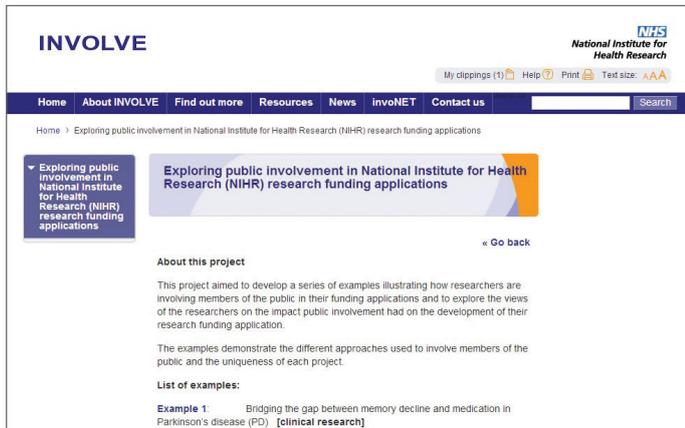


newsletter

Autumn 2013

Welcome to the Autumn 2013 issue of the INVOLVE newsletter, which begins with details of our new impact examples.

Exploring the impact of public involvement in research: examples



by Helen Hayes and Maryrose Tarpey

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.

The evidence that we have to date suggests that public involvement can make positive contributions to research (Brett, 2010¹).

Continued>>

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If you would like a copy of the newsletter in an audio or large print version, or if you would like it in another format, please contact us. Printed on recycled paper.

The structured literature review of the evidence funded by INVOLVE in 2009 (Staley, 2009²), 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.

Staley 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 (Staniszewska, 2011³), and more recently by the Public Involvement Impact Assessment Framework (PiiAF) Study (Popay et al, 2013⁴).

To build on this work INVOLVE has published two new series of short, concise examples of public involvement in research (www.invo.org.uk/resource-centre/examples/). Six researchers describe involvement in their study and its impact on research quality and ten researchers are interviewed on the impact of public involvement in the development of their funding applications.

The six examples on the impact on research quality (www.invo.org.uk/wp-content/uploads/2013/08/invoNETexamples2013.pdf) are all from invoNET members. They offer a range of different perspectives on public involvement in research, and describe quite different approaches to research.

The following themes in relation to the impact of public involvement on the quality of research were drawn from the six examples:

- 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.

This small piece of work aims to contribute to our thinking about how we report the impact of public involvement on research quality.

The ten examples of public involvement in National Institute for Health Research (NIHR) research funding applications are drawn from

a broad range of studies from across the NIHR (www.invo.org.uk/resource-centre/examples/).

This new series illustrates the uniqueness of the public involvement in each study and the researchers tell their story by describing:

- how members of the public were involved in the funding application
- the origin of the research question
- the difference public involvement made
- knowledge and learning to share with other researchers.

The researchers talk about the impact public involvement had on the:

- practical design of the research
- practical arrangements for the research
- outcome measures
- accessibility and acceptability of the research.

We hope that these two series of examples will provide learning and inspiration to other researchers. They will 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.

Thanks to Alison Faulkner and Kristina Staley who interviewed the researchers and wrote up the examples, to the researchers for giving their time and experience and to the advisory groups of both projects for their support and guidance.

References

- ¹ 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.
- ² Staley K (2009) Exploring Impact: Public involvement in NHS, public health and social care research. Eastleigh: INVOLVE.
- ³ Staniszewska S, Brett J, Mockford C, Barber R (2011) The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research. *International Journal of Technology Assessment in Health Care* 27:4.
- ⁴ Popay J, Collins M et al (2013) PiiAF – The Public Involvement Impact Assessment Framework and Guidance website: <http://piiaf.org.uk/>

INVOLVE Coordinating Centre news

INVOLVE 2014 conference

We will shortly be able to confirm the date and venue of our ninth national conference, which will take place in November 2014. In January 2014 we will be inviting people to send in their proposals to contribute to the conference. If you would like to receive regular conference updates, then sign up for email alerts and join our mailing list by visiting www.invo.org.uk/about-involve/keep-in-touch/sign-up-for-mailing-list/

