

newsletter

Welcome to our Autumn newsletter, which focuses on the theme of impact. It includes a range of articles from different perspectives – and we are delighted to be able to tell you about our new report ‘Exploring Impact: public involvement in NHS, public health and social care research’. The discussions and debate on the impact of public involvement in research will be continued at our 2010 Conference and we look forward to seeing you all there.

What difference does it make?

Many of us have asked this question of public involvement, wanting to know what the research evidence actually tells us. For the first time, evidence of the impact of public involvement on all types of health and social care research has been brought together into a single report, – Exploring Impact: Public involvement in NHS, public health and social care research. This report was commissioned by INVOLVE and written by **Kristina Staley from TwoCan Associates**, who comments on the work:

Gathering and interpreting the evidence has been an enormous challenge. Not only does everyone use different definitions [Continued →](#)

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Kristina Staley, TwoCan Associates

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of involvement and different terms to describe 'the public', but there is also a huge variation in the way people assess and report on impact. Most often researchers and the members of the public involved simply reflect on 'what it was like for them'. Occasionally, involvement undergoes a more formal evaluation. But the quality of the methods doesn't always guarantee the quality of the evidence. Some studies of involvement have proved inconclusive because they haven't allowed for the complexity of the process. Sometimes the simplest anecdotal evidence is the most convincing and the most powerful.

Because of these challenges, we haven't tried to judge the quality of the evidence. Nor have we tried to draw any conclusions about 'what works best' in terms of involvement. We have simply reported what is present in the literature. However, when brought together and considered as a whole, the evidence becomes much more compelling and convincing. In spite of all the variation, some strong and consistent themes have emerged. These include:

- public involvement has helped to boost recruitment to all types of research
- public involvement has had a major impact in qualitative research where participants are asked to share their views and experiences
- public involvement has been particularly valuable in clinical trials where it helped to improve trial design and ensured the use of relevant outcome measures
- public involvement has most often been reported to benefit the people involved and the research participants.

Many people will be familiar with the theory and discussions of how public involvement can potentially benefit research. For the first time,

this report describes in detail what difference it has actually made in practice. Because public involvement is a complex, social process, often its impact can only be fully understood with some knowledge of the background and context. For this reason, much of the evidence has been written up as case studies. These case studies provide vivid accounts of what actually changed in a project – and the consequences for the research, the researchers, the people involved and the wider community.

Importantly, this review has also identified where involvement has had a negative impact. Most often this has been a negative impact on the researchers and the people involved. Occasionally involvement has limited the quality of data collection. Such impacts have been overlooked in the past, because of the historical need to promote public involvement. However, it is essential that this evidence is captured and reported as it helps us learn how to maximise the benefits and minimise the problems.

Perhaps one of the most important contributions this report will make is to help us be clearer as to what evidence is still needed. Now that we have a clearer idea as to what is already out there, we can begin to identify the strengths and weaknesses of the evidence base, and consider how best to fill the gaps. An important first step will be to think about how best to report on impact. Researchers would benefit from some guidance as to which aspects of involvement need to be evaluated and how best to report on impact in journal articles and reports.

However it is likely that everyone who reads this report will have a different view as to which aspects are the most significant or the most convincing – as this will very much depend on their experience, questions and expectations.

We hope it will be of value to many different audiences – convincing the sceptics, motivating and inspiring the people who are about to get started, and supporting and encouraging those who are already active.

The full report and the summary are available to download from the publications section of the INVOLVE website:

www.invo.org.uk/All_Publications.asp

Hard copies are available from the Coordinating Centre; email: admin@invo.org.uk or telephone: 02380 651088.

