

# noticeboard

**Autumn 2014**

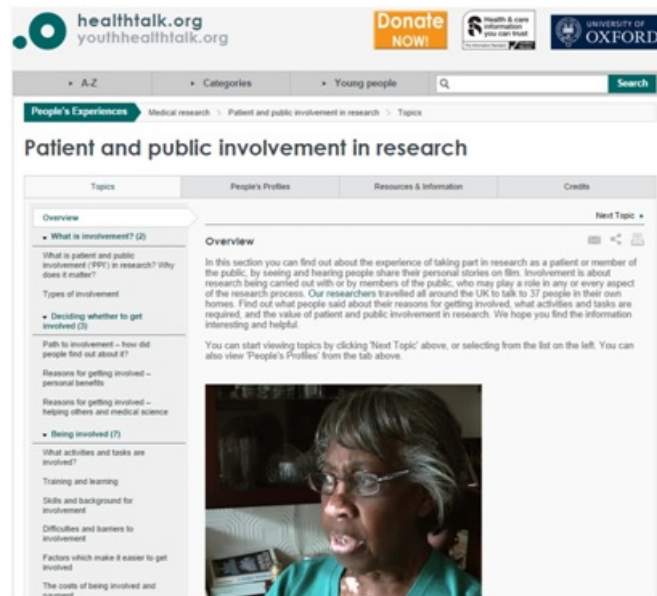
## **Patient and public involvement on healthtalk.org**

healthtalk.org ([www.healthtalk.org](http://www.healthtalk.org)) contains rigorously researched information for patients, carers, and health professionals about patients' experiences of health and illness conditions. The research is conducted by researchers at the University of Oxford. Funded by the National Institute for Health Research (NIHR) Biomedical Research Centre (<http://oxfordbrc.nihr.ac.uk/>), a new section has been launched on the site about patient and public involvement ([www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics](http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics)). It contains interviews with 37 patients and members of the public about their experiences of getting involved in health or medical research.

The project was overseen by a panel of patients, public members, health professionals and academics. After analysis, 22 reports were written on the key findings including how people became involved, why they stayed involved, and debates around payment and capturing the difference involvement makes. All the main points are illustrated by video or audio clips from the interviews, ensuring the patient/public voice is always present. In addition to creating this freely available online resource, other outputs will include several academic publications co-authored by the researchers ([www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/credits](http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/credits)) and public members. The next stage of this project is to find out about

involvement from the researchers' point of view. It will go live on healthtalk.org next year.

**Dr Anne-Marie Boylan, University of Oxford**



The screenshot shows the healthtalk.org website interface. At the top, there are logos for healthtalk.org, youthhealthtalk.org, a 'Donate NOW!' button, and the University of Oxford logo. Below the navigation bar, the page title is 'Patient and public involvement in research'. The main content area is divided into a left sidebar with a table of contents and a main text area. The table of contents includes sections like 'What is involvement? (2)', 'Types of involvement', 'Deciding whether to get involved (2)', 'Path to involvement - how did people find out about it?', 'Reasons for getting involved - personal benefits', 'Reasons for getting involved - helping others and medical science', 'Being involved (7)', 'What activities and tasks are involved?', 'Training and learning', 'Skills and background for involvement', 'Difficulties and barriers to involvement', 'Factors which make it easier to get involved', and 'The costs of being involved and payment'. The main text area has an 'Overview' section with a paragraph explaining the purpose of the site and a video thumbnail showing a woman speaking.

## North West London Hospital NHS Trust Patient Research Forum

North West London Hospital NHS Trust has a well-established Patient Research Forum. Thirty members provide support to researchers for their research applications, working closely with and guiding researchers throughout the process. The group has been actively involved in service and quality improvement projects in the Trust and won first prize for a poster in the Trust's Annual Research Awards. The group is now planning a project to be conducted in the community in North West London. The Collaboration for Leadership in Applied Health Research and Care (CLAHRC) and Academic Health Science Network will be working closely with R&D as this model is being seen as excellent practice. For further information please contact Sunder Chita on 020 8869 5829 or email: [sunderchita@nhs.net](mailto:sunderchita@nhs.net)

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## Summer 2014

### Four Nations Conference report

Involving People and Marie Curie Palliative Care Research Centre Cardiff hosted the Four Nations Conference on 9 May 2014. The day provided an exciting opportunity to share examples of public involvement in health research, with speakers from across the UK. A Conference report has been produced giving an overview of each presentation and workshop, together with a summary of delegate feedback.

[www.wales.nhs.uk/sites3/documents/1023/Four Nations Conference Report May 2014 Final.pdf](http://www.wales.nhs.uk/sites3/documents/1023/Four_Nations_Conference_Report_May_2014_Final.pdf)

### Booklet celebrating 15 years of Alzheimer's Society's Research Network

In 1999 Alzheimer's Society created its pioneering Research Network of people with dementia, carers and former carers. The Research Network has played an active role in setting the dementia research agenda, through the Society's own research programme and in a growing portfolio of research funded elsewhere. Two founding members, Barbara Woodward Carlton and Shirley Nurock, worked with current staff to collect the thoughts of researchers, Research Network volunteers, external organisations and current/former staff to celebrate this landmark anniversary in this new publication.

[www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2261](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2261)

# Research Design Service launch new website

The National Institute for Health Research (NIHR) Research Design Service (RDS) has recently launched its new website ([www.rds.nihr.ac.uk/](http://www.rds.nihr.ac.uk/)). The RDS advises and supports research teams in developing high quality applied health and social care grant applications to NIHR and other national peer-reviewed funding programmes. It does this through a regionally-delivered service across England. The new website includes information on patient and public involvement written for [researchers](http://www.rds.nihr.ac.uk/patient-and-public-involvement/for-researchers/) ([www.rds.nihr.ac.uk/patient-and-public-involvement/for-researchers/](http://www.rds.nihr.ac.uk/patient-and-public-involvement/for-researchers/)) and members of the public ([www.rds.nihr.ac.uk/patient-and-public-involvement/for-patients-and-the-public/](http://www.rds.nihr.ac.uk/patient-and-public-involvement/for-patients-and-the-public/)).

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## Spring 2014

### ‘The value of working together in health research’ event report

A report on ‘The value of working together in health research’ event, held by the North West People in Research Forum on 9 December 2013, is now available on their website: <http://northwestpeopleinresearchforum.org/wp-content/uploads/2014/03/Report-of-Working-Together-Event.pdf>. The event, which was organised by a working group of professionals and members of the public, aimed to identify ways to improve the process of working together towards positive shared outcomes in health research across the North West. The outcomes of the event will inform the North West People in Research Forum Strategy.

Future events will examine key issues raised and support further networking activities.

## **Helping to choose which trials Cancer Research UK funds: a patient's perspective**

Cancer Research UK is a major funder of more than 250 trials into cancer treatments. Decisions about which trials to fund are made by a committee of independent experts and patient representatives. The latter are able to give their views and perspectives on clinical trial applications and help ensure that the trials are practical and that patients' needs are at the centre of decisions. You can read an account of how one of these patient representatives got involved and her experiences of working on the Clinical Trials Advisory and Awards Committee on the Cancer Research UK website: <http://tinyurl.com/map5bzy>

## **Focus on Stroke**

The National Institute for Health Research (NIHR) has launched 'Focus on Stroke' ([www.crn.nihr.ac.uk/focus\\_on/stroke/](http://www.crn.nihr.ac.uk/focus_on/stroke/)), a new online resource aimed at raising public awareness about developments in stroke research. The resource highlights some of the work the NIHR is doing in this area and includes experiences of some people who are living with stroke and contributing to research.

The NIHR encourages members of the public to become actively involved in clinical research, forming a partnership with researchers to improve the relevance and design of studies. Information on ways to get involved with stroke research and the difference that involvement can make can be found on the 'Getting involved' section of the site: [www.crn.nihr.ac.uk/focus\\_on/stroke/getting\\_involved.htm](http://www.crn.nihr.ac.uk/focus_on/stroke/getting_involved.htm)

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## Winter 2013-14

# Preparing for patient and public involvement in research: training for researchers workshop

On 28 February 2014, the University of Salford is holding a full-day workshop on public involvement in research for researchers and research active staff. The facilitator is Dr Tracey Williamson (Research Fellow Public Engagement/User Involvement in Research) and she will be accompanied by Elaine Jones (Lay Researcher). The objectives of the day are to:

- identify good practice principles for successful public involvement in research
- understand the application of involvement principles in research design
- appreciate how to strengthen public involvement aspects of funding applications
- consider the impact of involvement – its ‘measurement’ and how to maximise it
- explore the realities of public involvement – challenges, benefits and difficulties.

For details of costs and other information and to book a place see

[www.salford.ac.uk/spd/coursedetails?courseid=PREPARwiCD&course name=course%20Details](http://www.salford.ac.uk/spd/coursedetails?courseid=PREPARwiCD&course name=course%20Details)

# Round 3 of the NIHR New Media Competition

The National Institute for Health Research (NIHR) has launched Round 3 of their New Media Competition. For the first time they are including two categories: one for researchers and one for patients and the public involved in NIHR research. The competition allows researchers, patients and members of the public involved in research to communicate their research, enthuse audiences, get creative and win prizes. The competition closes at midnight on 30 March 2014. For more information and guidance on how to enter see: [www.nihrtcc.nhs.uk/NIHRNewMediaCompetition/](http://www.nihrtcc.nhs.uk/NIHRNewMediaCompetition/)

## Update: The Public Involvement Impact Assessment Framework

The INVOLVE Autumn 2013 newsletter included an article introducing the Public Involvement Impact Assessment Framework (PiiAF), which has been produced to help researchers assess the impact of public involvement in their research.

Since its launch, the PiiAF website has been improved and is now easier to navigate. It includes a summary of the research on which development of the PiiAF was based as well as a new guidance document.

[www.piaf.org.uk/](http://www.piaf.org.uk/)

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**Autumn 2013**

# 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](mailto: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](mailto:mtarpey@invo.org.uk)

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## Summer 2013

### PURSUN UK

By Delia Muir

The Pressure Ulcer Research Service User Network (PURSUN UK) is a network of service users, patients and carers with personal experience of living with pressure ulcers or being at risk of developing pressure ulcers. Our network aims are:

- to help provide service users, patients and carers with a voice within pressure ulcer research
- to raise awareness of pressure ulcers and improve patient care
- to develop mechanisms which allow service users, patients and carers to be ethically and meaningfully involved in research

- to recognise and develop the skills and expertise of network members.

The network is supported by the Clinical Trials Research Unit at the University of Leeds. We try to offer a variety of involvement activities which build on the existing skills of our members. One example of our work is our involvement in interpreting data from the Severe Pressure Ulcer Project. We ran an innovative workshop which utilised theatre techniques and videos to help make the interpretation process inclusive and engaging for everyone involved. For more information see the videos at <http://youtu.be/bgg6zkbILrg> and [www.invo.org.uk/resource-centre/conference/involve-conference-gallery/](http://www.invo.org.uk/resource-centre/conference/involve-conference-gallery/)

[www.pursun.org.uk](http://www.pursun.org.uk)

## **NIHR Launches Journals Library**

The National Institute for Health Research (NIHR) has launched a new Journals Library, providing full publication and open access to an extensive body of health research. It comprises a suite of five programme-specific journal series, published online, which are fully searchable and provide a comprehensive record of work funded by these NIHR programmes. Building on the success of the existing Health Technology Assessment journal, the library will give accessible full publication of findings of the research commissioned by these programmes and will provide an important permanent and comprehensive record of the work which has been funded.

[www.journalslibrary.nihr.ac.uk/](http://www.journalslibrary.nihr.ac.uk/)

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# Spring 2013

## Be Involved – a new PPI website

South Yorkshire Collaborations in Leadership in Applied Health Research and Care (CLAHRC) have launched an exciting new website designed with a small group of service users and carers.

Visit the website to:

- view a film about why the voice of the public is vital in health research and to the work of CLAHRC for South Yorkshire
- find out how members of the public are working with researchers when they are planning their research
- find out how you can share your experiences and ideas with cutting-edge researchers developing treatments and services within the CLAHRC for South Yorkshire
- find out who was involved in developing the website.

