Exploring the impact of public involvement on the quality of research: examples

July 2013

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Contents

> **This report should be referenced as**:
>
> INVOLVE (2013) **Exploring the impact of public involvement on the quality of research: examples,** Eastleigh:INVOLVE

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About this project

This project aimed to explore the views and experiences of researchers in relation to the impact that public involvement has on the quality of their research.

INVOLVE has long been interested in gathering evidence about the impact of public involvement on research. In 2005 INVOLVE established invoNET (www.invo.org.uk/invonet/about-invonet/) as a network for researchers and others interested in developing evidence and learning about the impact of public involvement on research. In 2009 INVOLVE commissioned a report (Staley, 2009[1]) reviewing the evidence on impact and from June 2012 to April 2013 INVOLVE Group members formed a Task and Finish Group to help develop future resources for invoNET as well as consider its future direction.

Linked to the remit of this group, INVOLVE commissioned the six examples accompanying this report. They were gathered from invoNET members, exploring their views on the impact that public involvement has on the quality of their research.

This project was funded by INVOLVE. The work was carried out by Alison Faulkner from January to April 2013 with support from Maryrose Tarpey and Helen Hayes from the INVOLVE Coordinating Centre and Tina Coldham and Rosemary Barber (chair and vice-chair, invoNET Task and Finish Group) who provided ongoing project advice and detailed comments throughout.

Other members of the invoNET Task and Finish Group: Jonathan Boote, Louca Mai Brady, Ann-Louise Caress, Jim Elliott, Hugh McLaughlin, Tara Mistry, Mark Petticrew and Patricia Wilson were involved in the design of the project.

Overview

The evidence that we have to date suggests that public involvement can make positive contributions to research (Brett, 2010[2]). The structured literature review of the evidence funded by INVOLVE in 2009 (Staley, 2009[3]), reported that public involvement in research can influence the research topics and direction of research, project design and methods, recruitment and data collection, analysis and dissemination. Public involvement can also positively impact on the people involved in the research. The report concluded that the strongest evidence available indicates that public involvement:

- can help increase recruitment to all types of research;
- is of particular value in qualitative research where participants are asked to share their views and experiences;
- is of particular value in clinical trials where it can help to improve trial design and ensure the use of relevant outcome measures;
- benefits the people involved as well as the research participants.

The author makes a plea for 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; and helping researchers and the public to find the most useful ways of telling the 'story of involvement'. A similar recommendation was made by the authors of the 2010 systematic review which they followed up by proposing a 'GRIPP' checklist for reporting involvement (Staniszweska, 2011[4]).

The examples

In this piece of work, we asked six researchers to tell their stories of involvement and its impact on research quality. All were members of invoNET. They offered a range of different perspectives on public involvement in research, and described quite different approaches to research. The six researchers were interviewed over the telephone using a Topic Guide (see Appendix A). The questions aimed to ascertain the degree and nature of public involvement in each project, and the researchers' reflections on how and in what ways they felt that public involvement had influenced the quality of their research.

The researchers interviewed about their research were:

1. Jonathan Boote: the PLEASANT study: Prevention and Lessening Exacerbations of Asthma in School-age children Associated with a New Term - a cluster randomised controlled trial involving school-age children and their parents/carers (2012 to date).
2. Ann-Louise Caress: Working with a service user reference group of people with lung conditions (on-going).
3. Tina Cook: Towards Inclusive Living: participatory action research with people with neurological conditions, their family and carers (2008-10).

4. Patsy Staddon: Improving Support for Women with Alcohol Issue': user controlled research (2011-13).
5. Sophie Staniszewska and Jo Brett: The POPPY (Parents of Premature Babies) project: research involving parents of premature babies (2009).
6. Jill Thompson: PhD on public involvement in the National Cancer Research Network (2010).

The impact of public involvement on research quality

The underlying motivation for involving members of the public in research is informed by broad democratic principles of citizenship, accountability and transparency (INVOLVE, 2012[5]). Public involvement in research can lead to empowerment for people who use health and social care services, providing a route to influencing change and improvement in issues which concern them most.

Alongside this principled approach to involvement is the belief that public involvement also leads to better quality research: research that is more relevant, accessible and acceptable to participants, and which, by incorporating the perspectives of those who are on the receiving end of the services and treatments under scrutiny, leads to better practical outcomes.

However, there has been little evidence to support this position until recently, and there is no consensus about what good quality research might mean. Indeed, it is clear that some researchers believe that involving members of the public in their research will compromise its quality, leading, amongst other things, to extra cost and time and potentially difficult negotiations.

When asked about the quality of research, the researchers we interviewed generally began by drawing upon conventional means of assessing research quality such as the importance of appropriate methodology, robust and rigorous methods, the validity and reliability of the research and of the measures or instruments used. For example, Ann-Louise Caress and Sophie Staniszewska conceptualised quality in research in terms of:

- the rigour of research: appropriate methodology, rigour of methods, reliability and validity; and
- the content of the research, its relevance and meaning, uptake and use.

They both discussed how public involvement could contribute to both of these elements, and agreed that we do not have a way of including public involvement within the framework of assessing research quality. Sophie Staniszewska suggested that we need a new language to describe the contribution of public involvement to research quality. She coined the term 'community validity' to refer to the way in which public involvement can contribute to the content validity of, in this case, the development of Patient Reported Outcome Measures (PROMs). For Sophie, community validity becomes 'an assessment of the relevance,

comprehensiveness, and appropriateness of [PROM] content, as judged by the public when collaboratively involved'(Staniszewska, 2012[6]).