Webinar series

On 13 September we held the first in a series of webinars in partnership with the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). Over 100 people registered to listen to Mike Clark (SSCR), Simon Denegri (INVOLVE) and Tina Coldham (INVOLVE) give an overview of public involvement in adult social care research. If you missed the webinar you can view the slides and the questions that were asked during the session at www.invo.org.uk/posttypenews/nihr-school-for-social-care-research-and-involve-webinar-series-2/

Other webinars in the series will be based on some of the SSCR methods reviews and will aim to cover:

- lesbian, gay, bisexual and transgender (LGBT) sexualities in social care research
- research with black and minority ethnic people using social care services
- research with Deaf people
- research about social care services for visually impaired people
- end of life care research methods
- interviewing people with dementia
- user controlled research.

Standards for public involvement in research

We have now completed the first stage of a piece of work looking at principles and standards for public involvement in research. Marisha Palm undertook a review of what others have done on principles and standards for public involvement in research, which we have discussed with INVOLVE Advisory Group members. Over the coming months we will also be seeking wider feedback and discussion on the values and principles identified. For further details see www.invo.org.uk/about-involve/current-work/

Staff changes at INVOLVE

We are delighted to announce the appointment of Marisha Palm as Senior Public Involvement Advisor, leading on knowledge and communications.

Marisha first joined us in April to carry out project work looking at standards for involvement before taking on this new more permanent role in September. Her role will involve communicating and raising awareness of INVOLVE and public involvement in research, overseeing events, materials and resources and contributing to our strategic and operational work.

Helen Hayes has taken on a new role of Senior Public Involvement Advisor. Over the next six months, Helen will be working part-time on a number of projects, including developing plain English resources, planning a database of examples of public involvement in research and drawing up an equality and diversity policy for INVOLVE.

We are sorry to say goodbye to Lucy Simons, our Senior Public Involvement Advisor with the lead on policy and practice. Lucy has left to take up a new Research Fellow post in a National Institute for Health Research (NIHR) funded Healthcare Technology Cooperative in Nottingham. As Lucy's new role includes user involvement, we're sure we will have opportunities to work with her again in the future. We wish her every success in her new post.

INVOLVE website links

Our links page (www.invo.org.uk/resource-centre/links/) includes details of research websites and organisations that might be helpful for researchers and members of the public who have an interest in active public involvement in research. If you would like us to add a link to your website, you'll find a form and information on the type of links we publish on our 'Add your link' page (www.invo.org.uk/resource-centre/links/add-you-link/). And if you would like to link to our website, this page also includes details of where to direct your link and a short description of INVOLVE.



Interesting articles and publications

Impact of patient involvement in mental health research: longitudinal study

Liam Ennis and Til Wykes

The British Journal of Psychiatry, doi: 10.1192/bjp.bp.112.119818, epublication ahead of print

This study analysed the reports from the research projects registered on the Mental Health Research Network's database to look at the impact of involvement on the research. The statistical analysis found that studies that reported higher levels of involvement were more likely to have reached their targets for recruiting participants to the research. It also showed that involvement had increased over time and that studies funded by the National Institute for Health Research (NIHR) had more public involvement than studies funded by others.

www.ncbi.nlm.nih.gov/pubmed/24029538

Bring on the evidence

Sophie Petit-Zeman and Louise Locock

Nature, volume 501, 12 September 2013, pages 160-1

In this article, the authors comment on the need for better quality evidence to support patient and public involvement in research. They highlight the challenges around generating and reporting evidence of impact, defining who needs to be involved and drawing on the experience of a wide range of patients.

www.nature.com/news/health-care-bring-on-the-evidence-1.13697

Involving service users in trials: developing a standard operating procedure

Bridie Evans, Emma Bedson, Philip Bell, Hayley Hutchings, Lesley Lowes, David Rea, Anne Seagrove, Stefan Siebert, Graham Smith, Helen Snooks, Marie Thomas, Kym Thorne, Ian Russell and on behalf of the West Wales Organisation for Rigorous Trials in Health (WWORTH)

Trials, July 2013, 14:219, doi:10.1186/1745-6215-14-219

This article reports on the development of a standard operating procedure (SOP) for involving service users in a clinical trial. The SOP was developed by a group of researchers with experience of involvement working in a clinical

trials unit in Wales. The group first defined the key principles that underpin the SOP and then developed the guidance around how to achieve these principles. The SOP is divided into three sections. The first provides advice on planning involvement and understanding its purpose. The second discusses the implications for trial management in terms of who needs to be responsible for patient and public involvement, who needs to be involved and providing everyone with training. The third section describes how service users can be involved at different stages and defines a minimum level of involvement at each one.