<http://beinvolved-sy.org.uk/>

## Patient, carer and public involvement seminar series

Elaine McNichol from the University of Leeds has received funding from the Higher Education Academy to coordinate a series of five seminars about patient, carer and public involvement in health, education and research. Three seminars have already taken place and the next two are coming up in May and June 2013. A few places are left at each one and there is a waiting list in case of cancellations. If you can't get along in person, there is a collection of web-based resources to catch up on topics, presenters and discussions.

[www.healthcareconferences.leeds.ac.uk/conferences/details.php?id=10](http://www.healthcareconferences.leeds.ac.uk/conferences/details.php?id=10)

## Involvement4Access

A new web resource has been launched to support patients having a say in health research as a treatment choice in their local NHS hospital or health centre. Involvement4Access aims to encourage initiatives that support patients as 'Research Ambassadors' to help improve access to health research in the NHS locally.

The new web resource is the first step in creating a 'community of practice' to support the patient voice for research in the local NHS. It outlines what Involvement4Access is and what you can do locally, supported by hot tips, examples and resources. It also invites you to log your plans or initiative online.

Phase 2 of the web resource will see it becoming increasingly interactive with sharing of local initiatives across the country and the opportunity to interact with the people involved in them as part of a developing community.

[www.crncc.nihr.ac.uk/ppi/why\\_is\\_research\\_important/involvement4access](http://www.crncc.nihr.ac.uk/ppi/why_is_research_important/involvement4access)

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## Winter 2012-13

### Clinical Trials Toolkit

The National Institute for Health Research (NIHR) has launched a new online Clinical Trials (CT) Toolkit. The Toolkit

provides practical advice to researchers in designing and conducting publicly funded clinical trials in the UK. Through the use of an interactive, colour-coded routemap (based on the design of a tube map), the site provides information on best practice and outlines the current legal and practical requirements for conducting clinical trials.

[www.ct-toolkit.ac.uk/home](http://www.ct-toolkit.ac.uk/home)

Professional Development Award: User Involvement in Teaching and Research

UNTRAP (University User Teaching and Research Action Partnership) at Warwick Medical School, University of Warwick is running an accredited training course for service-users, carers, and professionals. The course covers various aspects of user involvement, including teaching, research and committee work in health and social work. It consists of six modules running on six Saturdays over 12 months and the next course starts in Autumn 2013. On completion participants receive a Level 3 or Level 4 'User Involvement in Teaching and Research Professional Development Award' through the Centre for Lifelong Learning at the University of Warwick. For more information, email [untrap@warwick.ac.uk](mailto:untrap@warwick.ac.uk) or phone 024 7652 3164.

[www.warwick.ac.uk/go/untrap](http://www.warwick.ac.uk/go/untrap)

## Autumn 2012

### **NICE Public Health Advisory Committee seeks community members**

The National Institute for Health and Clinical Excellence (NICE) is setting up new Public Health Advisory Committees to develop national guidance on actions to promote

health, prevent ill-health, and reduce inequalities in health between social groups. NICE is seeking applications from members of the public with experience of public health action to join the committees as 'core' community members alongside a small core group of professionals with technical expertise. The 'core' members will work on a range of different public health topics. They will be joined by professional and community 'topic expert' members who will be recruited later in the year and will cover specialist areas such as the health of people in prison or other offender institutions, work and health, oral health, older people's health and needle and syringe programmes.

For information on the skills and experience required for this role, the support available to members and how to apply visit [www.nice.org.uk/getinvolved/joinnwc/LayMemberPHAC.jsp](http://www.nice.org.uk/getinvolved/joinnwc/LayMemberPHAC.jsp)

Closing date for applications: 5pm on 2 November 2012

#### FAST-R service

Feasibility And Support to Timely recruitment for Research (FAST-R) is a national service provided by the South London and South East hub of the Mental Health Research Network (MHRN). FAST-R aids researchers with public involvement, recruitment, regulatory requirements and funding support. It offers researchers across England access to people with experience of mental health problems and their carers, who have been trained to offer advice about patient information sheets, consent forms, recruitment strategies and other protocol materials. All researchers including students and principal investigators working on large multi-centre and industry studies with a mental health focus can apply to use this fast, free and confidential service. To apply to use the service please visit [www.mhrn.info/pages/fast-r-service.html](http://www.mhrn.info/pages/fast-r-service.html)

# Summer 2012

## UK Clinical Trials Gateway survey

The [UK Clinical Trials Gateway \(UKCTG\)](#) provides information for members of the public and clinicians on clinical research trials being carried out in the UK. This information aims to help people to find out about trials that are relevant to their condition and which they may be able to participate in. An online survey is being carried out to find out your views on the Gateway and how best to strengthen and improve the website and the information it provides.

To give your views visit <https://www.surveymonkey.com/s/XK7NTBB> by the end of Tuesday 31 July 2012.

## Engaging patients in research

On 24 May Guardian Online hosted a live Question and Answer session on what are patients' perceptions of research and how can we improve their involvement? Simon Denegri, Chair of INVOLVE, was a member of the panel responding to the questions. You can view comments about the discussion on the [Guardian website](#)

## Information to share or not to share?

An independent panel of experts chaired by Dame Fiona Caldicott is conducting a review of information governance (the principles, processes and legal and ethical responsibilities for managing and handling information).

The review will make recommendations aimed at:

- improving the sharing of personal information to support the care of individuals
- enabling the further use of information more widely to improve health and social care services

- protecting individuals' confidentiality and respecting their wishes in relation to how their information is used.

<http://caldicott2.dh.gov.uk/>

## Spring 2012

### Launch of clinical trials online resources

Insight into the experience of being a child taking part in a clinical trial designed to test new medications or vaccines – as well as the experience of deciding whether to allow your child to participate in such a study – is provided in two new online resources.

Two new sections\* of the experiential health websites, [www.healthtalkonline.org](http://www.healthtalkonline.org) and [www.youthhealthtalk.org](http://www.youthhealthtalk.org), contain interviews with parents and children talking about how they found out about trials, why they decided to take part, or in some cases, decline an invitation to participate, as well as what information they needed and were given and how they felt about the experience.

\*Clinical trials: parents' experiences: [www.healthtalkonline.org/medical\\_research/clinical\\_trials\\_parents](http://www.healthtalkonline.org/medical_research/clinical_trials_parents)

\*Clinical trials in children and young people: [www.youthhealthtalk.org/Clinical\\_trials\\_in\\_children\\_and\\_young\\_people/](http://www.youthhealthtalk.org/Clinical_trials_in_children_and_young_people/)

### New accessibility resource

The Social Care Institute for Excellence (SCIE) has launched a new online resource for anyone who is organising an event and wants to make it accessible and inclusive. The resource is



based directly on the views and experiences of people who use services and is split into three main sections:

- choosing a venue
- planning the event
- the event.

[www.scie.org.uk/publications/accessibleevents/index.asp](http://www.scie.org.uk/publications/accessibleevents/index.asp)

‘Research People’ videos

The National Institute for Health Research (NIHR) Clinical Research Network has developed a series of short videos to increase understanding of the range of people involved in NHS-based research, what they do and how this benefits treatments and services.

[www.crncc.nihr.ac.uk/about\\_us/research\\_people/](http://www.crncc.nihr.ac.uk/about_us/research_people/)

## Winter 2011/12

Launch of International Collaboration for Participatory Health Research (ICPHR) website

The ICPHR was established in 2009 to strengthen the role of participatory health research in intervention design and decision-making on health issues. It is open to stakeholders from all countries interested in promoting the dissemination and further development of participatory health research approaches. The ICPHR carries out its work through three cross-cultural, multinational Action Groups. Learn more about the work of the Collaboration, find out how you can get involved with the Action Groups, and sign up for the quarterly newsletter by visiting the new website: [www.icphr.org](http://www.icphr.org)

New Wellcome Trust Sanger Institute survey

A new online survey has just been launched by an ethics team

from the Wellcome Trust Sanger Institute to capture public attitudes to sharing genomic results. They hope it will be the largest collection of opinions gathered to date.

Details of the survey project can be found in the press release at [www.sanger.ac.uk/about/press/2012/120131.html](http://www.sanger.ac.uk/about/press/2012/120131.html) . The survey itself can be accessed at [www.genomethics.org](http://www.genomethics.org)

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## **Interesting articles and publications**

### **Activity and views of service users involved in mental health research: UK survey**

S Patterson, J Trite and T Weaver. British Journal of Psychiatry, July 2014, 205 (1), 68-75

This article reports on the findings from a survey of service users involved in mental health research in the UK. The respondents included a range of people, from employed researchers through to volunteer service user representatives. The respondents reported that their involvement had a positive impact on the quality of research. In particular, they had helped identify topics and research questions, and contributed to research design. When involved in data collection, service users highlighted being able to reach 'hard to reach' groups and increasing the quality of information obtained in interviews and focus groups by ensuring participants 'felt understood'. More generally, they felt their presence

challenged academics to consider alternate worldviews. The majority of respondents found their involvement to be very positive, providing them with a sense of purpose and belonging, and enhancing their self-respect. However, a small minority felt involvement had a negative impact on their mental health. This was due to the pressure of work, exposure to distressing material or an experience of workplace conflict.

[www.ncbi.nlm.nih.gov/pubmed/24723628](http://www.ncbi.nlm.nih.gov/pubmed/24723628)

## **Learning from people with long-term conditions: new insights for governance in primary care**

F Ross, P Smith, R Byng, S Christian, H Allan, L Price and S Brearley. *Health and Social Care in the Community*, July 2014, 22 (4), 405-416

The authors report on the findings from a study of the governance of primary care. The aim was to find out how health professionals are managing the complex demands of centrally imposed changes to governance of health care (eg practice based commissioning) at the same time as greater emphasis is being placed on patient and public involvement. The researchers worked with service users at a national and local level and describe the difference that this made. The service user involvement added value by:

- validating understandings of governance, in particular how governance relates to the individual professional's emotional and practical experience of delivering care to service users;
- keeping the project focused on the issues that matter to service users;
- providing different perspectives that helped to open up

- discussions about governance at a local level;
- and helping to disseminate the findings locally.

[www.ncbi.nlm.nih.gov/pubmed/24612289](http://www.ncbi.nlm.nih.gov/pubmed/24612289)

## **Patient involvement in research programming and implementation: A responsive evaluation of the Dialogue Model for research agenda setting**

T Abma, C Pittens, M Visse, J Elberse and J Broerse. Health Expectations, May 2014, epublication ahead of print

The Dialogue Model involves multiple stakeholders in identifying and prioritising research questions. It was developed and is now used in the Netherlands. This study followed up nine different agenda-setting projects to see whether there was any subsequent impact on research programmes and funding. Fifty-four different stakeholders including patients, researchers and funding agencies were interviewed, and three focus groups were held to discuss the findings. The study found very limited impact of agenda setting on subsequent research. A wide range of factors had an influence. Firstly, commissioners of agenda-setting projects did not always consider what they wanted to do with the patient priorities, nor did patient involvement continue in the following stages. When researchers were involved in the agenda-setting process, there was a greater chance of the research priorities being adopted. Timing was a problem when priorities were set after deadlines for funding applications. Researchers may also need support and resources to develop new research areas in line with the patients' agenda. These issues need to be considered at the start of agenda-setting projects, to ensure that the exercise is meaningful.

# **Patient and public involvement in research and the Cancer Experiences Collaborative: Benefits and challenges**

K Froggatt, N Preston, M Turner and C Kerr. *BMJ Supportive & Palliative Care*, April 2014

This article reports on the experiences of eight people affected by cancer who were involved in supportive and palliative care research over a period of six years. Their views on the benefits and challenges of involvement were obtained by semi-structured interviews. The main benefits were reported as making a difference to the research and gaining personally from new knowledge, skills, increased confidence and personal support. The challenges included the emotional demands of the work that came from revisiting personal experiences, as well as practical issues, such as demands on people's time and researchers' use of complex, technical language. The service users also stated that they would like a clearer understanding of the long-term impact of their involvement on the projects.