INVOLVE Coordinating Centre News



INVOLVE Conference 2010

A date for your diary! Our next INVOLVE conference will be held on **November 16th and 17th 2010** at East Midlands Conference Centre, Nottingham. Visit our website and sign up for email alerts to make sure you hear about our call for presentations, which will be out during January 2010. www.invo.org.uk



INVOLVE Training Database

Would you like to find out who is providing training on public involvement in research? Visit our simple online database containing searchable information about training providers and the areas they specialise in. The information on the database is provided by the individual trainers. There are some useful tips to help you decide on your training needs, planning your

training programme and links to other resources. You can visit the training pages on our website at www.invo.org.uk/Training.asp If you are a training provider and you would like your details to appear on the training database, you can add them through the website or by sending your details to INVOLVE in hard copy. Information on our criteria for inclusion and code of conduct is posted at www.invo.org.uk/Add_Trainer.asp#Add



Payment for involvement – guidance agreed

INVOLVE has worked with the Department of Health and the NIHR research programmes to agree guidance for the payment of members of the public involved in their work. The guidance reflects the wide variation in the size of tasks such as attending/contributing to committee meetings and peer reviewing research grant applications. It can be downloaded from the publications section of the INVOLVE website: www.invo.org.uk/All_Publications.asp



Exploring Impact: Public involvement in NHS, public health and social care research

Have you ordered your copy of the report highlighted on the front page of this newsletter? Please do contact us if you would like further copies of the report, a newsletter article on the findings of the report or some text to go on your website. Email: admin@invo.org.uk



Noticeboard

Thanks to everyone who sent in articles to contribute to this edition of the newsletter, we had a fantastic response. In order to publish as many as possible, we have removed the Noticeboard for this edition – but it will be back next time, so please keep sending in details of your events and activities!

Interesting articles and publications

- **Reflections on engaging in participatory research**

Valerie Hall

Evidence based Midwifery 2009 volume 7 (2)
pages 40-45

This paper describes the recent growth of service user or public involvement in health research and aligns it to the emergence of a new paradigm that provides a framework to underpin this type of participatory research.

- **Getting back into the world – Reflections on lived experiences of recovery**

Sarah Ajayi, Julie Billsborough, Terry Bowyer, Pippa Brown, Alice Hicks, John Larsen, Peter Mailey, Ruth Sayers, Roger Smith (2009)

Rethink recovery series: volume 2

This report focuses on the experiences and perspectives of people facing the challenge of recovering from mental illness. Rethink's research team worked in partnership with seven people with personal experience of mental health problems and treatment, who interviewed 48 people with similar experiences across England. A copy of the report is free to download from www.rethink.org./intotheworld

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

Involving consumers in primary care research keeps you grounded

By Jane Stewart and Alison Steel, NHS Nottinghamshire County PCT

We made our first moves to develop consumer involvement in primary care research in 2005. We were funded by Nottingham Primary Care Research Partnership, a newly developed group of research active general practitioners. Rather than trying to recruit people who were interested in research around specific health issues such as diabetes or mental health, we thought that developing a group of consumers who were interested in health research more generally would work better for us as we worked across a wide variety of health issues.

A feature of Nottingham Primary Care Research Partnership is that researchers based in NHS primary care worked with academic GPs from the Division of Primary Care at the University of Nottingham.

We made some important decisions when we started this work. We worked with a local research active service user group to help us develop the way we approached consumer involvement. Working with this group made us realise that we could collaborate with consumers in more aspects of research work than we first thought – and this was the first impact we noticed.

Secondly, we applied for and got funding from Trent Research and Development Unit to allow us to carry out an evaluation undertaken by a consumer. This has meant that we were able to

document the impact consumer involvement had on the research undertaken by the Partnership.

Developing the consumer involvement group was very much a shared learning experience. The consumers gained a better understanding of research and the research cycle, and the researchers started to identify the benefits offered by a lay perspective.

A number of research studies were in their set up phase and we quickly saw some of these benefits coming through, as consumers re-drafted study letters and information leaflets, which greatly improved the readability of the documents. We have seen this consistently over a number of studies now.

Consumers have been involved in working with researchers in developing bids for research funding. Often applicants have to get specialised knowledge across to funders to justify why the research is important. Involving a consumer helps to make sure that ideas from specialised areas make sense to people without this knowledge. Having a group of consumers with an understanding of research means we have people on hand who are able to work with us and importantly can respond quickly as there is usually very short notice between a call for bids and dates for submission.

