NHS' in a white, sans-serif font, enclosed within a blue rectangular box.

*National Institute for
Health Research*

The invoNET logo features the word 'invoNET' in a dark red, sans-serif font. The letter 'o' is stylized with a circular graphic element that overlaps it, suggesting a network or connection.

The impact debate

**An invoNET workshop held on Wednesday
24th February 2010 at the King's Fund,
London**

Workshop Report

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Background

invoNET is a network of people working to build evidence, knowledge and learning about public involvement in NHS, public health and social care research. invoNET workshops offer network members an opportunity to share information on building the knowledge and an evidence base for public involvement in research. More information about the network and previous workshops can be found at:

www.invo.org.uk/invoNET.asp

The aim of the workshop was to provide an opportunity to network and share information on the **impact** of public involvement in research. 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.

Programme

The day was chaired by Alan Simpson, Senior Research Fellow and Lecturer in mental health in the School of Community and Health Studies at City University London.

The day started with a half-hour networking session called 'Speed Introductions'. Delegates were given the option to speak for a maximum of a minute, to say something about themselves, their organisation and/ or the issues which interested them.

In the rest of the morning session there were three presentations, each followed by plenary discussions. Two of the presentations discussed recent research into the impact of involvement and one discussed the impact of involvement in research in a Primary Care Trust.

In the afternoon, people split into smaller groups to reflect on the discussions from the morning session and to identify questions for an expert panel. The small groups were pre-selected to ensure that each table had a balance of different types of delegate.

Delegates

The workshop was attended by 45 delegates. People came from many different research settings including higher education research institutions, NHS research groups and networks, specific research projects, research charities, national NHS policy and commissioning organisations and independent researchers.

A full list of workshop delegates is included in **Appendix 1**.

Introducing the day

Sarah Buckland, Director of the INVOLVE Coordinating Centre welcomed everyone to the workshop and reminded people of the purpose of invoNET which is to:

- Share, strengthen and disseminate the knowledge base of public involvement in research
- Facilitate discussion of research into public involvement in research
- Increase awareness of current research and research findings
- Encourage collaborations between those involved in undertaking research in this field

She also emphasised the importance of networking and encouraged delegates to make the most of an extended lunch break to meet other people and exchange ideas.

Morning presentations

Kristina Staley from TwoCan Associates, shared her reflections based on her experience of working on INVOLVE's *Exploring Impact* report¹. She focused on the issues around reporting on impact and publishing articles about impact in peer reviewed journals. Her main points were:

- there is very limited reporting of impact in the literature
- the articles that do describe impact typically lack detail and are limited in scope.

She also identified potential barriers to writing about impact within the academic culture and within the traditional format of publishing research results. Some suggestions for tackling these issues included encouraging researchers to write about the impact of involvement separately to their research findings, developing guidance for researchers on how to write about impact and the different kinds of impact that can be assessed, and finally, thinking about how best to encourage and motivate researchers to report on their experiences of involvement.

The discussion that followed raised a number of points including:

- Whether reporting about involvement separately from research findings would run counter to the aim of embedding involvement in research and making it an integral part of 'how research is done'.
- The importance of involving service users in writing up research and describing the impact of involvement.
- Finding more creative ways to disseminate findings about research and the impact of involvement – and the current limitations because funders don't provide money for dissemination.
- The value of involvement throughout a research project – as it stops us asking the wrong questions and stops us wasting money.

- The importance of involving service users in bid development and the problems because of lack of funding available for this development work.

Rosemary Barber, Honorary Senior Research Fellow at the University of Sheffield, discussed some of the findings from her recent Delphi study², carried out with colleagues Jonathan Boote, Glenys Parry, Cindy Cooper, Sarah Cook and Philippa Yeeles. This study asked the question '*Is it feasible to evaluate the impact of public involvement in research?*'. The people who took part in the Delphi panel included a wide range of experts with knowledge and experience of involvement in research. The panel concluded that it is feasible to evaluate the impact of involvement on:

- Identifying and prioritising topics to be researched
- Disseminating research
- Key stakeholders: members of the public involved and the research team members

However the panel did not conclude that it is feasible to evaluate the overall impact of involvement on research, nor the impact of involvement on:

- Commissioning research
- Research design
- Managing research
- Collecting data
- Analysis and interpretation of research findings
- Determining the usefulness of research findings
- Implementing findings
- The overall quality of the public involvement
- The overall quality of research

The discussion that followed raised a number of points including:

- The differences in views between service users and researchers – service users were more optimistic in some instances, considering assessing impact to be more feasible.
- Surprise at the limited areas of involvement considered feasible for evaluation of impact.
- The importance of understanding and unpicking the reasoning behind the views expressed.
- Whether the conclusions were considered to be applicable to all types of research.
- The different kinds of methods for evaluating impact and which methods might be 'good enough' in terms of providing evidence of impact. There was some support for a qualitative approach – finding out the views of the various stakeholders involved.
- The challenges and limitations of a Delphi exercise.

Rose Clacy, member of the Nottingham Primary Care Consumer Research Advisory Group, and **Jane Stewart**, former lead for patient and public involvement (PPI) in primary care research NHS Nottinghamshire County, presented their perspectives on the impact of consumer involvement in primary care research.

Some of the main points they raised were:

Involvement at the beginning of a study:

- The value of involving users early on in the development of research because this helps to lead to better research. Although it may take more time, it saves time in the end by preventing poor research from being carried out. If service users are not involved at this stage, the potential for impact is more limited.
- The value of sharing the lessons from user involvement – researchers should be encouraged to share their learning so as to improve any subsequent studies.
- User involvement can bring projects to a grinding halt – sometimes for very good reasons if this leads to improvements – but sometimes for the wrong reasons, for example if people’s behaviour in meetings is inappropriate or difficult.

Involvement in the middle of a study:

- The value of involvement in improving all written material including material used to recruit participants as well as questionnaires, interview schedules etc.
- The value of training researchers who are uncertain or lack confidence around involvement – providing them with support can ease them in gently and lead to greater levels of involvement.
- Researchers can feel taking on involvement creates ‘another layer of pressure’ – particularly because it demands so much time. However, when done well, involvement can also give researchers greater confidence that their work is of high quality.
- Service users can have more freedom than researchers to speak up about concerns and offer constructive criticism – they can challenge senior people without being ‘in fear of losing their jobs’.
- Being involved can sometimes feel like a full time job for the service users involved, and demands on their time can be high. It is therefore important that both parties are clear as to where to draw the line.

Involvement at the end of a study:

- Involvement adds value to the analysis of qualitative research and to interpreting the results of any quantitative analysis.
- Service users can feel cut off at the end of a study, particularly if they are not involved in the writing up of the results.

The discussion that followed raised a number of points including:

- How to fund a 'consumer research panel'. The Nottinghamshire example was initially funded by pooling budgets across a number of GP practices that were all active in research. It thus became the 'Nottingham Primary Care Research Partnership' and was subsequently funded by Department of Health (DH) NHS Research and Development funding and hosted by NHS Nottinghamshire County. Since the DH funding is no longer available, the panel has been supported by the Primary Care Trust.
- Managing 'difficult' service users. It can help to hold pre-meetings with service users so that they can sharpen up their questions prior to the main meeting. It is also important to recognise that some people simply do not work well in meetings – and may need to be involved in different ways.
- The value of asking service users to write lay versions of the findings of research, to make them more accessible to a wider audience.
- The value and importance of involving a diverse range of users.

Afternoon session – Questions to an expert panel

The delegates got together in small groups to discuss the issues raised in the morning session and to bring their own experiences to the discussion. They were also asked to develop three questions to take to an expert panel to ask for their views and encourage further debate.

The expert panel included both service users and researchers with experience of involvement. It was run in a 'Question Time' format, chaired by Alan Simpson. The audience were also given opportunities to contribute to the debate.

The expert panel consisted of the following people:

Tina Coldham	User researcher, trainer and consultant in mental health research and mental health service user/ survivor.
Jim Elliott	Research Adviser at Macmillan Cancer Relief
Alison Faulkner	Freelance researcher, trainer and consultant in mental health research and mental health service user/ survivor.
Sian Maslin – Prothero	Dean of the Graduate School and Professor of Nursing at Keele University, Associate Editor of Nurse Education Today
Sophie Staniszewska	Senior Research Fellow at the Royal College of Nursing Research Institute, University of Warwick.