The interviews suggest that if we were to become more astute about expressing the contribution of public involvement to research quality, there would be more evidence of its role and value, which in turn would lead to additional reporting and evidence of its impact. However it is important to note that whilst public involvement in research can have significant impact , as is evident from the examples explored in this report, it can also lead to 'colliding worlds' (Faulkner, 2004)[7] when things go wrong. Without the bridge formed by good relationships, the different worlds of academic researcher and patient or service user can clash over different priorities, needs and opinions.

Themes from the examples

The six examples gave rise to the following themes in relation to the impact of public involvement on the quality of research:

- The relevance of the research topic;
- The design of the study;
- Data collection;
- Analysis and interpretation of findings;
- The implementation of research;
- Relationships and legacy.

The relevance of the research topic

All six of the researchers we interviewed agreed that involvement enhanced the relevance of research questions and topics, and that relevance is (or should be) a significant measure of the quality of research. Relevance can be significant for a number of reasons: if the research is seeking to answer a question that is meaningful to the patient community, it may mean that the research is more likely to be implemented in practice. Relevance can result in the research being more likely to garner public support for research, which may become increasingly important in the current economic climate but may also lead to higher levels of engagement and participation in the research. Ann-Louise Caress argued that if the topic is more meaningful to service users, the output is more likely to be implemented; she made a direct link between the relevance of the topic and the potential impact of research.

Relevance was a powerful motivation for Patsy Staddon to identify a valid and useful service response to alcohol problems for women. For Jill Thompson, a fundamental aspect of research quality is its relevance to the stakeholders and the audience for whom it is intended. In her example, public involvement ensured that the direction of the research was relevant to the lay panel's concerns and hence contributed to the shared knowledge about public involvement.

Design of research

All of the examples involved members of the public from the start or as an integral part of the design stage. There were several ways in which the researchers felt that public involvement improved the quality of the research design: identifying themes for questionnaires or interviews; helping to word the questions; and practical aspects of the research process such as lessening the burden on research participants.

Personal knowledge of the health condition or disability meant that members of the public could advise researchers about these issues. Jonathan Boote described the parents and children in the PLEASANT study advising researchers about when to send out approach letters to parents, the wording of the letters and who to send them to. Ann-Louise Caress described her user reference group as 'absolutely instrumental' in contributing topics to, and helping to phrase, the questionnaire in her study. As an example, the researchers were reticent about asking questions about death, but the user reference group felt strongly that these questions were important and should be asked.

Data collection

In several of the studies, data collection was improved indirectly through the improved research design (see above). In two of the examples, service users had a direct impact on data collection as they were involved in the interviewing. Both Patsy Staddon and Tina Cook reported that having service users or carers as interviewers made a significant difference to the quality of the interviews. The women in Patsy Staddon's study immediately trusted her as an interviewer and shared very personal information with her, in many cases for the first time. Several of the women told her that they had never shared certain information with anyone else before – that it made a difference to them that she had similar personal experience. Tina Cook felt that service users could ask more direct and searching questions of each other than she would feel able to do as a researcher. When interviewer and interviewee shared common experience there was a greater likelihood of more in-depth discussion of key issues.

Analysis and interpretation

People often talk of the potential for public involvement to influence research at the analysis and interpretation stages but it is not often reported. Jonathan Boote was of the view that there should be greater emphasis on involving people in interpreting the findings from the patient point of view.

Tina Cook's participatory action research (PAR) study[8] involved service users and carers in what she referred to as a 'recursive' analysis of the findings: this means taking the findings back to participants and involving them in the process of refining the analysis and interpretation through a number of reiterations. In Jill Thompson's research, the lay supervisor analysed some of the transcripts and these findings were checked back with the lay panel, which strengthened the credibility of the findings. In Patsy Staddon's study, both

of the service user researchers took part in the analysis and felt that this was uniquely informed by their direct experience. For Sophie Staniszewska, the impact of parents on the POPPY study was highly significant at the analysis stage when the model of care was developed; the involvement of parents brought about a realignment in the philosophy of care, putting the family at the centre of care in neonatal units (POPPY Steering Group, 2009[9]).

Implementation and impact of research

Most of the researchers interviewed talked of the contribution public involvement can make to the implementation of research findings, with a clear link back to its relevance to the patient and service user community. Sophie Staniszewska expressed the view that research implementation is an area with huge and largely untapped potential for public involvement to have an impact. Health professionals are themselves challenged by the implementation of research; the different networks brought by members of the public can open up new channels for implementation and impact. This may rely upon them being members of groups or voluntary sector organisations with an interest in the research topic and resources for dissemination, but they may also reach more people via social media, presentations at conferences, and accessible summaries of the findings.

Ann-Louise Caress suggested that the debate about public involvement in research needs to move away from looking at the impact of public involvement on rigour to addressing the impact agenda far more broadly, in line with the Research Excellence Framework (REF) [10] which now includes impact in its assessment. Public involvement can help us to make the link between the meaning or relevance of the research topic to service users, and the likelihood of the output taken up in practice – or at least, disseminated more widely and through channels that might engage further support for it. For Jill Thompson, the service users involved in her PhD research have been instrumental in continuing to disseminate the research long after it finished.

Relationships and legacy

For some of these examples, relationships were fundamental to the quality and success of the research. For Tina Cook, key to the research process was the building of relationships: listening to and respecting each other's views and being able to critically discuss the issues. Although some arguments took place, these were ultimately resolved through the relationships within the group, with new and unexpected understandings being the outcome of that critical debate. Fundamental to the quality of Jill Thompson's research was the quality of the relationships that developed with the service user group.

Jill suggested that if you are doing good public involvement in research, then you inevitably develop relationships with those involved. This can be difficult, in that it can introduce an emotional element if you are working with people who are experiencing chronic or

deteriorating health, but is essential for the success of the process. Both of these researchers point to the fundamental link between the quality of the relationships formed through public involvement and the quality of the research.