<http://spcare.bmj.com/content/early/2014/04/11/bmjspcare-2013-000548.abstract>

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**[From previous Newsletters:](#)**

**Summer 2014**

## **Enhancing public involvement in assistive technology design research**

Tracey Williamson, Laurence Kenney, Anthony T Barker, Glen Cooper, Tim Good, Jamie Healey, Ben Heller, David Howard, Martin Matthews, Sarah Prenton, Julia Ryan and Christine Smith. *Disability and Rehabilitation Assistive Technology*, April 2014, epublication ahead of print

This article reports on the findings from a within-project evaluation of patient involvement in the development of a new mobility aid. The researchers established a lay advisory group who were supported by a public involvement lead. The researchers attended an initial workshop to prepare them for working with the group. The practical details around setting up and supporting the group throughout the project are described in detail. The researchers report positive benefits in terms of improvements to the new device, making it more likely to be useful to patients, as well as improvements to the design of the subsequent clinical trial. This was thought to lead to better recruitment and retention of trial participants. The researchers' attitudes to involvement became more positive after witnessing its potential first-hand. The patients involved reported improved confidence, skills and self-esteem and valued being able to contribute to the care of others.

<http://informahealthcare.com/doi/abs/10.3109/17483107.2014.908247>

**Involving Patients in Research:**

# Considering Good Practice

R Goberman-Hill, A Burston, E Clark, E Johnson, S Nolan, V Wells, L Betts and PEP-R

Musculoskeletal Care, December 2013, volume 11, issue 4, pages 187–90

This open access editorial highlights some current practice and guidance on involving patients in research. The authors also reflect on the impact of patient involvement activity at the Musculoskeletal Research Unit in Bristol. They seek to involve patients in research design and conduct through a patient forum: Patient Experience Partnership in Research (PEP-R). PEP-R sessions are interactive, training and support is provided, and patients are compensated for their time and travel expenses. The authors asked patients and researchers to complete a questionnaire to evaluate the impact of patient involvement. Patients described their interest and learning about the topics and research in general, and how they valued feedback on their input. Researchers identified the benefits of patients' views on the importance, relevance and feasibility of projects and stressed the importance of early involvement. PEP-R has been supported by the National Institute for Health Research.

<http://onlinelibrary.wiley.com/doi/10.1002/msc.1060/pdf>

## **Patient and public involvement: how much do we spend and what are the benefits?**

Elena Pizzo, Cathal Doyle, Rachel Matthews and James Barlow  
Health Expectations, April 2014, epublication ahead of print

The aim of this literature review was to assess the potential benefits and costs of involvement and the challenges in carrying out an economic evaluation of patient and public

involvement (PPI). The authors found that the benefits of PPI include effects on the design and development of research and new services, on NHS governance and on citizenship and equity but that very few studies have assessed the economic impact. They have developed a framework to help identify the costs associated with PPI, including hidden ones, such as the cost to patients. They suggest that greater clarity about the costs and benefits of different approaches will help make a business case for PPI.

<http://onlinelibrary.wiley.com/doi/10.1111/hex.12204/pdf>

## **Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research: a modified Delphi study**

D Snape, J Kirkham, N Britten, K Froggatt, F Gradinger, F Lobban, J Popay, K Wyatt and A Jacoby. *BMJ Open*, May 2014, volume 4, issue 6

This Delphi study aimed to explore areas of consensus and conflict in relation to perceived barriers and drivers to public involvement (PI), perceived impacts of PI and ways of evaluating PI in health and social care research. The authors found high levels of consensus about the most important barriers and drivers and an acknowledgement that tokenism in public involvement was common. They found strong support for the view that tokenistic practice makes it difficult to demonstrate the impact and value of PI as well as clear support for the importance of evaluating impact. Research team cohesion and appropriate resources were considered essential elements for effective public involvement. The study findings have been used in the development of the Public Involvement Impact Assessment Framework (PiiAF) <http://piaaf.org.uk/> .



**Spring 2014**

## **Patient and Public Involvement in Your Research**

R Pandya-Wood and A Robinson in D-M Walker (2014) An Introduction to Health Services Research: A Practical Guide. London: SAGE. ISBN: 9781446247396 (paperback), 9781446247389 (hardback).

A new book has been published containing a chapter on public involvement in health services research. This chapter, which is about helping to plan appropriate involvement for the research being developed, guides readers through the theory and practice of patient and public involvement. Practical strategies are offered, helping researchers to consider why involvement is needed; who to involve and how to find them; how to involve and what tasks to involve people in; and at what points in the research journey to involve them. A real-life case study about survivors of head and neck cancers is used throughout the chapter to illustrate the theory into practice link. The chapter also offers some insights into reward and recognition of people's involvement; the challenges of involving patients and the public together; and the impact of patient and public involvement.

## **Adding SUGAR: Service User and Carer Collaboration in Mental**

# Health Nursing Research

Alan Simpson, Julia Jones, Sally Barlow, Leonie Cox, and Service User and Carer Group Advising on Research (SUGAR). Journal of Psychosocial Nursing and Mental Health Services, January 2014, volume 52, issue 1, pages 22-30

Service User and Carer Group Advising on Research (SUGAR) is an initiative that has been established to develop collaborative working in mental health nursing research among mental health service users, carers, researchers and practitioners at City University, London. This article, written by staff and members of SUGAR, describes its background, how it operates and some achievements to date. It includes researcher reflections and case studies of how the collaboration is influencing research. The article identifies the benefits and possible limitations of the collaboration, outlines future plans, and considers the findings in relation to literature on involvement and empowerment.

<http://tinyurl.com/p7ojxna>

## Consumer involvement in health research: a UK scoping and survey

Elsbeth Mathie, Patricia Wilson, Fiona Poland, Elaine McNeilly, Amanda Howe, Sophie Staniszezwska, Marion Cowe, Diane Munday and Claire Goodman. International Journal of Consumer Studies, January 2014, volume 38, issue 1, pages 35-44

This paper adds to the international evidence base on patient and public involvement (PPI) in research by providing an overview of current trends and impacts. The authors carried out a scoping exercise and survey of selected UK studies in order to understand the current extent and variation of PPI in research. They selected six research topic areas (cystic fibrosis, diabetes, arthritis, dementia, intellectual and

developmental disabilities, and public health) and contacted a total of 838 study authors. Key findings from the scoping exercise and survey include: steering committee membership and reviewing patient information leaflets are the most common PPI activities; there appears to be some blurred roles with patients participating as research subjects as well as carrying out PPI activities; and there is a limited amount of available information about PPI in publicly accessible research documents.

<http://onlinelibrary.wiley.com/doi/10.1111/ijcs.12072/full>

## **Values associated with public involvement in health and social care research: a narrative review**

Felix Gradinger, Nicky Britten, Katrina Wyatt, Katherine Froggatt, Andy Gibson, Ann Jacoby, Fiona Lobban, Debbie Mayes, Dee Snape, Tim Rawcliffe and Jennie Popay. *Health Expectations*, December 2013, epublication ahead of print

This narrative review is part of a larger Medical Research Council (MRC) funded study that is producing a framework and related guidance on assessing the impact of public involvement (PI) in health and social care research. This review aimed to identify and characterise the range of values associated with PI that are central elements of the framework. The authors undertook a review and narrative synthesis of diverse literatures of PI in health and social care research and identified three overarching systems/values. The first of these is concerned with ethical and political issues; the second with the consequences of PI in research; and the third with the conduct of PI in research. The authors recommend that research teams should consider and make explicit the values they attach to PI in research and discuss ways in which potential tensions may be managed in order to maximise the

benefits for researchers, lay experts and the research itself.

<http://onlinelibrary.wiley.com/doi/10.1111/hex.12158/full>

## **Social care scoping reviews and methods reviews**

Over the past couple of years, the National Institute for Health Research (NIHR) School for Social Care Research (SSCR) has published a number of scoping reviews and methods reviews. The five scoping reviews, which systematically evaluate the current literature in a particular area, include one on user controlled research written by Peter Beresford and Suzy Croft. There are currently 14 methods reviews, which aim to help researchers make the best use of the various approaches available. Topics include research governance and ethics, care homes and a new review which examines the Medical Research Council's guidance on developing and evaluating complex interventions and its application to research on palliative and end of life care. The two SSCR/INVOLVE public involvement and participation in adult social care research webinars (see page 1 of this newsletter) were based on these methods reviews.

<http://sscr.nihr.ac.uk/scopingreviews.php>

<http://sscr.nihr.ac.uk/methodsreviews.php>

## **Can research development bursaries for patient and public involvement have a positive impact on grant applications? A UK-based, small-scale service evaluation**

D M Walker and R Pandya-Wood

Health Expectations, doi: 10.1111/hex.12127, epublication ahead of print

This report describes the impact of a pre-funding bursary scheme that aims to support user involvement in the early stages of developing a grant application. Feedback from researchers who received a bursary suggests that the involvement helped to: refine research questions and design; develop dialogue between service users and researchers; identify service users for involvement in the remainder of the project; and create opportunities for researchers to learn about involvement and for service users to learn about research. The authors draw out a series of recommendations for setting up similar schemes.

<http://onlinelibrary.wiley.com/doi/10.1111/hex.12127/abstract>

## **Mental health service user involvement: where have we come from, where are we going?**

Helen Kara

Journal of Public Mental Health, volume 12, issue 3, pages 122-135

This article reports on the findings of a knowledge review which looked at the extent and value of mental health service user (MHSU) involvement in research in England. The review found that MHSU involvement has become mainstream and there is clear evidence that it adds value. However, it also identified some gaps in the literature concerning the experiences of non-service-user researchers working with MHSUs and the recognition of the multiple roles that anyone involved in research, including MHSUs and their carers, may play.

[www.emeraldinsight.com/journals.htm?articleid=17095793&show=abstract](http://www.emeraldinsight.com/journals.htm?articleid=17095793&show=abstract)

# **Supporting public involvement in research design and grant development: a case study of a public involvement award scheme managed by a National Institute for Health Research (NIHR) Research Design Service (RDS)**

J D Boote, M Twiddy, W Baird, Y Birks, C Clarke and D Beever  
Health Expectations, doi: 10.1111/hex.12130, epublication  
ahead of print

This report describes a funding award scheme to support public involvement in grant development. It includes examples of how awards have contributed to successful grant applications as well as findings from an evaluation of the scheme. The early public involvement in research design helped to: assess the feasibility of data collection processes; inform trial design; improve recruitment and consent processes; improve information for potential participants; agree outcomes and outcome measures; identify ways to involve the public in the conduct of research; and improve lay summaries for the application form. The evaluation of the scheme identified areas for improvement, including making sure members of the public/patients can be rapidly reimbursed for their expenses.

<http://onlinelibrary.wiley.com/doi/10.1111/hex.12130/abstract>

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**Autumn 2013**

# **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](http://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](http://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](http://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.

**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](mailto:mpalm@invo.org.uk)**

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## **Summer 2013**

### **Establishing local priorities for a health research agenda**

**R Whear, J Thompson-Coon, K Boddy, H Papworth, J Frier and K Stein**

Health Expectations, December 2012, advance e-publication

This paper describes a two-stage process for prioritising health research topics used by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for the South-West Peninsula (PenCLAHRC). Health research questions were collected from local clinicians, academics and service users. The first stage of the prioritisation included a review of the proposed questions by an Executive Group, which narrowed down the options to research questions that met explicit criteria. The second stage involved a large stakeholder group, including service users, who used a voting system to identify the final 25 projects. Researchers are now bidding for funding to take forward this work.

**[www.ncbi.nlm.nih.gov/pubmed/23216859](http://www.ncbi.nlm.nih.gov/pubmed/23216859)**

To see a short video of PenCLAHRC talking about the importance of public involvement in research priority setting, filmed at the INVOLVE 2012 Conference, visit [www.invo.org.uk/resource-centre/conference/involve-conference-gallery/](http://www.invo.org.uk/resource-centre/conference/involve-conference-gallery/)

## **PPI, paradoxes and Plato: who's sailing the ship**

**Jonathan Ives, Sarah Damery and Sabi Redwood**

Journal of Medical Ethics, January 2013, volume 39, issue 3, pages 181-185

In this article the authors unpick a 'paradox' within patient and public involvement (PPI), which highlights a tension between its moral and pragmatic motivations and its implementation. The authors argue that this 'professionalisation paradox' means we need to rethink the practice, and purpose, of PPI in research.