www.trialsjournal.com/content/14/1/219

How to develop a patient and carer advisory group in a quality improvement study

Fiona Loud, Neerja Jain and Nicola Thomas
Journal of Renal Care, volume 39, issue S2, pages 2-9, September 2013

This paper explores how a group of people with renal or other vascular conditions collaborated with renal practitioners in a quality improvement project to reduce variation in care for people with Stages 3–4 chronic kidney disease. The patient advisory group supporting the project took a leading role in the creation of self-management materials and subsequent training for healthcare professionals and patients. The role of the patient advisory group was evaluated informally throughout the project and it was found their confidence grew as the project developed. The authors recommend further evaluation of the role of advisory groups.

www.ncbi.nlm.nih.gov/pubmed/23941698

If you have written or know of any articles or publications relevant to public involvement in research that might be of interest to readers, please contact Marisha Palm at the Coordinating Centre with details: mpalm@invo.org.uk

Deadline for contributions for our next newsletter: **16 December 2013**

If you have any questions on contributing to the newsletter, please contact Paula Davis

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EQUIP: Building the skills of service users and carers to become involved in research

By Alison Faulkner

EQUIP: 'Enhancing the quality and purpose of care planning in mental health services', is an NIHR Programme Grants for Applied Research award led by Professor Karina Lovell and Dr John Baker at the University of Manchester in collaboration with Manchester Mental Health and Social Care NHS Trust, the University of Nottingham and Nottinghamshire Healthcare NHS Trust. The aim of the research programme is to improve service user and carer involvement in care planning in mental health services; it is currently seven months into the five-year award. This article is based on an interview with John Baker, lead researcher for public involvement and engagement on the project and Senior Lecturer in the School of Nursing, Midwifery and Social Work, University of Manchester.

The history of care planning in mental health is that, despite the policy imperatives to involve service users and carers in order to increase opportunities for choice and control over their own care, this frequently does not happen. Indeed, research has found that some service users do not even know that they have a care plan. Involvement in drawing up their care plan can be marginal at best.

From the start of this research, and to reflect the ethos of collaborative care planning, the research team wanted to ensure the meaningful involvement of service users and carers throughout. They applied for an NIHR Programme Development Grant to enable them to (amongst other things) design and run research training in order to give service users and carers the opportunity to collaborate from a more informed basis. The Programme Development Grant enabled the team to devise and run the training prior to commencement of the full Programme Grant, and to use this to develop strong service user and carer collaboration, increasing their capacity to get involved in the research itself.

The training, which has now been run three times, consists of six short days covering: study skills, the research process, qualitative and quantitative

research methods, searching and critiquing the literature, statistics and health economics, ethics and governance, and dissemination. The team made it possible for the service users to have full student status, including library cards. However, the course currently holds no credits and is not assessed as it needed to be non-fee paying.

The experience of taking part in the training together created a different environment for researchers and service users to come together. John felt that it changed the relationships between the research team and the service users: it changed the mindset of both so that they could collaborate on the research on more of an equal footing. Service users and carers got to know each other and the research team with whom they might be working in the future. The course and content was very well received by those who attended. All participants reported learning about research, including improved understanding about research design, qualitative and quantitative methods and cost effectiveness.

John said that the training had a 'massive impact' on the whole Programme Grant. Two service users and one carer became co-applicants on the grant, two service users are employed as part time research assistants, and others sit on steering groups for the different cohorts, or comment on documents. An extra training day was arranged for the group to comment on the primary outcome measures to be used in the research. As a result of their feedback (that none of the measures was fit for purpose), the research is now developing its own PROM (Patient Reported Outcome Measure) as part of the programme. Other service users and carers who participated in the training course have become involved in other research projects within the Trust or the University.