The full list of questions put forward for the panel included:

- How can we ensure implementation and monitoring of research findings where there has been public involvement?
- How can public involvement be mandatory for all research proposals – to make genuine involvement happen?
- How do we get people from minority, ethnic and religious and cultural groups involved in research?
- How do we stop people doing public involvement badly?
 - What's bad?
 - What's good?
 - What's good enough?
- What tips do the panel have for tactics to overcome academic culture and professional egos in committees/ meetings?
- National Institute for Health Research (NIHR) should provide a journal to publish impact of public involvement in studies? Will academics be able to include this in the Research Excellence Framework?
- What investment is being made to educate students about public involvement? To embed public involvement at an early stage.
- Are there any impact issues that unite all groups – funders, researchers, users?
- Which of the following do the panel think is more important for research funders to implement:
 - Monitoring and auditing of public involvement in projects
 - Production of a lay report produced by the public/ patients involved
 - A concurrent evaluation of the impact of involvement
- Who would you least like to be in an involvement exercise with?
- What carrots could be used to make researchers more interested in public involvement?
- Does the panel have any suggestions for better sharing of our knowledge about public involvement?
- Does the panel think that it is possible for 'lay' people to re-educate professionals on class and cultural issues?
- Should we be reporting public involvement separately or should it be embedded in the research report?
- Monitoring the impact of public involvement – how can this be done effectively?

In the time available, it was only possible to ask the panel a limited number. The questions asked and a summary of the panel's responses are listed below.

How can public involvement be mandatory for all research proposals to make genuine involvement happen?

Make public involvement a criterion for funding:

- It needs to start with the research funders making public involvement one of the criteria for funding. Funding committees should decide that applications with poor public involvement should not be funded. Reviewers therefore need to be skilled and equipped to judge the quality of public involvement in research proposals and be able to spot when involvement is purely a tick box exercise.
- When researchers become aware that funding is conditional on good quality public involvement, they will take it more seriously. However, there may need to be more follow up to check that any proposals for involvement are carried out in practice – to check that researchers are not just 'good at filling in forms'. One way to do this would be to ask that annual progress reports are accompanied by a short report from one of the service users involved, describing their involvement and its impact.
- Are funders willing to do this? There was some doubt that even the funders who are most supportive of public involvement would be willing to go as far as making public involvement a criterion for funding. However others were hopeful, given that bigger and unexpected changes have already happened.
- The process will require cultural change, which takes a long time and requires both top down and bottom up approaches to be combined. We need to learn from change management and behavioural change research about how to make change happen. At the moment, public involvement is being taken forward by the early adopters, while the majority of people are open minded at best and sceptical at worst. Change will happen gradually – we need to recognise that even the smallest changes now represent big steps forward.

Provide pre-application funding to support involvement

- Funding is needed to involve people at the proposal development stage. Some research groups/ university departments have been willing to invest in this type of involvement, either by pooling bits of money from other bids or by making this part of a bid for a programme grant. This has enabled researchers to set up long standing user involvement groups who are then available to help with a range of different projects at a number of different stages.
- One example of this type of user group meets monthly to discuss all the research projects that are currently underway in the department. Part of the meeting involves capacity building, developing the group's knowledge of the research process. This is essential to improve their skills. The researchers find the group invaluable and that it doesn't cost very much money.

- This approach needs investigators who genuinely believe that involvement will make a difference and so are willing to invest in it.

Does the panel have any suggestions for better sharing of our knowledge about public involvement?

Getting better at sharing our experiences

- People don't look in the right places for information about public involvement. There's masses of information in the grey literature and we need to help people find it.
- Get researchers who are doing involvement to talk to their peers about their experience of involvement – they will be able to explain how it can benefit research and provide a model for others to follow.

Encourage the students of today who will become the researchers of tomorrow

- Students are the people to influence, the people to work with at this point. Some people have found students very willing and able to take up the messages about involvement. Having heard about involvement, many students have worked with service users to develop their post graduate research.

Becoming more proactive about change

- We need to be more active about tackling change in the research culture. We need to change the goal posts. A lot of the current involvement is about keeping the existing structures quite safe, keeping the way research is done and funded the same. We need to blow it apart and make it different.

What carrots should be used to make researchers more interested in public involvement?