In conclusion, this small piece of work is intended to contribute to our thinking about how we report on the impact of public involvement on research quality. In the following section six researchers, all invoNET members, describe the public involvement in their research and reflect on how and in what ways they think that the involvement impacted on the quality of their research.

We hope that these examples not only illustrate the specific context within which public involvement in research is situated, but also contribute to a more generalisable understanding of the impact of public involvement on research quality.

Alison Faulkner
June 2013

References

[1] Staley K (2009) **Exploring Impact: Public involvement in NHS, public health and social care research**. Eastleigh: INVOLVE.

[2] Brett J, Staniszewska S, Mockford C. (2010) **The PIRICOM Study. A Systematic Review of the Conceptualisation, Measurement, Impact and Outcomes of Patient and Public Involvement in Health and Social Care Research,** London: United Kingdom Clinical Research Collaboration.

[3] Op Cit., Staley K. (2009).

[4] Staniszeweska S, Brett J, Mockford C, Barber R. (2011) **The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research,** Intl. J. Technology Assessment in Health Care 27:4

[5] INVOLVE (2012) **Briefing Notes for Researchers: public involvement in NHS, public health and social care research**, Briefing Note Three, p8. INVOLVE, Eastleigh

[6] Staniszewska S, Haywood K L, Brett J and Tutton L. (2012) **Patient and Public Involvement in Patient-Reported Outcome Measures: Evolution Not Revolution**, The Patient 3 D Eizo 5 (2), 1-9.

[7] Faulkner A (2004) **Capturing the experiences of those involved in the TRUE project: A story of colliding worlds,** Eastleigh: INVOLVE

[8] Winter & Munn-Giddings (2001) **A Handbook for Action Research in Health and Social Care**, Part 1 Ch 2, Routledge New York define Participatory Action Research (PAR) as 'the study of a social situation carried out by those involved in that situation in order to improve both their practice and the quality of their understanding'.

[9] POPPY Steering Group (2009) **Family-centred care in neonatal units. A summary of research results and recommendations from the POPPY project**. London: National Childbirth Trust. Link to the research report: www.poppy-project.org.uk/resources/Poppy+report+for+PRINT.pdf

[10] The **Research Excellence Framework** is the successor to the Research Assessment Exercise, a method of assessing the research of British higher education institutions. It will take place in 2014 to assess research that has taken place during the period 2008–13 inclusive.
REF 2014 defines impact of research as: 'any effect on, changes or benefits to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia' (www.ref.ac.uk)

The examples

1.   Jonathan Boote, the PLEASANT study

Jonathan Boote is a Research Fellow at the National Institute for Health Research (NIHR) Research Design Service for Yorkshire and the Humber with particular responsibility for patient and public involvement. He has been involved in a programme of research on patient and public involvement in health research at the University of Sheffield for the last 10 years.

The research project

Jonathan gave the example of the PLEASANT trial - 'Prevention and Lessening Exacerbations of Asthma in School-age children Associated with a New Term'. This is a cluster randomised controlled trial (RCT) funded by the NIHR Health Technology Assessment programme. The background to this study is that statistics show a peak of asthma problems in school-age children, aged four to sixteen, on return to school after the summer holidays. To help address this, the aim of the study is to trial sending a letter from GPs to parents to remind them to prepare for school in September by ensuring that they have sufficient medication. The study has just started with funding for £500,000.

Public involvement in the research project

Public involvement took place at the design stage of this project. The research team held a consultation event with children and parents/guardians in January 2011 prior to getting funding. The event resulted in the following:

1. There was a lot of support for the idea for the project, which the researchers could then use in the application to show that it was endorsed by people with the condition.
2. Discussion with both parents and children resulted in agreement that the letter itself should go to the parent or guardian rather than the child.
3. The wording of the letter was significantly changed. The original was quite long and complicated – it was refined and simplified at the meeting. Of particular importance was the opening paragraph which now starts 'Please read this important letter about your child's asthma' in bold to get their attention.
4. The timing of the intervention was discussed and it was agreed that the letter should go to parents two weeks after the beginning of the holidays.
5. The children also chose the logo for the project.

A second event was held when the funding was awarded to update the parents, to discuss changes to the letter, and to contribute to the lay summary of the Research Ethics Committee submission. Two parents were invited on to the Trial Steering Committee.

There will be another consultation event at the end of the study to present the findings, to discuss the interpretation of the data, and to produce a lay summary of findings.

The research is clearly 'researcher-led' but with significant public consultation at key points.

The impact of public involvement on the research

The input of the parents and children helped to shape the intervention for the study, and helped the researchers to justify the research. Essentially, public involvement in this study helped to maximise the impact of the intervention itself: the wording of the letter, who to send it to and the timing.

The impact of public involvement on research quality

Jonathan believes that public involvement improved the quality of the study – it made it 'a better piece of work'. Public involvement made the intervention stronger and therefore more likely to have an impact on the parents who read the letter, which should lead to better outcomes for the research.

In order to maximise the implementation of the research, the team aim to get Asthma UK on board to launch the study findings. They also plan a second wave - a shadow trial to see how the intervention rolls out in practice: this will be called PLEASANT 2.

Jonathan's reflections on public involvement and research quality

Quality should be about making sure that research questions are addressing something of importance to patients, ensuring that the questions have impact. Quality lies in the fact that the design and methods are as good as they can be to address these questions. For example, public involvement can have a key role in helping to decide upon the content of the control arm for an RCT or to ensure that the data collection methods will not be unnecessarily burdensome on study participants.

Members of the public can also contribute to data collection and analysis. Jonathan thinks there should be greater emphasis on involving people in interpreting the findings from the patients' point of view.