We have worked with consumers in large multi centre randomised controlled trials, and smaller qualitative studies. In one qualitative study we were able to work with consumers from the development stage; they were co-applicants for the ethics committee and research governance approvals. They suggested that the research design was more complicated than necessary, and they were right, so the study was simplified and was much more manageable. The

consumers felt the standard consent form was too complicated for the target audience and made modifications, which were not challenged by the ethics committee – and although we can't prove that this was because the changes were made by consumers, we think it was. The consumers were involved in developing and checking the analysis of the information that was collected through interviews with participants. This helped us to make sure we weren't just thinking about the issue from a professional perspective.

Sometimes it was difficult to see how we could involve consumers in some of the work that was undertaken. This was particularly the case for work that involved detailed statistical analysis of large complicated data sets. Here though consumers were able to work with us to help us start to think about the meaning of the results, so we identified that health outcomes for some groups of people were worse than for others, and the consumers were able to suggest reasons why this might be the case and we just would not have thought of these ourselves.

Some of the first large studies that consumers were involved in are now reaching completion, and consumers have been able to suggest ways of disseminating the findings, identifying local people working within the NHS that should be invited to a feedback meeting. Consumers have identified practical implications of getting successful interventions into practice.

The benefits of researchers being sited in NHS Primary Care Trusts (PCTs) has been recognised more than once during the course of our work. Researchers and consumers have links to PCT issues that may not be available to university based researchers. It gives us the opportunity to tap into existing [Continued →](#)

service user or carer groups within the PCT, to help us identify people we can ask if they would like to be involved in specific pieces of work. Researchers are more likely to be familiar with the current focus of the PCT's work. The positive impact of consumer involvement in primary care research is recognised amongst academics working in Primary Care Research in Nottingham and the researchers based in NHS Nottinghamshire County (PCT).

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Jane Stewart at jane.stewart@nottspct.nhs.uk

Being involved: the impact on individuals

By Gwen Harlow and Carolyn Morris, service user researchers

Work on impact to date has primarily looked at the difference involvement has made to research or to services. Far less focus has been on what it is like for those who become involved. That's what we wanted to look at: the benefits of being involved, the drawbacks, the motivations that drew people in, what keeps them involved, the skills and qualities they're using.

We are two consumer/service user researchers, active in cancer service improvement and research groups, and both with degrees in psychology. We worked as part of a research team and aimed to generate a more widely shared understanding of the benefits, and the barriers, that involved people experience. Our work was funded by Macmillan Cancer Support's User-Led Research competition. Our involvement as service user researchers ran from design through to dissemination.

Our participants were 64 service users involved in local, regional and national cancer research, cancer service and palliative care user groups, including some in hospices. We collected our data through focus groups, supplemented by individual interviews and a handful of questionnaires. We recorded sessions and analysed data together with a career researcher.

We heard that people's reasons for becoming involved are complex. We heard about payback for good treatment and about turning a negative experience of treatment into something constructive:

“ Something good out of something bad.”

A desire to join with others to change things for the better, to shape new and more appropriate treatment and research for others was another, common motivation:

“ I was excited about this chance to feed back the experiences of my parents' illnesses and hopefully make a difference for patients that will follow on from here.”

Once people had become involved, other factors came into play e.g. finding a role or something to replace former working lives:

“ You do feel worthless if you can't go back to work after treatment and you feel like you've been thrown on the scrap heap. This is an opportunity to give some of your skills from your working life.”

Some found that they gained new skills, new friendships and support. For some it was even a survival technique:

“ And then, it was a funny kind of almost like a superstition. I felt that, it sounds daft, but I felt that if I actually gave something back and helped other people it would somehow have

made a deal that my cancer wouldn't come back... It's quite nonsensical I know but it was a very, very strong sort of thought."

Being involved had often given back the confidence lost during illness. New skills had been learnt, and a sense of achievement gained from seeing the results of their suggestions and interventions:

"It has given me a sense of purpose. Has been a distraction and widened my horizons after having them shut down during cancer treatment."

"Life didn't stop or change: it grew."

"My self-esteem is greater. It does give me a buzz to think I can be of some help even though I'm not clinically trained or anything like that. I'm just using my experience for a positive."