There were a few challenges along the way. One was the discovery that they needed to make the training materials accessible to people with visual impairments, and with limited computer skills. They also encountered difficulties negotiating the University's financial procedures for paying service users and carers in cash on the training days. One of the main learning points was to avoid raising people's expectations about potential opportunities for involvement or employment. They found it was important to ensure that participants understood the long lead-in times and uncertainties involved in getting research projects off the ground, and to find other ways of sustaining people's interest in the meantime.

The training has been publicised by the Mental Health Research Network (MHRN) and by NICE as an example of good practice, as a result of which subsequent courses attracted participants from further afield and were oversubscribed. A series of shortened two-day courses was commissioned by the MHRN. John feels that they have tapped into an unmet need: many people want to access this kind of training in research but there is no obvious funding stream to enable it to happen.

The team are hoping to make the training materials available online as an e-learning package and in book form.

www.invo.org.uk/resource-centre/research-project-database/research-project/?id=794

<http://tinyurl.com/lyehtsm>

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The EQUIP project is funded by the NIHR under its Programme Grants for Applied Research Programme (RP-PG-1210-12007).

The Tourettes Listening Project

By Leah Songhurst

What is Tourette Syndrome?

Tourette Syndrome (TS) is a complex neurological condition, characterised by repetitive motor and vocal tics. The charity Tourettes Action estimates that it 'affects one schoolchild in every hundred and more than 300,000 children and adults in the UK'. Moderate to severe symptoms impact on all aspects of life and the situation for those living with TS is complicated further by the prevalence of co-morbid conditions (that is one or more diseases or conditions that occur together with the primary condition) such as obsessive compulsive disorder (OCD) and depression.

What is the project?

Project manager Dr Leah Songhurst has listened to discussions held within Tourettes Action's North East (NE) support group over the past three years. Service users involved with the group describe living with TS in a very different way to descriptions found elsewhere in research or the popular media.

The Tourettes Listening Project collects, analyses and disseminates findings from oral history interviews, in order to present a realistic portrait of life with TS. Encouraging those normally excluded from TS research to share their experiences, the project listens to individuals diagnosed with TS, but also people with an alternative perspective such as parents, partners, grandparents and friends of those with a diagnosis.

Involving service users in research

The project is service-user centred and from its conception has involved people with direct experience of living with TS. Members of the NE support group explained that they were grateful for ongoing TS research. However, they felt that focusing on treatment, prognosis and management means that research fails to explore day-to-day experiences. The Tourettes Listening Project was set up to understand existing attitudes to TS, to assess the availability of services and to provide service users with an opportunity to directly influence policy.

Keen to get started, members of the NE support group raised £150 through fundraising activities. A steering committee, including service users and advisors from Tourettes Action and the University of Exeter was formed. A digital recorder was purchased and 11 pilot interviews were recorded in a 'listening tent' at a camping weekend for people living with TS in May 2013.

Inevitably skilled input from advisors and the project manager was needed, however following the pilot interviews service users were asked for their opinions on the methodological approach. The notion that people living with TS do not need others to talk on their behalf was well received. It was agreed that oral history helps uncover the voices of those who are traditionally hidden within the TS narrative.

Challenges of service-user involvement

Managing service-user expectations has proved to be the biggest challenge so far. For those unfamiliar with the research process change cannot happen quickly enough. Unfortunately organising ethical approval, applying for funding and disseminating findings all take time. Explaining this fact from the outset helps to prevent disillusionment. Maintaining the involvement and enthusiasm of service users therefore requires patience and an open dialogue. Equally important is sensitivity to the fact that for some involved, the realities of living with TS take priority over their participation in research.



Support group members at the camping festival

Early findings

From project discussions and the pilot interviews it is evident that myths and stereotypes about TS impact negatively on everyday life. Repeated particularly in the popular media, these influence not only the perceptions of the public, but also those working to support people with TS such as medical practitioners, teachers and social workers. It is also apparent that those living with TS often find that co-morbid conditions have a greater impact on their daily life than the symptoms associated with TS.

Conclusion

Involving service users in TS research has proved inspirational. Without their input at all stages of the project's development, the subtle and private aspects of living with TS would remain hidden. Despite the humble beginnings of this project, the need for change has secured the future commitment from all involved and we are currently working hard to secure further funding.