At the end of a project, members of the public can contribute to thinking about how the findings can have the greatest impact: for example, reaching more people via relevant charities, social media, presentations at conferences, and accessible summaries of the

findings. They could also, for example, feed into the James Lind Alliance (www.jla.nihr.ac.uk) to identify ideas for further research.

Jonathan is concerned about the push for public involvement to be focused primarily on improving recruitment to clinical trials, for example, improving the wording and persuasiveness of information sheets to maximise recruitment. This is not a definition of quality, in his view. It is important to have this debate about the impact of public involvement on research quality.

Other comments…

It was a lot of fun. He really enjoyed it, and they have named the parents and children on the website as contributors, which gives possible personal development for them.

Jonathan is also interested in legacy: the impact of public involvement can be longer term, beyond the writing of a report or publishing a journal article. He referred to a study with Tina Cooke (see example 3, p18-20) looking at a repository for life stories of public involvement, and other longer-term impacts of participatory research studies.

Further information

The PLEASANT website is: www.shef.ac.uk/scharr/sections/dts/ctru/pleasant and includes information about the public involvement in the development of the study

The protocol for PLEASANT can be found at: www.shef.ac.uk/polopoly_fs/1.229694!/file/PLEASANT_Abridged_Protocol_v1.6.pdf

2.   Ann-Louise Caress: Working with a service user reference group

Ann-Louise Caress is a nurse who holds a joint professorial appointment between the University of Manchester and University Hospital of South Manchester NHS Foundation Trust. Her research focuses on living with and management of long-term and life-limiting conditions, especially respiratory and renal problems.

The research project

Ann-Louise gave the example of a research project exploring the risks of swine flu for people with chest problems. She worked with a service user reference group of people with lung problems, who were contacted via the British Lung Foundation.

How service users were involved in the research

The user reference group were involved from the start; the idea for the project came from them in that they identified swine flu as a priority issue for people with chest problems. They helped to conceptualise the project, and contributed to the study design, methods, and consideration of the burden on participants. In particular, they identified the areas to focus on in the questionnaire, and helped design and pilot it.

The impact of public involvement on the research

The fact that the group identified swine flu as a priority issue for people with chest problems had a significant impact in that the research would not have happened otherwise. The researchers would not have applied for the grant and the funder might not have seen people with chest problems as a priority group for research into swine flu.

The group were 'absolutely instrumental' in contributing topics to, and helping to phrase, the questionnaire. As an example, the researchers were reticent about asking questions about death, but the user reference group felt strongly that these questions were important and should be asked.

The involvement of the group helped the researchers in getting clinicians on board: they could say to clinicians 'this is what patients have told us they are concerned about'. Also, because the research fed back into policy, they are now able to say that public involvement has had an impact on policy.

When the questionnaire was finalised and used, the researchers received some feedback that it was too long. Ann-Louise reflected that the user reference group might have become

accustomed to research questionnaires through their role, and as a result, become less sensitive to this issue.

The impact of public involvement on research quality

Identifying the topic in the first place put swine flu as a potential risk for people with chest problems on the clinical research map.

Ann-Louise felt that several elements of the study were better tailored to the potential participants as a result of the public involvement. The topics covered in the questionnaire were of greater priority to the participants and end users of the research, and the acceptability of the questionnaire was improved by their input.

When they presented to the Ethics Committee, it was a considerable advantage to be able to say that the questionnaires had been checked out with a reference group of service users, particularly as it was covering sensitive topics in a questionnaire that would be sent out 'blind' to participants.

Sometimes people's reactions to individual topics or wording can be surprising. In this project, it was the inclusion of questions on death, which the service users thought important but the researchers had been cautious about including. Ann-Louise also gave an example from a previous project, where service users found the standard question about educational attainment 'What is the highest educational qualification you have achieved?' to be judgmental. Now she asks a different, more neutral question instead: 'Do you have any of the following qualifications?'

Ann-Louise's reflections on public involvement and research quality:

In Ann-Louise's view, there are two ways to consider research quality:

1. Does public involvement improve the rigour of the study – does it show that it has a positive impact on the research process itself – for example the topics, questionnaire, methods, burden on participants?
2. Does public involvement improve the relevance, uptake and usability of the research?

Public involvement can impact on both, but it can be harder to show the latter.

In relation to the first of these, you can show changes made to the research as a result of service user involvement. For example, researchers looking at lung cancer were proposing to carry out six bronchoscopies on study participants and wondered why few people were coming forward. Asking people with experience of bronchoscopies would have told them that this was not a viable method to use.

Other ways in which the design of a project can be shown to have improved include the timing and practical considerations relating to data collection. There is no point doing research first thing in the morning with people with lung conditions as it takes them time to get going, and by about 4.00 p.m. they will be tired. You also need to think about whether some people will use mobility scooters or carry ambulatory oxygen. Working with service users means that you are reminded of these issues and carry out the research in a manner more acceptable and less burdensome to the research participants.

In relation to the second question, it is more challenging to show the causal relationship between public involvement and improvements to the relevance and implementation of the research. However, Ann-Louise believes that the debate needs to move away from looking at the impact of public involvement on rigour and on to addressing the impact agenda far more broadly – in line with the Research Excellence Framework[1] (REF), with funders and the Research for Patient Benefit (RfPB) programme. Are we interested in 'better research' or 'more impact'? If the topic is more meaningful to service users, the output is more likely to be taken up in practice. Public involvement can help us to address the impact element of the REF; it is more persuasive to say that this is a topic of value to people and more likely to impact on practice as a result.

Additional impacts of this study were that one member of the group went on to do a PhD and Ann-Louise Caress became involved in the charity.