<http://jme.bmj.com/content/39/3/181.abstract>

## **There is no paradox with PPI in research**

**Kristina Staley**

Journal of Medical Ethics, January 2013, volume 39, issue 3, pages 186-7

This is a response to a previous article published by the Journal of Medical Ethics titled 'PPI, paradoxes and Plato: who's sailing the ship?' It addresses the apparent paradox that training patients and members of the public prior to involvement in research causes them to lose their lay perspective. It argues that this rarely happens as patients / members of the public are not often trained to the degree of becoming researchers, but are more often briefed so as to understand where their expertise brings added value. In the few cases where patients / members of the public are trained to the point of becoming researchers, an essential part of the training is ensuring they make best use of their lay perspective and therefore never lose sight of it. The author

concludes that therefore the proposed paradox does not exist in practice.

<http://jme.bmj.com/content/39/3/186.extract>

## **Mobilising the experiential knowledge of clinicians, patients and carers for applied health-care research**

**Pam Carter, Roger Beech, Domenica Coxon, Martin J Thomas and Clare Jinks**

Contemporary Social Science: Journal of the Academy of Social Science, March 2013, e-publication

This article considers the benefits of combining various types of knowledge for applied health research. It addresses the questions of how patient and public involvement (PPI) impacts on research design and funding, and which patients or members of the public should be involved in which aspects of research. The authors present case studies which demonstrate the advantages of actively involving patients with direct experience of the condition that is to be studied early on in the research process. They conclude that different types of knowledge are required for applied health research: methodological expertise, practice-based expertise, and the experiential expertise of patients or carers.

[www.tandfonline.com/eprint/8i2FzJwf3qBNZIfqJh7K/full#.Ua8\\_yJwqk4k](http://www.tandfonline.com/eprint/8i2FzJwf3qBNZIfqJh7K/full#.Ua8_yJwqk4k)

## **Expectations of new treatment in rheumatoid arthritis: developing a patient-generated questionnaire**

**Darija Hofmann, Fowzia Ibrahim, Diana Rose, David L Scott, Andrew Cope, Til Wykes and Heidi Lempp**

Health Expectations, April 2013, advance e-publication

This article reports on the development of a patient-generated expectancy measure for new treatments in rheumatoid arthritis (RA), using a participatory method. The first stage of the study involved three repeated focus groups and two expert panels with patients with RA conducted by a patient researcher. This generated items for the draft questionnaire which was assessed in the stage two feasibility study. The authors conclude that the participatory research method was useful in involving patients actively in research and to produce collaboratively a feasible, valid and acceptable measure in RA. The scale will be included in a longitudinal observational study with newly diagnosed patients.

[www.ncbi.nlm.nih.gov/pubmed/23614783](http://www.ncbi.nlm.nih.gov/pubmed/23614783)

### **Living with Psychosis: A report on research involving service users**

Researching Psychosis Together, Brunel University, November 2012

ISBN: 978 1 908549 05 1

In this report, the Researching Psychosis Together group explores the experiences of people living with psychosis. Starting from their own personal experiences, the group designed the research to find out what is helpful and to demystify psychosis. They held two focus groups, involving 15 people, who discussed what it is like to experience psychosis. They talked about what to do and the importance of talking to others and not avoiding problems. Many people agreed that finding ongoing skilled help was important, in order to feel safe and more receptive when unwell. The findings suggest that services should give priority to understanding individual experiences of psychosis, so support can be more effective and focused on practical problems in life. Doing this research as a group had benefits for everyone involved.

## Spring 2013

**Do not forget the professional – the value of the FIRST model for guiding the structural involvement of patients in rheumatology research**

Martin P T de Wit, Janneke E Elberse, Jacqueline E W Broerse and Tineke A Abma

Health Expectations, January 2013, advance e-publication

The FIRST model comprises five practical components that enable equal collaboration between patients and professionals in clinical rheumatology research: facilitate, identify, respect, support and training. This paper assesses the value of the FIRST model as a framework for setting up and guiding a network of patient research partners and clinical rheumatology departments in the Netherlands. The authors conclude that FIRST is a good model to implement sustainable relationships between patients and researchers and that it would benefit from further refinement.

[www.ncbi.nlm.nih.gov/pubmed/23363240](http://www.ncbi.nlm.nih.gov/pubmed/23363240)

**Designing a placebo device: involving service users in clinical trial design**

Rachel Gooberman-Hill, Clare Jinks, Sofia Barbosa Boucsas, Kelly Hislop, Krysia S Dziedzic, Carol Rhodes, Amanda Burston and Jo Adams

Health Expectations, January 2013, advance e-publication

This article describes and reflects on the process of involving service users in splint selection and the design of a placebo splint with the aim of enhancing the design of a future clinical trial. Two fora of service users discussed

their experience of hand splints for thumb-base osteoarthritis (OA), identified the design features of a variety of alternative splints and developed a potential design for a placebo splint. The authors conclude that service users are increasingly involved in product and device design and are ideally placed to identify features to make a placebo credible.

[www.ncbi.nlm.nih.gov/pubmed/23311756](http://www.ncbi.nlm.nih.gov/pubmed/23311756)

### **Why collaborate with children in health research: an analysis of the risks and benefits of collaboration with children**

Deborah Bird, Lorraine Culley and Monica Lakhanpaul

Archives of Disease in Childhood: Education and Practice Edition, January 2013, e-publication

Over the last 15 years children have become increasingly engaged in research and there has been a shift from research on children to research with children. This article discusses collaboration with children in health research: what this means and why (or why not) to do it. The definition of collaboration is discussed and the lines among collaboration, involvement, participation and participatory research are considered. The authors review the risks and benefits of collaboration and look towards the future.

[www.ncbi.nlm.nih.gov/pubmed/23303525](http://www.ncbi.nlm.nih.gov/pubmed/23303525)

### **How to develop a patient and carer advisory group in stroke care research**

Sarah Sims, Sally Brearley, Gillian Hewitt, Nan Greenwood, Fiona Jones, Fiona Ross and Ruth Harris

Nurse Researcher, January 2013, volume 20, number 3, pages 6-11

This paper reflects on the process of developing a stroke patient and carer advisory group as part of a research study.

It discusses the challenges and the benefits of developing the group and offers advice to other researchers undertaking a similar process. The authors conclude that with careful planning and consideration and the allocation of sufficient time and resources, stroke patients and their carers can be effectively involved.

<http://tinyurl.com/cotj5m8>

### **To what extent can people with communication difficulties contribute to health research?**

Rebecca Palmer and Gail Paterson

Nurse Researcher, January 2013, volume 20, number 3, pages 12-16

People with communication disorders are often precluded from involvement in research due to the high level of communication skills required. This paper describes creative techniques used to help an advisory group of people with aphasia and their carers to collaborate in research at all stages. Those involved reported increased confidence in communicating, stimulation and feelings of empowerment.

<http://tinyurl.com/brxemev>

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## **Winter 2012/13**

### **[User controlled research scoping review](#)**

Peter Beresford and Suzy Croft

National Institute for Health Research (NIHR) School for Social Care Research, 2012

The focus of this scoping review is user controlled research

in social care. The review looks at the characteristics, strengths and limitations of such research, explores its theory and uses examples to illuminate its policy and practice.

### [Patient and public involvement to support liver disease research](#)

D Hull, D Barton, K Guo, C Russell, B Aucott and D Wiles  
British Journal of Nursing, September 2012, volume 21, number 16, pages 972-6

This article reports on the development of the Patient and Public Involvement (PPI) panel at the National Institute for Health Research Birmingham Liver Biomedical Research Unit. The authors conclude that the panel has helped to:

- promote research locally and nationally
- improve recruitment to and participation in trials
- promote public engagement and education activities
- improve the quality and relevance of consent forms and information sheets for participants.

### [‘The missing links’: Understanding how context and mechanism influence the impact of public involvement in research](#)

Kristina Staley, Sarah Buckland, Helen Hayes and Maryrose Tarpey  
Health Expectations, October 2012, advance e-publication

The authors reflect on the findings of recent literature reviews, where most reports of public involvement that discuss impact are based on observational evaluations. The authors found that whilst the majority of reports of impact describe the context, how the involvement was carried out and the impact, they rarely make the explicit links between these factors. The authors conclude that a more intentional and explicit exploration of the links between context, mechanism and outcome, applying the principles of realistic evaluation to public involvement in research, could help to explain when



and how a particular approach to involvement works well.

[Credibility and the 'professionalised' lay expert: Reflections on the dilemmas and opportunities of public involvement in health research](#)

J Thompson, P Bissell, C Cooper, C Armitage and R Barber  
Health, November 2012, volume 16, number 6, pages 602-18

This article explores the experience and expertise that members of the public bring to research. It is based on the findings from a set of interviews with patients and carers involved in research within the National Cancer Research Network. The interviewees highlighted specific forms of expertise in their accounts about involvement, above and beyond experiential expertise, which they felt legitimated their claims to be credible participants within cancer research settings. Some interviewees also seemed to have become professionalised in patient and public involvement. The authors reflect on the implications for involvement.

[Hearing the voices of service user researchers in collaborative qualitative data analysis: the case for multiple coding](#)

A Sweeney, K Greenwood, S Williams, T Wykes and D Rose  
Health Expectations, September 2012, advance e-publication

This study used multiple coding (where each individual in a research team codes qualitative data) to analyse the data from a research project exploring cognitive behavioural therapy for psychosis. The data was analysed from the perspective of a service user researcher, a clinical researcher and a psychology assistant. The report describes how the team then discussed and debated the areas, where they agreed on the analysis and where their interpretations differed. The authors conclude that this approach is a valuable means of hearing service users' voices in qualitative data analysis.

# Autumn 2012

## [Involving the public in systematic reviews: a narrative review of organizational approaches and eight case examples](#)

Jonathan Boote, Wendy Baird and Anthea Sutton

Journal of Comparative Effectiveness Research, September 2012, volume 1, number 5, pages 409-420

This paper reviews the recent literature on public involvement in the systematic review process. It examines how relevant organisations involve the public in their review processes and how the public are involved in individual reviews. The authors identify strategies and recommendations for good practice and outline future research directions.

## [Evaluation of patient involvement in a systematic review and meta-analysis of individual patient data in cervical cancer treatment](#)

Claire Vale, Jayne Tierney, Nicolette Spera, Andrea Whelan, Alison Nightingale and Bec Hanley

Systematic Reviews, May 2012, volume 1, number 23

In April 2005, researchers based at the Medical Research Council Clinical Trials Unit set out to involve women affected by cervical cancer in a systematic review and meta-analysis of individual patient data to evaluate treatments for this disease. Each of the women had previously been treated for cervical cancer. This paper evaluates the process of involvement from the researcher and research partner perspective.

## [Public priorities for joint pain research: results from a general population survey](#)

Vicky Strauss, Pam Carter, Bie Nio Ong, John Bedson, Kelvin Jordan, Clare Jinks in collaboration with the Arthritis Research UK Research Users' Group

Rheumatology, August 2012

This study aimed to identify the priorities for joint pain research from a large general population survey and identify characteristics associated with these priorities. A question about research priorities was developed in collaboration with the Arthritis Research UK Primary Care Centre's Research Users' Group, and this question was embedded in a postal survey to an existing cohort of adults with self-reported joint pain. Respondents were asked to rank their top three priorities for research and the authors conclude that these were linked to lifestyle and self-management opportunities rather than pharmaceutical and invasive interventions.

### [Social care, service users and user involvement](#)

Edited by Peter Beresford and Sarah Carr

Published 2012, Jessica Kingsley Publishers

This recently published book provides an introduction to practical, philosophical and theoretical issues of user involvement. It explores practical examples of user involvement in different settings and contributions are from a diverse range of perspectives.

### [Understanding and improving transitions of older people: a user and carer centred approach: final report](#)

Jo Ellins, Jon Glasby, Denise Tanner, Shirley McIver, Deborah Davidson, Rosemary Littlechild, Iain Snelling, Robin Miller, Kelly Hall, Katie Spence and the Care Transitions Project co-researchers

National Institute for Health Research Service Delivery and Organisation programme, September 2012

This study aimed to explore older people's experiences of care transitions in two areas: entry into and moving between dementia services, and going into and leaving hospital. A further aim was to conduct the research in a way that would help to embed the findings in local policy and practice. A

group of older people were recruited as co-researchers, working in partnership with University of Birmingham researchers to design, plan, carry out and analyse the research and well as contributing to feeding back the findings to the case study areas. An independent evaluation of the co-research model was carried out, and it was felt by all stakeholders to have had positive impacts on the process and outcomes of the study.