<http://touretteslisteningproject.wordpress.com>

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Clinical Research Ambassador Group

By **Dr Mudassar Aslam, Teresa Melody and Sarah Pountain**

The role of patient and public involvement in the design and running of research trials is becoming increasingly important as researchers strive to discover the clinical questions that matter to patients and their loved ones. The National Institute for Health Research (NIHR) funds the

national advisory group INVOLVE, which aims to build support for active public involvement in NHS and public health research. However, it is also important that public involvement begins at the grassroots level within individual research departments and NHS trusts.

With this in mind, on 24 April 2013, the first meeting of the Clinical Research Ambassador Group (CRAG) was hosted by the Heart of England NHS Foundation Trust (HEFT) and the Academic Department of Anaesthesia, Critical Care, Pain and Resuscitation. A large turnout of patients, relatives, clinicians, researchers, managers and directors came together with the aim of promoting patient and public involvement.

Professor Fang Gao, Academic Department Lead, began the evening of seminars with a fascinating discussion of what a clinical trial is and why patient involvement is important in research. This set the scene for the rest of the event and highlighted that a clinical trial is designed with benefits to patient outcomes in mind, and therefore patient involvement has a paramount role to play in all stages of the clinical trial research cycle (figure 1). An example from the specialty of orthopaedic surgery demonstrated a discrepancy between the proportion of trials undertaken in different treatment spheres and patient opinion as to where research funding should be directed¹. This made it clear that while research may be taking place, it may not actually address the questions that matter to patients, their relatives and carers.

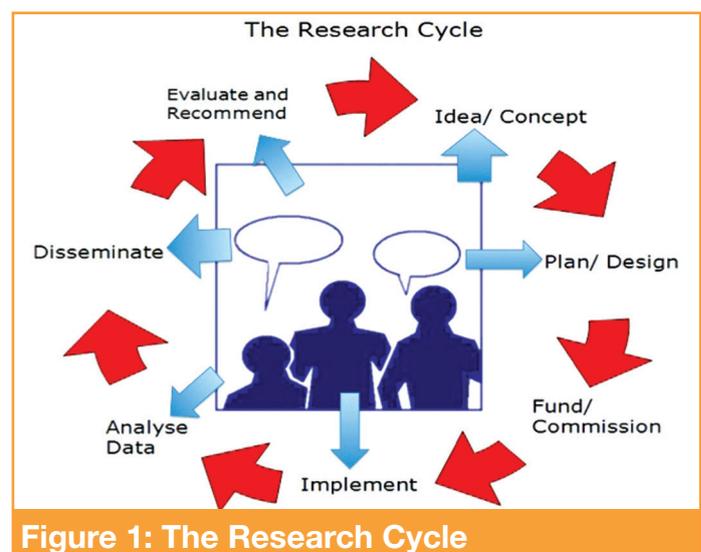


Figure 1: The Research Cycle

The evening moved on, with contributions from research fellow Dhruv Parekh and research managers Teresa Melody and Sarah Pountain. They discussed how public involvement was

being carried out and promoted within current trials by the department, and how much more work was still needed. One telling contribution to the evening was from a former patient, who recounted her experiences as both a researcher in public health and as a patient. She emphasised how her thought process as a researcher changed as she took on the patient role, and the many fears and anxieties that accompanied it. This struck a chord with our patient audience and stimulated much discussion. One woman pointed out that while seemingly strong-minded patients often contributed to public involvement conferences, “sometimes it is the shy patient with concerns and an opinion that just needs that bit of support and guidance to voice their opinion”.

The evening ended with a discussion of how patients and relatives could get involved with the research process and the Clinical Research Ambassador Group. The success of the Group was clearly demonstrated by the feedback and interest received following the event. Since the event, interviews have been held with patients and their carers to gather their opinions and input. We also held a successful coffee morning event on 28 August, where our research fellows discussed their particular studies with our patient members.



Clinical Research Ambassador Group meeting

Patient and public involvement is being acknowledged as a crucial component of the clinical trial process, as shown by an increasing emphasis in funding application forms. Patients are increasingly being asked for their opinion to ensure adequate emphasis on patient opinion and safety, while lay panel members are being employed to assess the feasibility and design of a trial. Our patients have always had a voice and opinion regarding the development of their treatment and care – all that was lacking was an avenue through which it could be heard.