"I think I've learnt to put other people forward... If you are going to help other people you've got to give them a belief in themselves and a hope for the future. And I think that's a skill, which possibly I didn't have to use before...this is empowering people."

"I have learnt how to set a website up and how to maintain a website. So I am getting skills, otherwise your brain goes dead."

Not everyone felt the skills and qualities they bring to their involvement are always recognised:

"I am more than my disease!"

The user groups we spoke with were most definitely not support groups, but we found a sense of closeness, camaraderie:

"It isn't a support group but my God it's a support group!" (laughter).

"We share something very significant. We've either personally looked death in the face or seen it for somebody that we love. So that does bring you together."



One of the focus groups

There were some drawbacks associated with being involved. For example there were unclear roles and expectations:

"It can be incredibly difficult to just find out what it is you're supposed to do, what people expect of you, you know, because there's no, there's no, no written in stone job roles."

Some service users feel undervalued and marginalised. Tokenism and negative perceptions – 'the usual suspects' – are still experienced. Frustrations were voiced about the pace of change and about lack of feedback: people often didn't know if they were having any impact.

There were personal downsides too. Fatigue, the sheer volume of work, time and travel were issues:

"I sometimes feel really bogged down with paperwork. You know we do get a lot of stuff and because I'm not well you want to try and do everything and help and sometimes I feel bad saying 'I can't do that.'"

Some found emotional exposure hard – losing people they'd become close to. Some found that information gained from being involved could contribute to stress:

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“ I was not fully prepared for the impact of the very wide amount of information, much of which is not very cheerful, in a situation which is already stressful.”

But we must also say involvement could be fun. Our transcripts record a lot of laughter.

When we analysed our findings we saw implications for recruitment, for retention, for making involvement work better for everyone. So we've made some recommendations in our report, to be published in full later this year. The report will be launched at the NCRI conference in October 2009 and is available to download at: www.southampton.ac.uk/mru/research/service_user/index.html

The voices of our participants sing loudly throughout; many thanks to them.

By Gwen Harlow and Carolyn Morris, on behalf of the research team: Phil Cotterell, Peter Beresford, Bec Hanley, Anita Sargeant, John Sitzia, and Kristina Staley.

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Deadline for contributions for our next newsletter: **21st December 2009**

If you have any questions about contributing to the newsletter, please contact Helen Hayes Tel: 023 8065 1088
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The personal impact of public involvement in research

Written by a member of the Research Users' Group (RUG) at the Arthritis Research Campaign National Primary Care Centre at Keele University.

I became involved with the Arthritis Research Campaign National Primary Care Centre at Keele University about seven years ago. I was invited by my GP to participate in a study about long-term chronic pain. I wrote a diary for six months. I enjoyed doing this but it made me realise how much my condition affected my life and my family. I was a part-time phlebotomist at the local hospital, doing a job that I loved. Then at the age of 31, I was struck down with fibromyalgia and have never been able to work since.

As a result of being in the research study, about 18 months ago, I was invited to join a Research Users' Group (RUG) at the Centre. This group was set up to assist researchers in the research process and to focus on how research can contribute to improving primary care and people's quality of life. All of the members of the RUG have a musculoskeletal condition. We discuss new projects before funding and different methods of getting the information from patients. Patients have been involved in reviewing leaflets, questionnaires, giving presentations and are co applicants on grant applications.

The Centre was shortlisted to become the Arthritis Research Campaign (arc) National Primary Care Centre. Myself and two other RUG members were asked to meet the arc

panel. We gave an outline of how involved we are. It was a nerve racking experience. They asked us questions but their reaction was very positive. At the end of the visit, the reviewers described us as 'inspirational'. We were later informed that the Centre's application had been successful.

It is so amazing and is hard to believe that people are interested in what we have to say about our experiences. When I first joined the RUG I was very quiet. Because I had not worked for so long, it is amazing how your confidence suffers. I also found it hard being in a group to speak and give my opinions. I have to say that the more I became involved, the more my confidence grew and I realised that I did have something to say and that people would listen to me.