### [Co-research with older people with dementia: Experience and reflections](#)

Denise Tanner

Journal of Mental Health, June 2012, volume 21, number 3, pages 296-306

This paper discusses the implications for people with dementia of involvement in research as co-researchers. The project that informed the study was part of a larger national study (see above). It aimed to involve older people with dementia in all stages of the research process, including planning the research methods, conducting interviews and making sense of the findings. The study found that it is possible to involve older people with dementia in a meaningful way in research processes and that both co-researchers and participants can benefit significantly from their participation.

### [NDA \(New Dynamics of Ageing\) News](#)

New Dynamics of Ageing Research Programme, University of Sheffield, May 2012

The seventh edition of NDA News, the newsletter of the New Dynamics of Ageing (NDA) Research Programme focuses on involving older people in research from both the perspective of researchers and of older people themselves. It features an article on the practical impact of involvement written by Dr Tracey Williamson, Research Fellow (User Involvement/Public Engagement in Research) at the University of Salford.

## [Mental Health Research Network guide to finding and reading a research paper](#)

Joanna Carpenter for the National Institute for Health Research Mental Health Research Network, June 2012

This guide is aimed at helping the general public, service users, and carers gain access to the results of mental health research. It explains how research is published as research papers, what the different sort of papers are, how they are structured, how to identify a particular research paper and how to get hold of it. Many useful links are also provided.

## **Summer 2012**

### ['But is it a question worth asking?' A reflective case study describing how public involvement can lead to researchers' ideas being abandoned](#)

J Boote, M Dalglish, J Freeman, Z Jones, M Miles and H Rodgers

Health Expectations – published online May 2012

This case study presents an account of what happened when an academic-led idea for funding was not supported by stroke survivors and carers who were asked to contribute to its development. The lack of patient and carer support led to the research idea being abandoned. Those involved in the research consultation reflect that the resultant public money savings should be seen as an important benefit of public involvement.

### [Consumer involvement in systematic reviews of comparative effectiveness research](#)

J Kreis, M Puhan, H Schünemann and K Dickersin

Health Expectations – published online March 2012

This study aimed to explore current approaches to involving consumers in United States-based and key international organisations and groups conducting or commissioning systematic reviews. Through a series of interviews and a review of organisations' websites, the study found that organisations involve consumers in a variety of ways and for various reasons. It also identified instances of training in research methods but noted that little formal evaluation of the effects of involvement is currently carried out.

### [Good practice guidance for involving carers, family members and close friends of service users in research](#)

Mental Health Research Network

The National Institute for Health Research (NIHR) Mental Health Research Network has published guidance that aims to provide practical, accessible guidance for researchers who seek to involve carers in mental health research. Severe mental health problems impact on the individual and also the people who spend the most time with them, their family members and close friends.

Drawing on a number of case studies, the guidance sets out how carers should be included in research, at what stages of the research process carers can be involved and identifies the core principles for the inclusion of carers.

## **Spring 2012**

**An evaluation of service user involvement in studies adopted by the Mental Health Research Network**

Kristina Staley, TwoCan Associates

Published January 2012

[www.mhrn.info/data/files/MHRN\\_PUBLICATIONS/REPORTS/Service\\_user\\_involvement\\_evaluation.pdf](http://www.mhrn.info/data/files/MHRN_PUBLICATIONS/REPORTS/Service_user_involvement_evaluation.pdf)

The Mental Health Research Network (MHRN) has published this evaluation which identifies what more they and others could do to promote successful service user involvement in adopted studies. Lead researchers from 45 studies selected at random from the MHRN portfolio were interviewed for the evaluation. Lessons relating to good practice were drawn out in a series of case studies following further in-depth interviews with researchers and service users.

**Involvement of consumers in studies run by the Medical Research Council (MRC) Clinical Trials Unit: Results of a survey**

Claire Vale, Lindsay Thompson, Claire Murphy, Silvia Forcat and Bec Hanley

Trials, volume 13, issue 9, January 2012

[www.trialsjournal.com/content/13/1/9/abstract](http://www.trialsjournal.com/content/13/1/9/abstract)

This study aimed to establish levels of consumer involvement in randomised controlled trials (RCTs), meta-analyses and other studies carried out by the UK Medical Research Council (MRC) Clinical Trials Unit.

**The knowledgeable patient: communication and participation in health**

Edited by Sophie Hill

Published 2011, Wiley-Blackwell , ISBN: 9781444337174

This Cochrane handbook is aimed at consumers, healthcare professionals, health service managers, students and policy makers. It examines communication and participation issues and explores the surrounding evidence base. Practical information on how to access and use evidence is also included. The book

is based on a variety of different sources, including consumer stories, evidence found in systematic reviews and examples drawn from the community, health services and policy making.

### **Towards co-production: taking participation to the next level**

Social Care Institute for Excellence

Published February 2012

[www.scie.org.uk/publications/reports/report53.asp](http://www.scie.org.uk/publications/reports/report53.asp)

This short report details the findings of an independent evaluation of the Social Care Institute for Excellence (SCIE) participation function and describes SCIE's new strategy to work towards co-production.

### **VOICE: Developing a new measure of service users' perceptions of inpatient care, using a participatory methodology**

J Evans, D Rose, C Flach, E Csipke, H Glossop, P McCrone, T Craig and T Wilkes

Journal of Mental Health, volume 21, issue 1, pages 57-71, February 2012

[www.ncbi.nlm.nih.gov/pubmed/22257131](http://www.ncbi.nlm.nih.gov/pubmed/22257131)

This article reports on the development of a patient-reported outcome measure of perceptions of acute care in mental health. Service user researchers carried out the study and constructed the measure, VOICE, from the qualitative data.

## **Winter 2011-12**

### **Critical perspectives on user involvement**

Edited by Marian Barnes and Phil Cotterell



Published 2012, The Policy Press

ISBN 9781847427502

Drawing on contributions from service users and academic researchers, this book looks at the history and current state of user involvement in health and social care. It considers user movements / groups, and user involvement in services and research. The collection is aimed at students studying health and social care and social work, researchers developing participative research practice, and service users.

**Handbook of user involvement in nursing and healthcare research**

Elizabeth Morrow, Annette Boaz, Sally Brearley and Fiona Mary Ross

Published 2011, John Wiley and Sons Ltd

ISBN: 9781444334722

This book provides practical advice on service user involvement in nursing and healthcare research. Aimed at anyone working or involved in nursing and healthcare research, it provides a step-by-step guide to the principles and process of involvement, including understanding the rationale for involvement, designing involvement, working with service users, and evaluating what has been achieved.

**Testing treatments: better research for better healthcare (second edition)**

Imogen Evans, Hazel Thornton, Iain Chambers and Paul Glasziou

Published 2011, Pinter & Martin Ltd

ISBN 9781905177486

[www.testingtreatments.org/new-edition/](http://www.testingtreatments.org/new-edition/)

Aimed at patients and professionals, Testing treatments presents an argument for better, more reliable, more relevant research, with unbiased or 'fair' trials, and explains how patients can work with doctors to achieve this goal. This new edition incorporates some extensive revision and updating.

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## **Interesting articles and publications**

### **Activity and views of service users involved in mental health research: UK survey**

S Patterson, J Trite and T Weaver. British Journal of Psychiatry, July 2014, 205 (1), 68-75

This article reports on the findings from a survey of service users involved in mental health research in the UK. The respondents included a range of people, from employed researchers through to volunteer service user representatives. The respondents reported that their involvement had a positive impact on the quality of research. In particular, they had helped identify topics and research questions, and contributed to research design. When involved in data collection, service users highlighted being able to reach 'hard to reach' groups and increasing the quality of information obtained in interviews and focus groups by ensuring participants 'felt understood'. More generally, they felt their presence challenged academics to consider alternate worldviews. The majority of respondents found their involvement to be very

positive, providing them with a sense of purpose and belonging, and enhancing their self-respect. However, a small minority felt involvement had a negative impact on their mental health. This was due to the pressure of work, exposure to distressing material or an experience of workplace conflict.

[www.ncbi.nlm.nih.gov/pubmed/24723628](http://www.ncbi.nlm.nih.gov/pubmed/24723628)

## **Learning from people with long-term conditions: new insights for governance in primary care**

F Ross, P Smith, R Byng, S Christian, H Allan, L Price and S Brearley. *Health and Social Care in the Community*, July 2014, 22 (4), 405-416

The authors report on the findings from a study of the governance of primary care. The aim was to find out how health professionals are managing the complex demands of centrally imposed changes to governance of health care (eg practice based commissioning) at the same time as greater emphasis is being placed on patient and public involvement. The researchers worked with service users at a national and local level and describe the difference that this made. The service user involvement added value by:

- validating understandings of governance, in particular how governance relates to the individual professional's emotional and practical experience of delivering care to service users;
- keeping the project focused on the issues that matter to service users;
- providing different perspectives that helped to open up discussions about governance at a local level;
- and helping to disseminate the findings locally.

# **Patient involvement in research programming and implementation: A responsive evaluation of the Dialogue Model for research agenda setting**

T Abma, C Pittens, M Visse, J Elberse and J Broerse. Health Expectations, May 2014, epublication ahead of print

The Dialogue Model involves multiple stakeholders in identifying and prioritising research questions. It was developed and is now used in the Netherlands. This study followed up nine different agenda-setting projects to see whether there was any subsequent impact on research programmes and funding. Fifty-four different stakeholders including patients, researchers and funding agencies were interviewed, and three focus groups were held to discuss the findings. The study found very limited impact of agenda setting on subsequent research. A wide range of factors had an influence. Firstly, commissioners of agenda-setting projects did not always consider what they wanted to do with the patient priorities, nor did patient involvement continue in the following stages. When researchers were involved in the agenda-setting process, there was a greater chance of the research priorities being adopted. Timing was a problem when priorities were set after deadlines for funding applications. Researchers may also need support and resources to develop new research areas in line with the patients' agenda. These issues need to be considered at the start of agenda-setting projects, to ensure that the exercise is meaningful.

# **Patient and public involvement in research and the Cancer Experiences Collaborative: Benefits and challenges**

K Froggatt, N Preston, M Turner and C Kerr. *BMJ Supportive & Palliative Care*, April 2014

This article reports on the experiences of eight people affected by cancer who were involved in supportive and palliative care research over a period of six years. Their views on the benefits and challenges of involvement were obtained by semi-structured interviews. The main benefits were reported as making a difference to the research and gaining personally from new knowledge, skills, increased confidence and personal support. The challenges included the emotional demands of the work that came from revisiting personal experiences, as well as practical issues, such as demands on people's time and researchers' use of complex, technical language. The service users also stated that they would like a clearer understanding of the long-term impact of their involvement on the projects.

<http://spcare.bmj.com/content/early/2014/04/11/bmjspcare-2013-000548.abstract>

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**[From previous Newsletters:](#)**

**Summer 2014**

# **Enhancing public involvement in assistive technology design research**

Tracey Williamson, Laurence Kenney, Anthony T Barker, Glen Cooper, Tim Good, Jamie Healey, Ben Heller, David Howard, Martin Matthews, Sarah Prenton, Julia Ryan and Christine Smith. Disability and Rehabilitation Assistive Technology, April 2014, epublication ahead of print

This article reports on the findings from a within-project evaluation of patient involvement in the development of a new mobility aid. The researchers established a lay advisory group who were supported by a public involvement lead. The researchers attended an initial workshop to prepare them for working with the group. The practical details around setting up and supporting the group throughout the project are described in detail. The researchers report positive benefits in terms of improvements to the new device, making it more likely to be useful to patients, as well as improvements to the design of the subsequent clinical trial. This was thought to lead to better recruitment and retention of trial participants. The researchers' attitudes to involvement became more positive after witnessing its potential first-hand. The patients involved reported improved confidence, skills and self-esteem and valued being able to contribute to the care of others.