Help researchers see the link between involvement and good quality research

- What often makes research exciting for researchers is the potential for their research to make a difference and to improve people's lives. Researchers need to understand that if they involve people in their research, it makes it more likely that their research will have an impact. This doesn't seem to be immediately obvious to researchers, and they need to be able to really feel that.
- One way to encourage researchers to focus on the impact of their research is to ask them to describe what they will do with their findings as part of their funding application. If their research is genuinely going to benefit patients, then it should be easy to explain how the findings could bring about improvements for service users.
- Researchers also need to be made aware that public involvement can offer them a way to enhance the way their research is carried out – for example by improving the design of questionnaires. This could be a helpful way to change mindsets.

The research evaluation framework (REF)

- The REF is replacing the research assessment exercise (RAE) and will have a big influence on researchers. It will become the way that researchers are assessed in terms of outputs and will influence decisions about their future funding. The REF asks researchers to write a statement about the difference their research is making i.e. how it's having a wider impact. Involving the public in their research will enable researchers to make stronger and more robust statements about impact, gaining credibility in the REF. The REF can thus become an effective means of encouraging involvement. However, the REF was under development at the time of the meeting, and there was some debate as to whether the final format would encompass the kinds of social impact achieved through public involvement.

Create a demand for public involvement through journals

- Journal editors could provide guidance to researchers on how to report on public involvement in their journal. They can encourage submission of articles that describe involvement through special issues focusing on involvement, and editorials that discuss involvement.
- Any guidance for authors needs to be very specific. It needs to ensure that researchers describe how the involvement was carried out and what difference it made. Peer reviewers would then need to assess whether an article provides sufficient information about the quality of the involvement and its impact. This is important to make the learning about involvement more visible. A lot of good involvement is happening, but it's difficult to find out about it.
- If the National Institute for Health Research (NIHR) were to develop a journal to publish findings from the research it funds, public involvement could be made a condition for publication.
- All journals should encourage joint authorship of articles where there has been public involvement, as this will give the research greater credibility, and keep the findings real and grounded, i.e. more accessible to a lay audience.

Make it part of staff appraisals

- Public involvement can be one of the skills/ achievements assessed through staff appraisals – this also requires that the organisation put in support structures to help researchers involve people.

Recognise and address researchers' fears

- One of the biggest threats from involvement is the loss of power. We need to recognise these fears and address them honestly.

Who would you least like to be in an involvement exercise with?

- Someone who is there because they are a big name, but doesn't make any contribution.
- Someone who won't work collaboratively. They become impossible to work with whether they are researchers or service users. Involvement can become an emotional labour when it doesn't work well.
- Involvement can often come down to simple face-to-face negotiation between a researcher and a service user. This can also be an emotional experience. The difference is that service users can't help but bring their life into that discussion. They are there because they have a life experience and knowledge of a condition. The academic does not do that at all and in the worse case, can simply play devil's advocate as part of an abstract, theoretical discussion. Researchers are used to stepping back from the real world, but service users can't necessarily do that.

What tips for tactics do the panel have for overcoming academic culture and professional egos in committees?

- One of the most important skills is listening, and affirmation of other people's perspectives, saying 'I can see where you're coming from'. This helps to establish a connection and trust. If you then make a point in that context, it is more likely to be heard. If you make a point in a way that's threatening, it won't be heard. You need to choose your tactics – researchers can be scared of users too.
- Use humour as a way to engage people and bring them round.
- Select a good chair, brief them well and ensure they are working within a strong policy framework that governs the way the committee is working and can hold them to account. There are new guidelines for chairs on how to support public involvement in a committee⁴.
- From a service user perspective, having more than one service user involved helps to boost your confidence. If you have to face these barriers alone, then you may choose to take your energy elsewhere and abandon the project.
- Ensure the group has clear terms of reference and has agreed a way of working together. This requires thinking about the power dynamics and addressing them.
- As a lay person, you may need to start thinking strategically. You may get chewed up and spat out a few times and maybe vote with your feet in those situations, but don't be put off as a punter and keep putting your point across.
- Remind professionals that they are patients too.
- Academics and clinicians have a duty to lay people to make sure they are properly informed and supported so they can make a full contribution to meetings. This can simply involve getting meeting papers to them in advance, and holding pre-meetings to prepare them ahead of time.
- Have someone else take on the tasks you find difficult – to help share the load.