Further information
Caress A-L, Duxbury P, Woodcock A, Luker KA, Ward D, Campbell M and Austin L. (2010) **Exploring the needs, concerns and behaviours of people with existing respiratory conditions in relation to the H1N1 'swine influenza' pandemic: a multicentre survey and qualitative study**. Health Technology Assessment; Vol. 14: No. 34, 1–108

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[1] The **Research Excellence Framework** is the successor to the Research Assessment Exercise, a method of assessing the research of British higher education institutions. It is to take place in 2014 to assess research that has taken place during the period 2008–13 inclusive.
REF 2014 defines impact of research as: 'any effect on, changes or benefits to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia' (www.ref.ac.uk)

3. Tina Cook: Towards Inclusive Living

Tina Cook is a Reader in Inclusive Methodologies at Northumbria University. Her work focuses on inclusive practice in research. Using qualitative research, particularly collaborative action research, she seeks ways of facilitating the inclusion, as research partners, of those who might generally be excluded from research that concerns their own lives.

The research project

The Towards Inclusive Living project started from a consultation day about the plans for new premises following a hospital closure. The day was attended by people living with long-term neurological conditions, carers and family members and people from the voluntary sector who supported people with long-term conditions such as the MS Society and Headway. During the course of the day, one member of staff held a session asking people what research they would like to see taking place in the new department. This led to a discussion about whether more inclusive treatment would be more effective. The group worked with a researcher for two years, learning about research and developing a proposal for funding. They received funding from the Department of Health in 2008 for a three-year project.

The aim of the research was to find out whether there is a link between the way people with neurological impairments are included in the NHS community and the way they use knowledge from treatment to develop their skills and independence.

How service users and carers were involved in the research

The study used participatory action research (PAR). PAR is broadly defined as 'the study of a social situation carried out by those involved in that situation in order to improve both their practice and the quality of their understanding' (Winter & Munn-Giddings, 2001[2]). A core group shaped the design of the project, and everyone, including the research participants, took part in the analysis. For the most part, interviewers were matched with interviewees: service users interviewed service users, carers interviewed carers, and so on.

The analysis was carried out through a 'recursive' process which means that people addressed the same questions of the data in a repetitive cycle. The aim of this was to reach a better collaborative understanding of the data: both to address the challenge of appreciating different perspectives and to reach an understanding of what inclusive living meant to people: what were the core principles for inclusion?

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[2] Winter & Munn-Giddings (2001) **A Handbook for Action Research in Health and Social Care**, Part 1 Ch 2, Routledge New York.

Key to this process was the building of relationships: listening to and respecting each other's views and being able to critically discuss the issues. Some arguments took place, but ultimately were resolved through the relationships within the group, with new and unexpected understandings being the outcome of that critical debate.

The impact of public involvement on research quality

Building relationships is an important part of the quality process. The quality of the recursive approach to analysis together with the ability of the team to have really good critical discussions together, meant that they reached an understanding of the issues at a much deeper level than they might have otherwise.

The quality of the interviews benefited from the matching process. Tina felt that service users, for example, could ask more direct and searching questions of each other than she would feel able to do as a researcher. When interviewer and interviewee shared common experience there was a greater likelihood of more in-depth discussion of key issues.

Data analysis was integral to the research process and the team used multiple perspectives to locate and clarify key themes and concepts. The use of a recursive design allowed researchers to analyse the first stage of the work as an initial step and return the themes back to participants for further discussion and critique (a modified Delphi[3] technique). Analysis of data that is re-visited and critiqued by participants is likely to be closer to participants' experiences and concerns. The analysis went through several stages involving participants and researchers and ended in a Big Conversation Day, in which over 50 people (participants and core group researchers) came together to discuss the trustworthiness of the findings.

Essentially, a project about inclusion came to be about communication: honest communication being at the heart of inclusion. The project design modelled the kind of communication that could make services more inclusive. A key finding was that more inclusive practice is essential for developing services that are appropriate for service users with long-term neurological conditions.

Tina's reflections on public involvement and research quality

Firstly, it is important to be clear about the purpose of the research; this is central and should indicate the most suitable approach to be used.

Secondly, building good relationships is central to the quality of involvement in participatory action research as it is core to the process, enabling other things to happen (such as the

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[3] The Delphi process is a structured method of exploring agreement among a group of experts, using several rounds of questionnaires combined with feedback.

critical discussions mentioned earlier). It is essential that people have agency in the whole process.

Thirdly, we should get better at building in a model of what we might expect from participatory action research and public involvement in general. In other words, we should be able to articulate at the start of a project: 'If we do this, then this should be improved…' This even applies to the involvement of the public in designing information sheets. But certainly, in this example of participatory action research 'Towards Inclusive Living', we could be explicitly stating at the start: 'If we build good relationships, we should expect to understand the issues beyond the usual rhetoric. '

Fourthly, because the research participants were involved in the Big Conversation day, the researchers would expect their analysis of what matters to people in relation to inclusion to be much closer to what really does matter to people.

Finally, involvement in participatory action research also has an impact on the quality of research ethics. If you discuss these issues openly as a group, the result is to achieve a more ethical approach in the conduct of the research. You can explain the ethics of involvement with those for whom it has practical meaning and discuss how to put safeguards in place throughout the project.

Additional information

Tina Cook is involved in the International Collaboration for Participatory Health Research www.icphr.org. Through funding received from Jisc/NCCPE[4] she worked with colleagues to design a prototype for a knowledge base, bringing together writers/authors to begin to articulate the quality of research through its participatory action dimensions: what are the quality indicators and what impact do they have? www.publicengagement.ac.uk/about/impact-analysis.

This is currently part of an international proposal for funding (Canadian Institute of Health Research) to take this to scale as part of improving the articulation of the quality and impact of involvement through participatory action research.