I was asked if I would like to go to London as a lay representative for a back pain research project. There were 13 of us altogether. I was very daunted but everyone made me feel very welcome. I was very unsure what would happen next. We arrived at the hotel and were ushered into a room with a large table and about 12 people sitting on one side. In turn each member of our group spoke. Then, it was my turn! I was asked how I became involved. My heart was beating so fast as I was nervous. I thought I would open my mouth and nothing would come out. But, to my surprise, I was fine and answered all of their questions.

On the way home on the train, I was on such a high. I had not known what to expect and worried why they would want to listen to my opinion and was amazed that they did. Unfortunately, I spent the next two days in bed as I was mentally and physically exhausted. I very often felt this way but I had enjoyed the day immensely. Keele did very well and received the funding to do the

back pain research and I am very proud of my contribution.

I really am enjoying learning all of these new skills and I am beginning to grow in confidence. I never thought that I would be able to talk to a group of people, and now at the RUG I am able to speak with ease and give my opinions without worrying. I also feel far more knowledgeable and that helps immensely. Keele Research Centre are so supportive and they have given me a mentor and I can meet with her at anytime if I have any worries or concerns about my involvement in research.

For further information on the Research Users' Group please contact: Dr Clare Jinks, Senior Lecturer in Health Services Research, Arthritis Research Campaign National Primary Care Centre, Primary Care Sciences, Keele University, Staffordshire ST5 5BG

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Training for NHS service users

An inaugural Spring School for NHS Service Users, organised by the School of Health and Human Sciences at the University of Essex, was a great success. Ten service users from a range of services, including oncology, disability, orthopaedics and mental health, spent a week at the University's Colchester Campus. The event was designed as an introduction to the principles of research, from reading through published research papers to understanding research that draws on survey materials (i.e. quantitative research) and interview materials (i.e. qualitative research). The content was related to issues of health, and the very practical implications of how research

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impacts upon understandings of health were fully explored throughout the week. Service users learnt about research processes in healthcare contexts, with particular emphasis on how they, as service users, could be meaningfully and centrally involved.

In future years, the Spring School will look to spend more time developing research ideas amongst the participants in conjunction with the research methods training, providing a better balance between study and some more practical components of service user research experiences (allowing service users to identify their own thinking specifically about research in their own areas of interest). In addition, participants have since become actively involved in the Patient and Public Involvement (PPI) group within the NIHR Research Design Service for the East of England, and one participant is interested in becoming a member of an NHS Research Ethics Committee.

As well as the teaching sessions there were additional presentations by representatives of a Mental Health Service User Research Group, who talked about their own experiences as user/researchers; a local NHS Ethics Committee and NHS professionals. All participants were given a Course Certificate at the end of the week.

The event was supported by the National Institute for Health Research Design Service for the East of England and the East of England Strategic Health Authority. The training was provided free of charge. It is anticipated that a similar event for service users in the East of England will run in April 2010. For more information or to be added to a mailing list for the 2010 Spring School, contact Lyn Loaring: email: rdsc@essex.ac.uk or tel: 01206 874 856. Any questions about the content of the course can be addressed to: Ewen Speed: email esspeed@essex.ac.uk

After the fall: Making experience count

By Daphne Westwood, Lay member, Public Involvement in Research Group, Centre for Research in Primary and Community Care (CRIPACC), University of Hertfordshire

My interest in research started at the Annual General Meeting of the local Primary Care Trust. A presentation was given about the formation of the Falls Collaborative, a national initiative involving local authorities, aiming to cut the number of falls in elderly people and the subsequent hospital admissions. As I had experienced falling in the past (it hurt! – and the effects often last for weeks or months) and had two replacement hips, the thought came – “I wonder if anyone on this group has actually fallen?” To cut a very long story short, I joined the committee, learnt a lot and made, I hope, a valued contribution to the activities.

Because of this experience I was asked to join the steering group of a study on falls prevention being undertaken by the Centre for Research in Primary and Community Care (CRIPACC), at the University of Hertfordshire.