<http://informahealthcare.com/doi/abs/10.3109/17483107.2014.908247>

## **Involving Patients in Research: Considering Good Practice**

R Goberman-Hill, A Burston, E Clark, E Johnson, S Nolan, V Wells, L Betts and PEP-R

Musculoskeletal Care, December 2013, volume 11, issue 4, pages 187–90

This open access editorial highlights some current practice and guidance on involving patients in research. The authors also reflect on the impact of patient involvement activity at the Musculoskeletal Research Unit in Bristol. They seek to involve patients in research design and conduct through a patient forum: Patient Experience Partnership in Research (PEP-R). PEP-R sessions are interactive, training and support is provided, and patients are compensated for their time and travel expenses. The authors asked patients and researchers to complete a questionnaire to evaluate the impact of patient involvement. Patients described their interest and learning about the topics and research in general, and how they valued feedback on their input. Researchers identified the benefits of patients' views on the importance, relevance and feasibility of projects and stressed the importance of early involvement. PEP-R has been supported by the National Institute for Health Research.

<http://onlinelibrary.wiley.com/doi/10.1002/msc.1060/pdf>

## **Patient and public involvement: how much do we spend and what are the benefits?**

Elena Pizzo, Cathal Doyle, Rachel Matthews and James Barlow  
Health Expectations, April 2014, epublication ahead of print

The aim of this literature review was to assess the potential benefits and costs of involvement and the challenges in carrying out an economic evaluation of patient and public involvement (PPI). The authors found that the benefits of PPI include effects on the design and development of research and new services, on NHS governance and on citizenship and equity but that very few studies have assessed the economic impact.

They have developed a framework to help identify the costs associated with PPI, including hidden ones, such as the cost to patients. They suggest that greater clarity about the costs and benefits of different approaches will help make a business case for PPI.

<http://onlinelibrary.wiley.com/doi/10.1111/hex.12204/pdf>

## **Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research: a modified Delphi study**

D Snape, J Kirkham, N Britten, K Froggatt, F Gradinger, F Lobban, J Popay, K Wyatt and A Jacoby. *BMJ Open*, May 2014, volume 4, issue 6

This Delphi study aimed to explore areas of consensus and conflict in relation to perceived barriers and drivers to public involvement (PI), perceived impacts of PI and ways of evaluating PI in health and social care research. The authors found high levels of consensus about the most important barriers and drivers and an acknowledgement that tokenism in public involvement was common. They found strong support for the view that tokenistic practice makes it difficult to demonstrate the impact and value of PI as well as clear support for the importance of evaluating impact. Research team cohesion and appropriate resources were considered essential elements for effective public involvement. The study findings have been used in the development of the Public Involvement Impact Assessment Framework (PiiAF) <http://piiاف.org.uk/> .

<http://bmjopen.bmj.com/content/4/6/e004943.full.pdf+html>



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**Spring 2014**

## **Patient and Public Involvement in Your Research**

R Pandya-Wood and A Robinson in D-M Walker (2014) An Introduction to Health Services Research: A Practical Guide. London: SAGE. ISBN: 9781446247396 (paperback), 9781446247389 (hardback).

A new book has been published containing a chapter on public involvement in health services research. This chapter, which is about helping to plan appropriate involvement for the research being developed, guides readers through the theory and practice of patient and public involvement. Practical strategies are offered, helping researchers to consider why involvement is needed; who to involve and how to find them; how to involve and what tasks to involve people in; and at what points in the research journey to involve them. A real-life case study about survivors of head and neck cancers is used throughout the chapter to illustrate the theory into practice link. The chapter also offers some insights into reward and recognition of people's involvement; the challenges of involving patients and the public together; and the impact of patient and public involvement.

## **Adding SUGAR: Service User and Carer Collaboration in Mental Health Nursing Research**

Alan Simpson, Julia Jones, Sally Barlow, Leonie Cox, and Service User and Carer Group Advising on Research (SUGAR).

Journal of Psychosocial Nursing and Mental Health Services, January 2014, volume 52, issue 1, pages 22-30

Service User and Carer Group Advising on Research (SUGAR) is an initiative that has been established to develop collaborative working in mental health nursing research among mental health service users, carers, researchers and practitioners at City University, London. This article, written by staff and members of SUGAR, describes its background, how it operates and some achievements to date. It includes researcher reflections and case studies of how the collaboration is influencing research. The article identifies the benefits and possible limitations of the collaboration, outlines future plans, and considers the findings in relation to literature on involvement and empowerment.

<http://tinyurl.com/p7ojxna>

## **Consumer involvement in health research: a UK scoping and survey**

Elsbeth Mathie, Patricia Wilson, Fiona Poland, Elaine McNeilly, Amanda Howe, Sophie Staniszezwska, Marion Cowe, Diane Munday and Claire Goodman. International Journal of Consumer Studies, January 2014, volume 38, issue 1, pages 35-44

This paper adds to the international evidence base on patient and public involvement (PPI) in research by providing an overview of current trends and impacts. The authors carried out a scoping exercise and survey of selected UK studies in order to understand the current extent and variation of PPI in research. They selected six research topic areas (cystic fibrosis, diabetes, arthritis, dementia, intellectual and developmental disabilities, and public health) and contacted a total of 838 study authors. Key findings from the scoping exercise and survey include: steering committee membership and reviewing patient information leaflets are the most common PPI activities; there appears to be some blurred roles with

patients participating as research subjects as well as carrying out PPI activities; and there is a limited amount of available information about PPI in publicly accessible research documents.

<http://onlinelibrary.wiley.com/doi/10.1111/ijcs.12072/full>

## **Values associated with public involvement in health and social care research: a narrative review**

Felix Gradinger, Nicky Britten, Katrina Wyatt, Katherine Froggatt, Andy Gibson, Ann Jacoby, Fiona Lobban, Debbie Mayes, Dee Snape, Tim Rawcliffe and Jennie Popay. *Health Expectations*, December 2013, epublication ahead of print

This narrative review is part of a larger Medical Research Council (MRC) funded study that is producing a framework and related guidance on assessing the impact of public involvement (PI) in health and social care research. This review aimed to identify and characterise the range of values associated with PI that are central elements of the framework. The authors undertook a review and narrative synthesis of diverse literatures of PI in health and social care research and identified three overarching systems/values. The first of these is concerned with ethical and political issues; the second with the consequences of PI in research; and the third with the conduct of PI in research. The authors recommend that research teams should consider and make explicit the values they attach to PI in research and discuss ways in which potential tensions may be managed in order to maximise the benefits for researchers, lay experts and the research itself.

<http://onlinelibrary.wiley.com/doi/10.1111/hex.12158/full>

# **Social care scoping reviews and methods reviews**

Over the past couple of years, the National Institute for Health Research (NIHR) School for Social Care Research (SSCR) has published a number of scoping reviews and methods reviews. The five scoping reviews, which systematically evaluate the current literature in a particular area, include one on user controlled research written by Peter Beresford and Suzy Croft. There are currently 14 methods reviews, which aim to help researchers make the best use of the various approaches available. Topics include research governance and ethics, care homes and a new review which examines the Medical Research Council's guidance on developing and evaluating complex interventions and its application to research on palliative and end of life care. The two SSCR/INVOLVE public involvement and participation in adult social care research webinars (see page 1 of this newsletter) were based on these methods reviews.

<http://sscr.nihr.ac.uk/scopingreviews.php>

<http://sscr.nihr.ac.uk/methodsreviews.php>

## **Can research development bursaries for patient and public involvement have a positive impact on grant applications? A UK-based, small-scale service evaluation**

D M Walker and R Pandya-Wood

Health Expectations, doi: 10.1111/hex.12127, epublication ahead of print

This report describes the impact of a pre-funding bursary

scheme that aims to support user involvement in the early stages of developing a grant application. Feedback from researchers who received a bursary suggests that the involvement helped to: refine research questions and design; develop dialogue between service users and researchers; identify service users for involvement in the remainder of the project; and create opportunities for researchers to learn about involvement and for service users to learn about research. The authors draw out a series of recommendations for setting up similar schemes.

<http://onlinelibrary.wiley.com/doi/10.1111/hex.12127/abstract>

## **Mental health service user involvement: where have we come from, where are we going?**

Helen Kara

Journal of Public Mental Health, volume 12, issue 3, pages 122-135

This article reports on the findings of a knowledge review which looked at the extent and value of mental health service user (MHSU) involvement in research in England. The review found that MHSU involvement has become mainstream and there is clear evidence that it adds value. However, it also identified some gaps in the literature concerning the experiences of non-service-user researchers working with MHSUs and the recognition of the multiple roles that anyone involved in research, including MHSUs and their carers, may play.

[www.emeraldinsight.com/journals.htm?articleid=17095793&show=abstract](http://www.emeraldinsight.com/journals.htm?articleid=17095793&show=abstract)

## **Supporting public involvement in**

# **research design and grant development: a case study of a public involvement award scheme managed by a National Institute for Health Research (NIHR) Research Design Service (RDS)**

J D Boote, M Twiddy, W Baird, Y Birks, C Clarke and D Beever  
Health Expectations, doi: 10.1111/hex.12130, epublication  
ahead of print

This report describes a funding award scheme to support public involvement in grant development. It includes examples of how awards have contributed to successful grant applications as well as findings from an evaluation of the scheme. The early public involvement in research design helped to: assess the feasibility of data collection processes; inform trial design; improve recruitment and consent processes; improve information for potential participants; agree outcomes and outcome measures; identify ways to involve the public in the conduct of research; and improve lay summaries for the application form. The evaluation of the scheme identified areas for improvement, including making sure members of the public/patients can be rapidly reimbursed for their expenses.

<http://onlinelibrary.wiley.com/doi/10.1111/hex.12130/abstract>

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**Autumn 2013**

**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](http://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](http://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](http://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.

**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](mailto:mpalm@invo.org.uk)**

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## **Summer 2013**

### **Establishing local priorities for a health research agenda**

**R Whear, J Thompson-Coon, K Boddy, H Papworth, J Frier and K Stein**

Health Expectations, December 2012, advance e-publication

This paper describes a two-stage process for prioritising health research topics used by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for the South-West Peninsula (PenCLAHRC). Health research questions were collected from local clinicians, academics and service users. The first stage of the prioritisation included a review of the proposed questions by an Executive Group, which narrowed down the options to research questions that met explicit criteria. The second stage involved a large stakeholder group, including service users, who used a voting system to identify the final 25 projects. Researchers are now bidding for funding to take forward this work.

**[www.ncbi.nlm.nih.gov/pubmed/23216859](http://www.ncbi.nlm.nih.gov/pubmed/23216859)**

To see a short video of PenCLAHRC talking about the importance

of public involvement in research priority setting, filmed at the INVOLVE 2012 Conference, visit [www.invo.org.uk/resource-centre/conference/involve-conference-gallery/](http://www.invo.org.uk/resource-centre/conference/involve-conference-gallery/)

### **PPI, paradoxes and Plato: who's sailing the ship**

**Jonathan Ives, Sarah Damery and Sabi Redwood**

Journal of Medical Ethics, January 2013, volume 39, issue 3, pages 181-185

In this article the authors unpick a 'paradox' within patient and public involvement (PPI), which highlights a tension between its moral and pragmatic motivations and its implementation. The authors argue that this 'professionalisation paradox' means we need to rethink the practice, and purpose, of PPI in research.

<http://jme.bmj.com/content/39/3/181.abstract>

### **There is no paradox with PPI in research**

**Kristina Staley**

Journal of Medical Ethics, January 2013, volume 39, issue 3, pages 186-7

This is a response to a previous article published by the Journal of Medical Ethics titled 'PPI, paradoxes and Plato: who's sailing the ship?' It addresses the apparent paradox that training patients and members of the public prior to involvement in research causes them to lose their lay perspective. It argues that this rarely happens as patients / members of the public are not often trained to the degree of becoming researchers, but are more often briefed so as to understand where their expertise brings added value. In the few cases where patients / members of the public are trained to the point of becoming researchers, an essential part of the training is ensuring they make best use of their lay perspective and therefore never lose sight of it. The author concludes that therefore the proposed paradox does not exist

in practice.

<http://jme.bmj.com/content/39/3/186.extract>

## **Mobilising the experiential knowledge of clinicians, patients and carers for applied health-care research**

**Pam Carter, Roger Beech, Domenica Coxon, Martin J Thomas and Clare Jinks**

Contemporary Social Science: Journal of the Academy of Social Science, March 2013, e-publication

This article considers the benefits of combining various types of knowledge for applied health research. It addresses the questions of how patient and public involvement (PPI) impacts on research design and funding, and which patients or members of the public should be involved in which aspects of research. The authors present case studies which demonstrate the advantages of actively involving patients with direct experience of the condition that is to be studied early on in the research process. They conclude that different types of knowledge are required for applied health research: methodological expertise, practice-based expertise, and the experiential expertise of patients or carers.