The Full Report and Executive Summary of the **Towards Inclusive Living project** (2008-10) can be found at //www.ltnc.org.uk/Research%20pages/impact_inclusive.html

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[4] Jisc/NCCPE: Jisc is a registered charity working on behalf of UK higher education, further education and skills to champion the use of digital technologies. NCCPE is the National Co-ordinating Centre for Public Engagement – it supports universities to engage with the public: www.publicengagement.ac.uk

4.   Patsy Staddon: Improving Support for Women with Alcohol Issues

Patsy Staddon is a survivor of alcohol services and a user of the mental and neurological health services. She is a researcher and a Visiting Fellow at Plymouth University, with a special interest in challenging conventional approaches to alcohol use by women. Patsy is co-chair of the Social Perspectives Network (SPN) and chair of Women's Independent Alcohol Support (WIAS).

The research project

The project, Improving Support for Women with Alcohol Issues, is a service user-controlled research study based at Plymouth University. It was funded by Folk.us[5] and explores the way that needs may not always be met by conventional treatment and mutual aid. The advisory group included two academics from Plymouth University and two service user researchers. The research involved telephone interviews with 13 women in Devon and Cornwall, to explore their experiences of help-seeking for alcohol issues; what had helped and what help they would like to have had, leading to recommendations for service provision.

The involvement of service users in the research

The research was initiated, led and carried out by service user researchers. The lead researcher, Patsy Staddon, has personal experience of alcohol issues and she involved another service user, a woman with similar experiences, in the research. Patsy led the research and carried out the interviews. A second service user researcher was involved in all of the advisory group meetings, the design of the research and in the analysis of the interviews. She was also present as a support to Patsy during the interview phase. Two academics based in Plymouth University provided expertise and advice when requested to do so by the researchers throughout the project.

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[5] Folk.us supports patients, service users and carers to design and undertake their own research across health or social care issues that are important to them. Folk.us is hosted by, and is part of, the Peninsula College of Medicine and Dentistry. For more information see: www.folkus.org.uk

Patsy's reflections on the impact of service user leadership on the quality of the research

In Patsy's view, the main impact of the service user involvement was on the initiation and design of the study, the quality of the interviews and the analysis. The shared backgrounds of the two service user researchers gave them insider knowledge regarding the issues affecting women with alcohol problems. They felt confident that women were not being served well by existing services and that therefore there was a significant research topic to be explored. This, for Patsy, is a significant measure of the quality of research – that it is answering a question of relevance to the people it is about. It was a powerful motivation for her to identify a service response to alcohol problems that is valid and useful to women. The relevance of the research questions followed from this direct experience and 'insider' knowledge.

Patsy felt that the quality of the material was strongly influenced by the identity of the interviewer. The women immediately trusted her as an interviewer and shared very personal information with her, in many cases for the first time. Several of the women told her that they had never shared certain information with anyone before – that it made a difference to them that she had similar personal experience. The women had a fear of revealing something they regarded as shameful with people they knew and trusted because of the potential effect it would have on these relationships.

Both of the service user researchers took part in the analysis and felt that this was uniquely informed by their direct experience. There were many occasions when it was necessary to stop and reflect. Personal memories emerged and had to be dealt with, and then it was necessary to weigh up the extent to which such memories might be colouring interpretation of what the interviewees had said, or the extent that such memories helped to focus them. It helped to be able to talk to each other about this. Although the interviews, the transcription and the analysis were emotionally draining for the lead researcher, she gained support from her colleague throughout.

All of the women in the study stated that being able to speak with another woman who had also been a service user was of great significance to them. All said they would greatly value a regular phone-line where they could talk through their alcohol and other issues safely with another woman with a similar background. Most said that they would also welcome and use an interactive website. Many said they would welcome the presence of a drop-in or other centre where they could talk to other service users, as well as to social care and medical 'experts', if and when they felt ready to do so. In this way it would be hoped that their issues might be resolved in a friendly and non-judgmental environment.

These findings indicate that same sex, service user support for women with alcohol issues would lead to considerable improvements in women's recovery from alcohol misuse.

Further information

The research will be publicised in conference papers and articles, and also in the wider Press. Meanwhile funding is being sought in Bristol by Patsy's organisation, 'Women's Independent Alcohol Support' (WIAS) to set up a helpline and website to offer information and support which is non-directive and anonymous.

Publications

Staddon, P. (forthcoming June 2013) **Theorising a social model of 'alcoholism': service users who misbehave** in Mental health service users in research: a critical sociological perspective, Ed. Staddon, P. Bristol: Policy Press.

Staddon, P. (2012) **No blame, no shame: towards a social model of alcohol dependency - a story from emancipatory research**, Social Care, Service Users and User Involvement: Building on Research, Carr S and Beresford P, Jessica Kingsley Publishers.

Staddon, P. (2011) **The Bigger Picture**, Mental Health Today September

Staddon, P. (2011) **The Bigger Picture**, Mental Health Today February

Staddon, P. (2011) **Many Roads to Recovery**, Big Issue January 10

Staddon, P. (2011**) Service user led research in the NHS: wasting our time**? Critical Perspectives on User Involvement, Barnes, M. and Cotterell, P. Polity Press.

Staddon, P. (2009) **'Making Whoopee'? : An exploration of understandings and responses around women's alcohol use**, PhD thesis, Plymouth University, Plymouth. (Online) Available at http://hdl.handle.net/10026.1/415 (accessed 12 December 2012).

5. Sophie Staniszewska and Jo Brett: The POPPY project

Dr Sophie Staniszewska is a Senior Research Fellow, Patient and Public Involvement and Patient Experiences and Jo Brett is a Research Fellow; both are based at the Royal College of Nursing (RCN) Research Institute, Warwick Medical School, University of Warwick.