Reference

¹ Tallon D, Chard J, Dieppe P. Relation between agendas of the research community and the research consumer. *Lancet* 2000; 355 (9220): 2037-40

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Launch of the Public Involvement Impact Assessment Framework

By Marisha Palm

The Public Involvement Impact Assessment Framework (PiiAF) is a resource that was developed with funding from the Medical Research Council to support researchers to develop ways of assessing the impact of public involvement in health and social care research. The PiiAF research was a collaboration between the Universities of Lancaster, Exeter and Liverpool, and it also involved the Medicines for Children and Mental Health Research Networks.

The new resource was launched in central London on Friday 6 September to an invited audience of approximately 50 people. Professor Jennie Popay, the research lead, welcomed the audience and Simon Denegri, National Institute for Health Research (NIHR) National Director of Public Participation and Engagement in Research and Chair of INVOLVE, spoke about the potential for the PiiAF in a national context. Professor Ann Jacoby and other members of the research team joined Jennie Popay to speak in more detail about the development and testing of the resource.

The PiiAF was informed by a narrative review of diverse literature and a Delphi-type exercise. Key findings from these earlier stages of the research showed that:

1. values are important in shaping the way that public involvement is undertaken and can shape the impacts it may have
2. the health and social care community agree that it is important to assess the impact of public involvement
3. there is widespread agreement that best practice standards for public involvement would be valuable.

The PiiAF has been designed to support researchers to develop tailored impact

assessment plans, and the team who have developed it do not present it as a quick fix, but rather as a thoughtful process that will yield a plan designed specifically for each individual research study.

The PiiAF resource is divided into two parts. In part one the PiiAF encourages research teams to explore the factors that can influence impacts:

- values associated with public involvement
- approaches to public involvement
- research focus and study design
- practical issues shaping public involvement (such as the funding available to support involvement).

Following exploration of these factors, part two supports the development of an impact assessment plan taking users through four development phases:

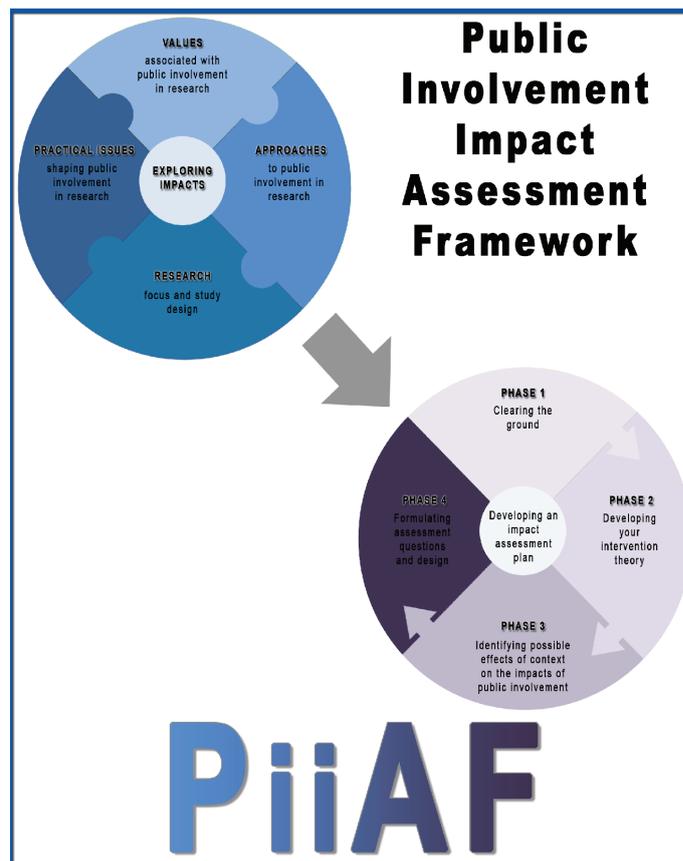
- clearing the ground
- developing an intervention theory
- identifying possible effects of context on the impacts
- formulating assessment questions and an evaluation design.

There was praise from Simon Denegri and the members of the audience about the way in which the PiiAF incorporates values and allows the team to reflect on these at the outset of the impact assessment planning process. The PiiAF is comprehensive in its approach and it was acknowledged that this can be seen as both a strength and a weakness. The time commitment required could be seen as a barrier, but it may also be necessary to produce an appropriate and robust impact assessment plan.