[www.tandfonline.com/eprint/8i2FzJwf3qBNZIfqJh7K/full#.Ua8\\_yJwqk4k](http://www.tandfonline.com/eprint/8i2FzJwf3qBNZIfqJh7K/full#.Ua8_yJwqk4k)

## **Expectations of new treatment in rheumatoid arthritis: developing a patient-generated questionnaire**

**Darija Hofmann, Fowzia Ibrahim, Diana Rose, David L Scott, Andrew Cope, Til Wykes and Heidi Lempp**

Health Expectations, April 2013, advance e-publication

This article reports on the development of a patient-generated expectancy measure for new treatments in rheumatoid arthritis (RA), using a participatory method. The first stage of the study involved three repeated focus groups and two expert panels with patients with RA conducted by a patient researcher. This generated items for the draft questionnaire which was assessed in the stage two feasibility study. The authors conclude that the participatory research method was useful in involving patients actively in research and to produce collaboratively a feasible, valid and acceptable measure in RA. The scale will be included in a longitudinal observational study with newly diagnosed patients.

[www.ncbi.nlm.nih.gov/pubmed/23614783](http://www.ncbi.nlm.nih.gov/pubmed/23614783)

### **Living with Psychosis: A report on research involving service users**

Researching Psychosis Together, Brunel University, November 2012

ISBN: 978 1 908549 05 1

In this report, the Researching Psychosis Together group explores the experiences of people living with psychosis. Starting from their own personal experiences, the group designed the research to find out what is helpful and to demystify psychosis. They held two focus groups, involving 15 people, who discussed what it is like to experience psychosis. They talked about what to do and the importance of talking to others and not avoiding problems. Many people agreed that finding ongoing skilled help was important, in order to feel safe and more receptive when unwell. The findings suggest that services should give priority to understanding individual experiences of psychosis, so support can be more effective and focused on practical problems in life. Doing this research as a group had benefits for everyone involved.

[www.brunel.ac.uk/\\_data/assets/pdf\\_file/0020/277004/living-wit](http://www.brunel.ac.uk/_data/assets/pdf_file/0020/277004/living-wit)

[h-psychosis-report-FINAL-221012.pdf](#)

**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 Helen Hayes at the Coordinating Centre with details: [hhayes@invo.org.uk](mailto:hhayes@invo.org.uk)**

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## **Spring 2013**

**Do not forget the professional – the value of the FIRST model for guiding the structural involvement of patients in rheumatology research**

Martin P T de Wit, Janneke E Elberse, Jacqueline E W Broerse and Tineke A Abma

Health Expectations, January 2013, advance e-publication

The FIRST model comprises five practical components that enable equal collaboration between patients and professionals in clinical rheumatology research: facilitate, identify, respect, support and training. This paper assesses the value of the FIRST model as a framework for setting up and guiding a network of patient research partners and clinical rheumatology departments in the Netherlands. The authors conclude that FIRST is a good model to implement sustainable relationships between patients and researchers and that it would benefit from further refinement.

[www.ncbi.nlm.nih.gov/pubmed/23363240](http://www.ncbi.nlm.nih.gov/pubmed/23363240)

**Designing a placebo device: involving service users in clinical trial design**

Rachel Gooberman-Hill, Clare Jinks, Sofia Barbosa Boucsas, Kelly Hislop, Krysia S Dziedzic, Carol Rhodes, Amanda Burston and Jo Adams

Health Expectations, January 2013, advance e-publication

This article describes and reflects on the process of involving service users in splint selection and the design of a placebo splint with the aim of enhancing the design of a future clinical trial. Two fora of service users discussed their experience of hand splints for thumb-base osteoarthritis (OA), identified the design features of a variety of alternative splints and developed a potential design for a placebo splint. The authors conclude that service users are increasingly involved in product and device design and are ideally placed to identify features to make a placebo credible.

[www.ncbi.nlm.nih.gov/pubmed/23311756](http://www.ncbi.nlm.nih.gov/pubmed/23311756)

### **Why collaborate with children in health research: an analysis of the risks and benefits of collaboration with children**

Deborah Bird, Lorraine Culley and Monica Lakhanpaul

Archives of Disease in Childhood: Education and Practice Edition, January 2013, e-publication

Over the last 15 years children have become increasingly engaged in research and there has been a shift from research on children to research with children. This article discusses collaboration with children in health research: what this means and why (or why not) to do it. The definition of collaboration is discussed and the lines among collaboration, involvement, participation and participatory research are considered. The authors review the risks and benefits of collaboration and look towards the future.

[www.ncbi.nlm.nih.gov/pubmed/23303525](http://www.ncbi.nlm.nih.gov/pubmed/23303525)

### **How to develop a patient and carer advisory group in stroke care research**

Sarah Sims, Sally Brearley, Gillian Hewitt, Nan Greenwood, Fiona Jones, Fiona Ross and Ruth Harris

Nurse Researcher, January 2013, volume 20, number 3, pages

6-11

This paper reflects on the process of developing a stroke patient and carer advisory group as part of a research study. It discusses the challenges and the benefits of developing the group and offers advice to other researchers undertaking a similar process. The authors conclude that with careful planning and consideration and the allocation of sufficient time and resources, stroke patients and their carers can be effectively involved.

<http://tinyurl.com/cotj5m8>

### **To what extent can people with communication difficulties contribute to health research?**

Rebecca Palmer and Gail Paterson

Nurse Researcher, January 2013, volume 20, number 3, pages 12-16

People with communication disorders are often precluded from involvement in research due to the high level of communication skills required. This paper describes creative techniques used to help an advisory group of people with aphasia and their carers to collaborate in research at all stages. Those involved reported increased confidence in communicating, stimulation and feelings of empowerment.

<http://tinyurl.com/brxemev>

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## **Winter 2012/13**

### **[User controlled research scoping review](#)**

Peter Beresford and Suzy Croft

National Institute for Health Research (NIHR) School for Social Care Research, 2012

The focus of this scoping review is user controlled research in social care. The review looks at the characteristics, strengths and limitations of such research, explores its theory and uses examples to illuminate its policy and practice.

### [Patient and public involvement to support liver disease research](#)

D Hull, D Barton, K Guo, C Russell, B Aucott and D Wiles  
British Journal of Nursing, September 2012, volume 21, number 16, pages 972-6

This article reports on the development of the Patient and Public Involvement (PPI) panel at the National Institute for Health Research Birmingham Liver Biomedical Research Unit. The authors conclude that the panel has helped to:

- promote research locally and nationally
- improve recruitment to and participation in trials
- promote public engagement and education activities
- improve the quality and relevance of consent forms and information sheets for participants.

### [‘The missing links’: Understanding how context and mechanism influence the impact of public involvement in research](#)

Kristina Staley, Sarah Buckland, Helen Hayes and Maryrose Tarpey  
Health Expectations, October 2012, advance e-publication

The authors reflect on the findings of recent literature reviews, where most reports of public involvement that discuss impact are based on observational evaluations. The authors found that whilst the majority of reports of impact describe the context, how the involvement was carried out and the impact, they rarely make the explicit links between these factors. The authors conclude that a more intentional and explicit exploration of the links between context, mechanism



and outcome, applying the principles of realistic evaluation to public involvement in research, could help to explain when and how a particular approach to involvement works well.

[Credibility and the 'professionalised' lay expert: Reflections on the dilemmas and opportunities of public involvement in health research](#)

J Thompson, P Bissell, C Cooper, C Armitage and R Barber  
Health, November 2012, volume 16, number 6, pages 602-18

This article explores the experience and expertise that members of the public bring to research. It is based on the findings from a set of interviews with patients and carers involved in research within the National Cancer Research Network. The interviewees highlighted specific forms of expertise in their accounts about involvement, above and beyond experiential expertise, which they felt legitimated their claims to be credible participants within cancer research settings. Some interviewees also seemed to have become professionalised in patient and public involvement. The authors reflect on the implications for involvement.

[Hearing the voices of service user researchers in collaborative qualitative data analysis: the case for multiple coding](#)

A Sweeney, K Greenwood, S Williams, T Wykes and D Rose  
Health Expectations, September 2012, advance e-publication

This study used multiple coding (where each individual in a research team codes qualitative data) to analyse the data from a research project exploring cognitive behavioural therapy for psychosis. The data was analysed from the perspective of a service user researcher, a clinical researcher and a psychology assistant. The report describes how the team then discussed and debated the areas, where they agreed on the analysis and where their interpretations differed. The authors conclude that this approach is a valuable means of hearing service users' voices in qualitative data analysis.

# Autumn 2012

## [Involving the public in systematic reviews: a narrative review of organizational approaches and eight case examples](#)

Jonathan Boote, Wendy Baird and Anthea Sutton

Journal of Comparative Effectiveness Research, September 2012, volume 1, number 5, pages 409-420

This paper reviews the recent literature on public involvement in the systematic review process. It examines how relevant organisations involve the public in their review processes and how the public are involved in individual reviews. The authors identify strategies and recommendations for good practice and outline future research directions.

## [Evaluation of patient involvement in a systematic review and meta-analysis of individual patient data in cervical cancer treatment](#)

Claire Vale, Jayne Tierney, Nicolette Spera, Andrea Whelan, Alison Nightingale and Bec Hanley

Systematic Reviews, May 2012, volume 1, number 23

In April 2005, researchers based at the Medical Research Council Clinical Trials Unit set out to involve women affected by cervical cancer in a systematic review and meta-analysis of individual patient data to evaluate treatments for this disease. Each of the women had previously been treated for cervical cancer. This paper evaluates the process of involvement from the researcher and research partner perspective.

## [Public priorities for joint pain research: results from a general population survey](#)

Vicky Strauss, Pam Carter, Bie Nio Ong, John Bedson, Kelvin Jordan, Clare Jinks in collaboration with the Arthritis Research UK Research Users' Group

Rheumatology, August 2012

This study aimed to identify the priorities for joint pain research from a large general population survey and identify characteristics associated with these priorities. A question about research priorities was developed in collaboration with the Arthritis Research UK Primary Care Centre's Research Users' Group, and this question was embedded in a postal survey to an existing cohort of adults with self-reported joint pain. Respondents were asked to rank their top three priorities for research and the authors conclude that these were linked to lifestyle and self-management opportunities rather than pharmaceutical and invasive interventions.

### [Social care, service users and user involvement](#)

Edited by Peter Beresford and Sarah Carr

Published 2012, Jessica Kingsley Publishers

This recently published book provides an introduction to practical, philosophical and theoretical issues of user involvement. It explores practical examples of user involvement in different settings and contributions are from a diverse range of perspectives.

### [Understanding and improving transitions of older people: a user and carer centred approach: final report](#)

Jo Ellins, Jon Glasby, Denise Tanner, Shirley McIver, Deborah Davidson, Rosemary Littlechild, Iain Snelling, Robin Miller, Kelly Hall, Katie Spence and the Care Transitions Project co-researchers

National Institute for Health Research Service Delivery and Organisation programme, September 2012

This study aimed to explore older people's experiences of care transitions in two areas: entry into and moving between dementia services, and going into and leaving hospital. A further aim was to conduct the research in a way that would help to embed the findings in local policy and practice. A

group of older people were recruited as co-researchers, working in partnership with University of Birmingham researchers to design, plan, carry out and analyse the research and well as contributing to feeding back the findings to the case study areas. An independent evaluation of the co-research model was carried out, and it was felt by all stakeholders to have had positive impacts on the process and outcomes of the study.

### [Co-research with older people with dementia: Experience and reflections](#)

Denise Tanner

Journal of Mental Health, June 2012, volume 21, number 3, pages 296-306

This paper discusses the implications for people with dementia of involvement in research as co-researchers. The project that informed the study was part of a larger national study (see above). It aimed to involve older people with dementia in all stages of the research process, including planning the research methods, conducting interviews and making sense of the findings. The study found that it is possible to involve older people with dementia in a meaningful way in research processes and that both co-researchers and participants can benefit significantly from their participation.