The research project

The POPPY project[6] (Parents of Premature Babies Project) had three stages: a systematic review of interventions that enable a better parent experience; a qualitative study exploring the experiences of parents in seven neonatal units; and a survey of neonatal units across the UK.

The study had its origins in conversations between Sophie and mothers at a National Childbirth Trust (NCT) sale: mothers who had given birth to pre-term babies and spent varying lengths of time in Special Care Baby Units. They talked of painful experiences, and Sophie was inspired to work with the mothers to address the key issues relating to their experiences. She went to a meeting of the Warwickshire Pre-Term Support Group to talk about her ideas and over the next 14 months they developed a proposal for funding together.

Public involvement in the POPPY Project

Parents were involved from the inception of the project through to the end including dissemination. Sophie described it as an 'embedded' model of public involvement. For the systematic review, it was the parents who identified the core components to investigate: communication, information and support. Throughout the review, Jo engaged parents to explore their perspectives on the findings, particularly where issues arose about which there was little research evidence.

In the qualitative stage, neonatal nurses were recruited to assist in carrying out the interviews. The parents were involved in reading through the data and helping to clarify and discuss themes that Jo and Sophie had identified. Finally, Sophie and Jo developed a new model of care for pre-term babies and their parents, in collaboration with the parents and researchers drawing on all three stages of the research. In a sense, the evidence base was 'moulded' by the parents into the key components of the experience, to develop the model

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[6] POPPY Steering Group (2009**) Family-centred care in neonatal units. A summary of research results and recommendations from the POPPY project**. London: National Childbirth Trust, http://www.poppy-project.org.uk/resources/Poppy+report+for+PRINT.pdf

which reflected the parents' journey. The synthesis of the different types of data provided a strong underpinning for the POPPY model of care.

Together, the researchers, parents and clinicians identified that at the heart of what had been happening previously was the 'separation and marginalisation' of the parents, and that this situation needed to change. It also touched on human rights issues as, on occasions, parents were denied access to their babies for periods of time after the birth.

Involvement of two charities, the National Childbirth Trust (NCT) and BLISS (who provide care and support to families with premature and sick babies) was also key to the research. With their extensive networks, they were able to situate the research into the wider policy context and disseminate the results to great effect.

The impact of public involvement on the research

Parents had a number of impacts on the study. The development of the research questions, the development of methods and the analysis of data were important areas where parents influenced the study. Parents tested the utility, relevance and applicability of the systematic review, and were involved in analysing and reviewing the qualitative data (Staniszewska, 2007,[7] Brett, 2012[8]). Perhaps their most significant impact was in the development of the model of care where the involvement of parents brought about a realignment in the philosophy of care, putting the family at the centre of care in neonatal units (Staniszewska 2012[9]).

With the power of experience behind them, the parents took part in presentations at conferences and in the National Institute for Health and Care Excellence (NICE)[10] consultations. POPPY is referenced in a Department of Health neonatal toolkit and the United Nations Children's Fund (UNICEF) has included it in their quality standards for neonatal units.

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[7] Staniszewska S, Jones N, Newburn M and Marshall S. (2007) **User involvement in the development of a research bid: barriers, enablers and impacts**, Health Expectations, 10, pp.173–183.

[8] Brett J, Staniszewska S, Newburn M, Jones N and Taylor L. (2011) **A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants**, BMJ Open, Vol.1 (No.1). e000023. ISSN 2044-6055 wrap.warwick.ac.uk/38847/1/WRAP_Brett_BMJ_Open-2011-Brett-bmjopen-2010-000023.pdf

[9] Staniszewska S, Haywood K L, Brett J and Tutton L. (2012) **Patient and Public Involvement in Patient-Reported Outcome Measures: Evolution Not Revolution**, The Patient 3 D Eizo 5 (2), 1-9.

[10] NICE – the National Institute for Health and Care Excellence – provides national guidance and advice to improve health and social care. www.nice.org.uk/aboutnice/whoweare/who_we_are.jsp

The impact of public involvement on research quality

Overall the parents were instrumental in shaping the direction and the outcome of the study. Sophie talked about the research having 'community validity', a term she coined in relation to the development of Patient Reported Outcome Measures or PROMs (Staniszewska, 2012[11]). 'Community validity' refers to the idea that the involvement of parents gave the research meaning and validity for the people for whom the research was intended.

Sophie and Jo's reflections on public involvement and research quality

Quality is often expressed in terms of methodology, robust and rigorous methods, validity and reliability. We do not currently have the language for the contribution that public involvement makes to research quality, but Sophie thinks there is some relationship to the 'content validity'[12] in any study, for which she coined the term 'community validity'. For the Patient Reported Outcome Measures (PROMs), for example, they looked at 'face validity' and 'content validity', both of which are important areas to which public involvement can make a contribution. They argue that often public involvement components are looked at in terms of the content of the research, when they should be embedded in methodological textbooks as part of the quality framework for research.

There are clearly quality elements to public involvement in research but we need to get better at articulating them. Sophie suggests there are two ways of looking at quality:

1. the content of the study – is the focus right, does it have meaning to the people it is about? and
2. the specifics of research: methods and processes.

Public involvement has potential impact on constructing the validity of the research, to determine whether a measure is measuring something meaningful to the people concerned. The development of PROMS has put this into sharp relief. However, the language of research can be challenging for others and we need to develop a common understanding in order to generate a meaningful dialogue.

Sophie and Jo believe that the implementation of research is an area with huge, largely untapped, potential for public involvement to have an impact; health professionals are themselves challenged by the implementation of research.

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[11] Op Cit Staniszewska S et al (2012).