A prototype PiiAF web resource is now live and can be found at www.piiaf.org.uk. The site illustrates the structure of the PiiAF and provides prompts, resources, a glossary of terms and links to further reading. Researchers who are working through the first part of the PiiAF can also download a Word document that provides space to record elements of their discussion for use as building blocks for the development of an impact assessment plan.



PiiAF launch participants



PiiAF structure

A downloadable version of the PiiAF and the PiiAF resources are currently being finalised and will be available from the website shortly.

To provide feedback on the site go to www.piiaf.org.uk/feedback.php

For information about the site please contact Libby Osbourne: l.osbourne@lancaster.ac.uk

The lived experience of co-producing research

By Sarah Gibson

The Peer Worker Research Project – New Ways of Working in Mental Health Services¹ – looked at what supports and hinders peer worker roles being introduced into mental health services and how international research evidence applies to service contexts in England. Peer workers were defined as ‘people with lived experience of mental health problems who are employed, in a paid or unpaid capacity, to explicitly use those experiences to support others using mental health services’.

We used a co-production approach to research. This values the lived experience of service user

researchers, peer-led service leaders and peer workers alongside clinical and academic expertise in research. This was vital since the focus of our research was people using lived experience in delivering mental health services. We conducted and compared ten different case studies of services where peer worker roles had been introduced. In each case study we interviewed service users, peer workers, their colleagues, managers and strategic managers/ commissioners.

The PEER Group – a group of local mental health service users and carers who work alongside researchers at St George’s – were part of shaping the research questions, aims and the evidence framework that the research tested. Two members of the PEER Group were then formally recruited to the project steering group.

Two service user researchers, Sarah Gibson and Katherine Owen, undertook the day-to-day work of the study engaging with case study sites, designing interview schedules, collecting and analysing interview data and writing up and presenting our final report and findings. All this was done alongside the lead researcher, Steve Gillard, with reference to the wider research team and steering group. This enabled multiple perspectives to be sought and interwoven into our work.

Support for the service user researchers’ roles included their own peer-to-peer support, good line management and supervision from Steve and external mentoring from a more experienced service user researcher. Sarah and Katherine then supported the PEER Group members on the steering group, through pre-briefing and debriefing, enabling their contributions to be heard.

Co-production was also included in the analysis. The service user researchers developed themes from the research participants’ interviews. These were discussed with the multi-perspective research team, refined and then used to analyse all the interviews. Early findings were then fed back for discussion with research participants and stakeholders representing all the roles included in the study at workshop events. This enabled researchers to identify gaps and understand priorities for applying these findings to practice.

Finally, the study findings were shared with people interested in developing peer worker roles in NHS and voluntary sector mental health services at an end of study conference with speakers including NHS strategic managers, peer workers, mental

health nursing and voluntary sector peer-led service leads alongside the researchers.

The way co-production worked to produce new knowledge in our study is the topic of an independent study currently being undertaken by Kati Turner. However the impacts for us were obvious. The place of people working from lived experience alongside voluntary sector and NHS service leads, academics and clinicians in our team mirrored the culture that the services we were researching were aiming to achieve. This helped people to engage with our research.

Interviewees spoke to us from the heart, recognising our understanding of the topic, as we worked from our own lived experience. We were well equipped and supported to deal with complex issues like negotiating roles, boundaries, confidentiality and the costs of and blessings of working from lived experience in mental health. Our experience as service user researchers was also useful in supporting other service users involved in the PEER Group, research team, steering group and as participants in interviews, the feedback workshops and conference.

Co-producing this research about services where people work from multiple perspectives made us aware of the risks of imposing any single research perspective on the people we interviewed. As we honoured multiple perspectives in our research team this led naturally to multiple perspectives being honoured in the research settings and findings. This should give our findings greater relevance to the real life contexts of introducing peer worker roles into mental health services.

www.peerworker.sgul.ac.uk

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¹ This research was led from St George’s, University of London with a number of university, NHS and voluntary sector partners. The project was funded by the National Institute for Health Research (NIHR) and ran from July 2011 to May 2013.