References

1. Staley K. (2009) *Exploring impact: Public involvement in NHS, public health and social care research*. INVOLVE, Eastleigh.
2. A journal article has been submitted and is currently undergoing peer review.
3. Nickeas R. and Stewart J. (2010) *Developing Consumer Involvement in Primary Care Research: Final Report of a developmental evaluation* (forthcoming). Will be available to download at: www.rdnottspct.nhs.uk
4. TwoCan Associates for the UKCRC and NCRI (2010) *Patient and public involvement (PPI) in research groups – Guidance for Chairs*. Available to download at: www.twocanassociates.co.uk/pdfs/GuidanceForChairs2.pdf

Terms used

Delphi

A method for obtaining agreement amongst a group of people. The group are sent a series of questionnaires and given controlled feedback on other people's responses. This process continues until an agreement is reached.

INVOLVE

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

National Cancer Research Institute www.ncri.org.uk

NIHR

National Institute for Health Research www.nihr.ac.uk/Pages/default.aspx

RfPB

Research for Patient Benefit funding programme, National Institute for Health Research
www.nihrccf.org.uk/site/programmes/rfpb/default.cfm

RAE

The Research Assessment Exercise is an exercise to evaluate the quality of research in UK higher education institutions. This assessment informs how funding is distributed by the UK higher education funding bodies.

REF

The Research Excellence Framework is the new system for assessing the quality of research in UK higher education institutions. It will replace the Research Assessment Exercise.

UKCRC

UK Clinical Research Collaboration www.ukcrc.org.uk

Appendix 1: Delegate list

Name	Organisation (if applicable)
Aranda Kay	Research Design Service South East
Rosemary Barber	Sheffield Health and Social Care NHS Foundation Trust/University of Sheffield/INVOLVE Group member
Sue Beatty	Oxford NIHR Biomedical Research Centre
Sue Boase	General Practice and Primary Care Research Unit, University of Cambridge
Sally Brearley	National Nursing Research Unit, King's College London
Sarah Buckland	INVOLVE Coordinating Centre
David Buglar	Social Science Research Unit
Pamela Carter	Keele University
Rosemary Clacy	
Tina Coldham	
Tina Cook	Northumbria University
Barbara Dawkins	INVOLVE Coordinating Centre
Jim Elliott	INVOLVE Group member
Angela Evans	Swansea University
Alison Faulkner	INVOLVE Group member
Andy Gibson	Peninsula Medical School
Julie Grant	University of Cambridge
Malcolm Harrison	
Helen Hayes	INVOLVE Coordinating Centre

Margot Holmes-Smith	Centre for Research in Primary and Community Care
Poonam Jain	INVOLVE Group member
Clare Lavis	NIHR Evaluation, Trials and Studies Coordinating Centre
Martin Lodemore	Diabetes Research Network
Sian Maslin-Prothero	Keele University
Geraldine Mason	NIHR Mental Health Research Network FACTOR – Families/Friends and Carers together in research
Alex Mendoza	Centre for Research in Primary and Community Care Hertfordshire University
Diane Munday	Centre for Research in Primary and Community Care Hertfordshire University
Mary Nettle	INVOLVE Group member
Carey Ostrer	
Raksha Pandya	Research Design Services for the East Midlands
Rachel Purtell	Folk.us
Rebecca Rees	Social Science Research Unit, Institute of Education
Asmina Remtulla	
Jacqueline Romero	Patient and Public Involvement in Research NHS Norfolk
Ann Seymour	British Paediatric Surveillance Unit
Alan Simpson	School of Community and Health Studies
Lucy Simons	INVOLVE Coordinating Centre
Patsy Staddon	University of Plymouth
Barbara Staffa	NHS Norfolk
Kristina Staley	TwoCan Associates

Sophie Staniszewska	INVOLVE Group member
Jane Stewart	Nottinghamshire County PCT
Ruth Stewart	Social Science Research Unit, Institute of Education, London
Maryrose Tarpey	INVOLVE Coordinating Centre
Sam Taylor	NIHR Clinical Research Network Coordinating Centre
James Walker	Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust

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