[12] Face validity relates to whether a test or measure appears to be valid – or looks as if it is measuring what it says it is measuring. Content validity is more rigorous than face validity: it refers to the extent to which a measure represents all of the known characteristics of what it is measuring.

Further information

POPPY Steering Group (2009) **Family-centred care in neonatal units. A summary of research results and recommendations from the POPPY project**. London: National Childbirth Trust. www.poppy-project.org.uk/resources/Poppy+report+for+PRINT.pdf

Brett J, Staniszewska S, Newburn M, Jones N and Taylor L. (2011) **A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants**, BMJ Open, Vol.1 (No.1). e000023. ISSN 2044-6055 wrap.warwick.ac.uk/38847/1/WRAP_Brett_BMJ_Open-2011-Brett-bmjopen-2010-000023.pdf

Staniszewska S, Haywood K L, Brett J and Tutton L. (2012) **Patient and Public Involvement in Patient-Reported Outcome Measures: Evolution Not Revolution**, The Patient 3 D Eizo 5 (2), 1-9.

Staniszewska S, Jones N, Newburn M and Marshall S. (2007) **User involvement in the development of a research bid: barriers, enablers and impacts**, Health Expectations, 10, pp.173–183.

6. Jill Thompson: Public involvement in the National Cancer Research Network (PhD)

Jill Thompson is a Researcher at the University of Sheffield School of Health and Related Research (ScHARR), Section of Public Health. Her research interests include experiences of chronic illness, service user needs, and the relationships between patients, professionals and public involvement in research.

The research project

Jill's PhD was undertaken at ScHARR; she investigated public involvement in the National Cancer Research Network, in order to explore roles, relationships and the nature of credible expertise in public involvement.

Public involvement in the research

Due to the nature of the topic, it was essential that Jill involve members of the public in the research in order to demonstrate that she was 'practising what she preached'. In the initial stages of the research, she took her ideas to a lay research panel of patients and members of the public already in existence in South Yorkshire. She consulted them informally about her ideas and they influenced not only her decisions about how to approach the research but also changed her initial research questions.

When Jill secured the funding, she continued to consult with the lay panel as well as appointing one member as a research supervisor. She had regular sessions with the supervisor and the panel's role as advisors evolved into them becoming a case study. In this way, the research methodology evolved into participatory action research.

The lay supervisor analysed some of the research transcripts and these findings were checked back with the panel, which added to their credibility. Finally, panel members were actively involved in disseminating the research; one of them always mentions the study in his presentations which ensures that the research continues to be discussed and used.

The impact of public involvement on the research

In the initial stages, Jill was interested in investigating the impact of public involvement on decision-making processes, but it proved difficult to pinpoint the impact of involvement on specific decisions. Discussions with the panel explored what was and was not feasible to investigate. For example, it emerged that much of their involvement took place via emails and so Jill needed to explore how to access and analyse emails.

As a result of the panel's influence, the investigation evolved into exploring relationships and became more of a sociological investigation or ethnography. The focus became the roles that people play in public involvement and the nature of 'credible expertise'. Jill undertook participant observation with the panel, acting as their administrator for two years in order to observe how they operated and the nature of the relationships that developed.

In summary, the panel was instrumental in deciding the direction and nature of Jill's research and in determining the methods that were adopted. However, it was difficult to separate out how members of the panel influenced the research subsequently as they were so integral to the process.

The impact of public involvement on the quality of the research

A fundamental aspect of research quality is its relevance to the stakeholders and the audience for whom it is intended. In this example, public involvement ensured that the direction of the research was relevant to the panel's concerns and hence contributed to the shared knowledge about public involvement. The panel and, in particular, the individual supervisor improved the quality of the researcher's learning experience. The credibility of the research and of its findings were strengthened by the public involvement.

Fundamental to the quality of the research was the quality of the relationships. Jill suggested that if you are doing good public involvement in research, then you inevitably develop relationships with those involved. This can be difficult – it introduces an emotional element if you are working with people who are experiencing chronic or deteriorating health – but is essential for the success of the process.

Public involvement can influence how the research is taken up rather than just shelved.

Jill's reflections on public involvement and research quality

The success of public involvement can depend on who you involve. It can be important to involve people who are bringing specific experiences to the table, rather than consulting with generic patient and public involvement panels who may know little about the specific topic under investigation. Jill thought that researchers often do not give people much opportunity to influence the quality of a research project. For example, they may invite comments when the direction of a project is already decided or only consult members of the public about the design of a patient information sheet. This can be frustrating for members of the public and for researchers interested in promoting public involvement in research.

Appendix A: topic guide

What impact does public involvement have on the **quality** of research?

The aim of this piece of work is to explore with members of InvoNET their views about the impact that public involvement has had on the quality of research. We know that 'quality' in research can mean different things to different people – and we would like to explore this with you.

We aim to compile a set of case study examples which will share this learning with others. The questions below are a guide to what we shall be asking you.

1. A brief summary of the research you have been doing
   - Did you have a particular theoretical approach to the research – and if so, what was it?

2. How were members of the public involved in the research
   - At what stages
   - In what roles?

3. What difference(s) do you think public involvement made to the research?
   - Both positive and negative

4. How do you think the research was changed by public involvement?
   - Can you say how you know this – e.g. give examples of changes made as a result of public involvement

5. Do you think public involvement made a difference to the quality of the research?
   - Can you say a bit more about your understanding of 'quality' in research in this context?

6. What difference were you hoping public involvement would make to the research?
   - Was there anything unexpected or surprising about the impact of public involvement on the research?

7. Can you say if PPI had an impact on the implementation of the research?

8. Any final thoughts

INVOLVE

INVOLVE is a national advisory group that is funded by and part of the National Institute for Health Research (NIHR). INVOLVE supports public involvement in NHS, public health and social care research.

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