Public involvement/ participation/engagement in research

By Maryrose Tarpey

INVOLVE advisory Group members met for a two-day symposium at the end of September and one of the many discussions we had was about the confusion language can create, for example what we mean when we use the terms ‘public’ ‘involvement’, ‘engagement’ and ‘participation’ in research and how others may have a different understanding for the same words. This was also raised in our recent webinar on public involvement in social care research. So quoting from our Briefing notes for researchers (Briefing note two – www.invo.org.uk/posttypereource/what-is-public-involvement-in-research/) we thought we would reprint what INVOLVE means when we say:

“Public involvement in research”

We define public involvement in research as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants.

When using the term ‘public’ INVOLVE include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

What public involvement in research is not

Researchers and others use different words to describe public involvement, such as engagement and participation. When INVOLVE uses the term ‘public involvement’ we are not referring to researchers raising awareness of research, sharing knowledge or engaging and

creating a dialogue with the public. We are also not referring to the recruitment of patients or members of the public as participants in research. However, these different activities – involvement, engagement and participation – are often linked and although they are distinct can complement each other. For example, the public can and do play a valuable role in advising on recruitment of patients as participants and on ways of engaging with the public. INVOLVE uses the following terms to distinguish between the different activities:

Involvement – where members of the public are **actively** involved in research projects and in research organisations. Examples of public involvement are:

- as joint grant holders or co-applicants on a research project
- involvement in identifying research priorities
- commenting and developing patient information leaflets or other research materials
- undertaking interviews with research participants
- user and/or carer researchers carrying out the research.

Participation – where people take part in a research study. Examples of participation are:

- people being recruited to a clinical trial or other research study to take part in the research
- completing a questionnaire or participating in a focus group as part of a research study.

Engagement – where information and knowledge about research is provided and disseminated. Examples of engagement are:

- science festivals open to the public with debates and discussions on research
- open day at a research centre where members of the public are invited to find out about research
- raising awareness of research through media such as television programmes, newspapers and social media
- dissemination to research participants, colleagues or members of the public on the findings of a study.

noticeboard

This is a regular column which can be used to advertise events, initiatives and publications about public involvement in research and development. If you would like to put an item on our noticeboard please contact the Coordinating Centre.

The Value of Working Together in Health Research

The North West People in Research Forum is holding a one-day free event 'The Value of Working Together in Health Research' in Manchester on 9 December 2013. The event will look at the benefits of patients, the public, carers, health professionals and researchers researching together and the different values that people bring to this process. It aims to identify ways to improve the process of working together in health research across the North West. Speakers include Dr Katherine Froggatt (Lancaster University), Professor Ann Jacoby (Liverpool University), Professor Carrol Gamble (Liverpool University) and Dr Philip Bell. The day will be facilitated by Derek Stewart, OBE. In the afternoon people will discuss their own experiences in small groups to explore the benefits and challenges of working together in health research and how working together is viewed from different perspectives. The event aims to ensure an equal spread of members of the public, patients, carers, researchers and health professionals. There is a small budget for travel expenses for non-professionals who might not otherwise be able to attend.

For further information contact the North West People in Research Forum Facilitator:
melanie.chapman@researchnorthwest.nhs.uk

Making sure the voice of patients and carers is heard in primary care research

Are you a patient, carer or member of the public who has been involved in **primary care research** or a member of staff who has supported involvement? If so, we want to hear from you! We know that patients, carers and the public are involved in many different aspects of primary care research. Sometimes this works well, other times the work is not always shared and celebrated to promote more involvement. We want to learn from examples that have worked well, and where there have been problems so

that we can develop new resources to make sure that patients' and carers' voices are heard in all future primary care research. We are looking for examples and case studies of experiences and impacts both positive and challenging. Examples can relate to any aspect of primary care research including: setting the strategic direction for research, identifying research priorities, designing research, overseeing the progress of research and helping to disseminate findings of research. If you have an example to share, or know of someone who does, please send details to Maryrose Tarpey at the INVOLVE Coordinating Centre: mtarpey@invo.org.uk

Friendly disclaimer: The views expressed in this newsletter and in any enclosures are those of the authors and not necessarily those of INVOLVE or the National Institute for Health Research. Articles are selected for the sole purpose of stimulating ideas and debate on public involvement in research.

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INVOLVE is a national advisory body funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research and development. If you would like to receive a copy of the newsletter or find out more about INVOLVE please do contact us.