Here I discovered more about the research process and methods, including quantitative and qualitative analysis, focus groups, questionnaires etc. But perhaps even more important, the whole research ethos and the people involved. I know that my principal usefulness at these meetings was that I looked at things from a different point of view – from someone who had experienced falls, and as someone for whom the outcomes of the research would affect. Also, I asked ‘awkward’ questions and challenged the use of acronyms.

During this time another exciting initiative was starting – the formation of a group of lay people who were either interested in or already part of research projects with researchers in CRIPACC. I was asked to be involved and we eventually called ourselves the Public Involvement in Research (PIR) group.

Gradually from our combined experiences on various studies it became obvious to both researchers and the lay members that an introduction to research course would be valuable in enabling us to grasp the bigger picture of research – from submitting bids through to disseminating the results. This was developed and the whole course was excellent. I enjoyed it, learnt much and have probably forgotten more!

Much of what we learnt enabled and equipped some of us to take part in a study on the experiences of older people's end of life care in care homes. Here, as older people ourselves, we are working alongside the researchers in the care homes to help explain the study to individuals and to encourage them to become involved. We will also be leading focus groups at the end of the study.

A recent different but very interesting experience has been becoming involved in a study from the very beginning. The idea for the study came about through conversations with some of the CRIPACC researchers about our mutual interests in people socialising and eating together, in which I talked about my experiences of a twice-weekly cafe held at my church. Our ideas crystallised and formed the basis of a pilot project which explores the social and nutritional contribution of community meals. I have been able to facilitate meetings with the organisers of the cafe and worked with the researchers to be present at the first contact between them

and 'those being researched'. I believe it was helpful for me to be at the meeting to add some lay perspectives to the researchers' explanations and to draw out experiences from the church's meals team. This study is in its very early stages and I am looking forward to being more involved, maybe helping with some of the interviews, data collection and analysis, and seeing the findings used for the benefit of community nutrition and social living.

Being a lay member of research studies as a member of CRIPACC's Public Involvement in Research Group for the past four to five years has been, and continues to be, a rewarding, useful and stimulating experience.

Contact: Daphne Westwood, Lay member, Public Involvement in Research Group; CRIPACC, Health and Human Sciences Research Institute, University of Hertfordshire, Hatfield AL10 9AB
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NIHR School for social care research

By Jill Manthorpe and Gill Hastings, the NIHR School for Social Care Research

The National Institute for Health Research (NIHR) School for Social Care Research is a partnership between the London School of Economics and Political Science, King's College London and the Universities of Kent, Manchester and York. The School began work in May 2009 and has five-year funding to conduct and commission research on adult social care practice in England. The School is working with INVOLVE and a key aim is to build on the strong tradition of service user and carer involvement in social care. We are initially going to involve users and carers in three areas: Continued →

1: On the School's Advisory Board, which has both service user and carer representation.

2: A service User, Carer and Practitioner Reference Group has been set up and their first meeting was in July 2009. Members of this group are contributing to the commissioning of research by reviewing research proposals and making recommendations about their relevance, quality and the way they are carried out. They will be asked to comment not only on the extent to which people using services and carers will be involved in the funded studies, but also on the relevance of the research, reimbursement, dissemination and diversity.

3: All studies funded by the School will be expected to include people using services and carers in a number of ways in the research process.

Our research will focus on five key programme areas:

- Prevention and promotion
- Empowerment and safeguarding
- Care and work
- Service interventions, commissioning and change
- Resources and interfaces

Early studies being funded by the School include in-depth work on support for people with profound and complex needs for social care, and research on social care practice with carers when undertaken by specialist 'carers' staff. A recent call for proposals has attracted wide interest. The School will be developing resources on methodological approaches that are relevant to social care research and making them widely available. In this way, researchers will be helped

to improve or update their skills with ideas and evidence. Such resources should also be of use to user and carer researchers who may value the opportunity to learn from other people's experiences.

If you would like to know more about the School's activities, have ideas for research or wish to receive updates, newsletters, research findings, and calls for proposals, please contact: NIHR School for Social Care Research, London School of Economics and Political Science, Houghton Street, London WC2A 2AE.
Tel: 020 7955 6528 Email: sscr@lse.ac.uk
Website: www.lse.ac.uk/collections/NIHRSSCR/Default.htm

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