### [NDA \(New Dynamics of Ageing\) News](#)

New Dynamics of Ageing Research Programme, University of Sheffield, May 2012

The seventh edition of NDA News, the newsletter of the New Dynamics of Ageing (NDA) Research Programme focuses on involving older people in research from both the perspective of researchers and of older people themselves. It features an article on the practical impact of involvement written by Dr Tracey Williamson, Research Fellow (User Involvement/Public Engagement in Research) at the University of Salford.

## [Mental Health Research Network guide to finding and reading a research paper](#)

Joanna Carpenter for the National Institute for Health Research Mental Health Research Network, June 2012

This guide is aimed at helping the general public, service users, and carers gain access to the results of mental health research. It explains how research is published as research papers, what the different sort of papers are, how they are structured, how to identify a particular research paper and how to get hold of it. Many useful links are also provided.

## **Summer 2012**

### ['But is it a question worth asking?' A reflective case study describing how public involvement can lead to researchers' ideas being abandoned](#)

J Boote, M Dalglish, J Freeman, Z Jones, M Miles and H Rodgers

Health Expectations – published online May 2012

This case study presents an account of what happened when an academic-led idea for funding was not supported by stroke survivors and carers who were asked to contribute to its development. The lack of patient and carer support led to the research idea being abandoned. Those involved in the research consultation reflect that the resultant public money savings should be seen as an important benefit of public involvement.

### [Consumer involvement in systematic reviews of comparative effectiveness research](#)

J Kreis, M Puhan, H Schünemann and K Dickersin

Health Expectations – published online March 2012

This study aimed to explore current approaches to involving consumers in United States-based and key international organisations and groups conducting or commissioning systematic reviews. Through a series of interviews and a review of organisations' websites, the study found that organisations involve consumers in a variety of ways and for various reasons. It also identified instances of training in research methods but noted that little formal evaluation of the effects of involvement is currently carried out.

### [Good practice guidance for involving carers, family members and close friends of service users in research](#)

Mental Health Research Network

The National Institute for Health Research (NIHR) Mental Health Research Network has published guidance that aims to provide practical, accessible guidance for researchers who seek to involve carers in mental health research. Severe mental health problems impact on the individual and also the people who spend the most time with them, their family members and close friends.

Drawing on a number of case studies, the guidance sets out how carers should be included in research, at what stages of the research process carers can be involved and identifies the core principles for the inclusion of carers.

## **Spring 2012**

**An evaluation of service user involvement in studies adopted by the Mental Health Research Network**

Kristina Staley, TwoCan Associates

Published January 2012

[www.mhrn.info/data/files/MHRN\\_PUBLICATIONS/REPORTS/Service\\_user\\_involvement\\_evaluation.pdf](http://www.mhrn.info/data/files/MHRN_PUBLICATIONS/REPORTS/Service_user_involvement_evaluation.pdf)

The Mental Health Research Network (MHRN) has published this evaluation which identifies what more they and others could do to promote successful service user involvement in adopted studies. Lead researchers from 45 studies selected at random from the MHRN portfolio were interviewed for the evaluation. Lessons relating to good practice were drawn out in a series of case studies following further in-depth interviews with researchers and service users.

**Involvement of consumers in studies run by the Medical Research Council (MRC) Clinical Trials Unit: Results of a survey**

Claire Vale, Lindsay Thompson, Claire Murphy, Silvia Forcat and Bec Hanley

Trials, volume 13, issue 9, January 2012

[www.trialsjournal.com/content/13/1/9/abstract](http://www.trialsjournal.com/content/13/1/9/abstract)

This study aimed to establish levels of consumer involvement in randomised controlled trials (RCTs), meta-analyses and other studies carried out by the UK Medical Research Council (MRC) Clinical Trials Unit.

**The knowledgeable patient: communication and participation in health**

Edited by Sophie Hill

Published 2011, Wiley-Blackwell , ISBN: 9781444337174

This Cochrane handbook is aimed at consumers, healthcare professionals, health service managers, students and policy makers. It examines communication and participation issues and explores the surrounding evidence base. Practical information on how to access and use evidence is also included. The book

is based on a variety of different sources, including consumer stories, evidence found in systematic reviews and examples drawn from the community, health services and policy making.

### **Towards co-production: taking participation to the next level**

Social Care Institute for Excellence

Published February 2012

[www.scie.org.uk/publications/reports/report53.asp](http://www.scie.org.uk/publications/reports/report53.asp)

This short report details the findings of an independent evaluation of the Social Care Institute for Excellence (SCIE) participation function and describes SCIE's new strategy to work towards co-production.

### **VOICE: Developing a new measure of service users' perceptions of inpatient care, using a participatory methodology**

J Evans, D Rose, C Flach, E Csipke, H Glossop, P McCrone, T Craig and T Wilkes

Journal of Mental Health, volume 21, issue 1, pages 57-71, February 2012

[www.ncbi.nlm.nih.gov/pubmed/22257131](http://www.ncbi.nlm.nih.gov/pubmed/22257131)

This article reports on the development of a patient-reported outcome measure of perceptions of acute care in mental health. Service user researchers carried out the study and constructed the measure, VOICE, from the qualitative data.

## **Winter 2011-12**

### **Critical perspectives on user involvement**

Edited by Marian Barnes and Phil Cotterell



Published 2012, The Policy Press

ISBN 9781847427502

Drawing on contributions from service users and academic researchers, this book looks at the history and current state of user involvement in health and social care. It considers user movements / groups, and user involvement in services and research. The collection is aimed at students studying health and social care and social work, researchers developing participative research practice, and service users.

**Handbook of user involvement in nursing and healthcare research**

Elizabeth Morrow, Annette Boaz, Sally Brearley and Fiona Mary Ross

Published 2011, John Wiley and Sons Ltd

ISBN: 9781444334722

This book provides practical advice on service user involvement in nursing and healthcare research. Aimed at anyone working or involved in nursing and healthcare research, it provides a step-by-step guide to the principles and process of involvement, including understanding the rationale for involvement, designing involvement, working with service users, and evaluating what has been achieved.

**Testing treatments: better research for better healthcare (second edition)**

Imogen Evans, Hazel Thornton, Iain Chambers and Paul Glasziou

Published 2011, Pinter & Martin Ltd

ISBN 9781905177486

[www.testingtreatments.org/new-edition/](http://www.testingtreatments.org/new-edition/)

Aimed at patients and professionals, Testing treatments presents an argument for better, more reliable, more relevant research, with unbiased or 'fair' trials, and explains how patients can work with doctors to achieve this goal. This new edition incorporates some extensive revision and updating.

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# A new patient reported outcome measure of antipsychotic medication side effects

Abstract:

**Key issue:** Anti-psychotic medications are associated with negative side effects that can impact on quality of life and are associated with poor adherence and relapse (Haddad et al., 2011). Therefore, there is a need for regular side effects monitoring. Service users may have additional and different concerns to clinicians. It would be of value to increase the level of information used to evaluate the side effects of antipsychotics from the point of view of the service user.

**Aim:** To develop a patient-reported outcome measure of anti-psychotic medication side effects using an innovative participatory methodology to maximise the opportunity for service user involvement (Rose et al., 2011).

**Method:** An initial bank of items was drawn from three existing side effects measures. A group of psychiatrists and pharmacists determined the importance of specific side effects for use in the new measure. Service user focus groups

identified their most important side effects. From these data, service user researchers constructed the measure. Service users who take anti-psychotic medication or antidepressant medication completed the measure twice to investigate the properties and feasibility of the measure.

**Results:** The measure is easy to understand and complete by service users. The measure showed strong stability over time and was able to discriminate different patterns between people experiencing depression and those with a diagnosis of schizophrenia although there was a lot of overlap. Participants with high levels of psychosis symptoms did not endorse more side effects.

**Conclusions:** A participatory methodology was used to generate a self-report questionnaire measuring service users' experience of anti-psychotic medication side effects. This research is a demonstration of how service users can be involved throughout the research process.

[Download poster](#)

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## **Induction materials for research staff new to public involvement**

The following provides introductory text and links for staff new to public involvement.

# 1. INVOLVE's definition and resources

INVOLVE is the national advisory group that supports public involvement in health and social care research. INVOLVE offers a definition for 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;
- undertaking interviews with research participants.

When using the term **'public'** we 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.

INVOLVE's starting point is a series of ten briefing notes for researchers, covering a range of topics from 'what is involvement' to 'how to involve people in research'. Case studies and templates are included. INVOLVE also provides an 'Evidence Library' of published research about involvement and resources documenting how involvement has been put into practice.

[www.invo.org.uk/resource-centre/resource-for-researchers/](http://www.invo.org.uk/resource-centre/resource-for-researchers/)

## **2. General introduction to clinical research for staff**

### **UK Clinical Research Facility Network Induction Framework for Clinical Research Staff, Version 5, 2019**

This document provides an excellent introduction for staff working in clinical research. It is designed so that staff can dip in and out, and select topics relevant to their role and at different levels, depending on prior experience and knowledge.

Theme 12 introduces staff to Patient and Public Involvement in Research and is a good starting point for staff with limited time and resource to get an insight into public involvement. Although targeted at staff working within a clinical research facility setting, the document has generic relevance for all staff working in clinical research and is used extensively across NIHR infrastructure and beyond.

Download the document [here](#).

Download the supporting PPI presentation [here](#)

## **3. Guide for researchers working with public contributors**

This document is produced by the University of Oxford; it offers a comprehensive guide covering many topics a new researcher needs to consider, such as advertising for contributors, developing role descriptions and good practice for running meetings. Some minor aspects are specific to the university (such as contacting their pool of contributors), but the overall advice is highly relevant to any researcher and anyone new to working in public involvement.

[www.phc.ox.ac.uk/get-involved/ppi/information-for-researchers/guide-for-researchers-in-working-with-ppi-contributors-17.pdf](http://www.phc.ox.ac.uk/get-involved/ppi/information-for-researchers/guide-for-researchers-in-working-with-ppi-contributors-17.pdf)

## **4. A tool kit approach to public involvement**

Cancer Research UK has produced a tool kit using a step by step approach. Aiming to help make patient and public involvement in research a valuable and meaningful activity.

[www.cancerresearchuk.org/funding-for-researchers/patient-and-public-involvement-ppi-toolkit-for-researchers](http://www.cancerresearchuk.org/funding-for-researchers/patient-and-public-involvement-ppi-toolkit-for-researchers)

## **5. Useful videos**

Health Talk Online has produced online videos and links to researchers' experiences of public involvement. Ideas of ways to encourage thinking around good practice in PPI work. It is intended as a reference tool only. There are useful templates to download and links to videos to watch:

[www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics](http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics)

## **6. Useful case studies**

YouTube has many case study videos that demonstrate how public involvement is put into practice:

[www.youtube.com/watch?v=s9wEXxvr218](http://www.youtube.com/watch?v=s9wEXxvr218)

The above NIHR video leads to others relevant to public involvement. And there is a 'How to join in' page on the NIHR website for members of the public:

[www.nihr.ac.uk/patients-and-public/opportunities/](http://www.nihr.ac.uk/patients-and-public/opportunities/)

## **7. See how some NIHR organisations approach public involvement and engagement**

The Central Commissioning Facility (CCF) manages several NIHR infrastructure initiatives. Every year, each part of the infrastructure provides a progress report. The patient and public involvement and engagement (PPIE) sections of these annual reports provides a brief summary of the progress in

implementing PPIE strategies of:

- Biomedical Research Centres and Biomedical Research Units (BRC/BRUs)
- Collaborations for Leadership in Applied Health Research and Care (CLAHRCs)
- Clinical Research Facilities for Experimental Medicine (CRFs)
- Diagnostic Evidence Co-operatives (DECs)
- Health Protection Research Units (HPRUs)
- Healthcare Technology Co-operatives (HTCs)
- Patient Safety Translational Research Centres (PSTRCs)
- Research Design Service (RDS)
- Research Schools

These are a useful source of information and can help to give ideas on public involvement activities, impact and outputs:

[www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/nihr-central-commissioning-facility/ccf-ppi/ppie-annual-reports.htm](http://www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/nihr-central-commissioning-facility/ccf-ppi/ppie-annual-reports.htm)

## 8. Useful Networks

**UK Clinical Research Facilities' Network** provides information to individuals working in research across the UK and Ireland, for the operational delivery and management of experimental medicine studies. This network shares and disseminates good practice, creating a support network for existing and new Clinical Research Facilities, and developing and facilitating relevant projects through its work streams.

If you are responsible for public involvement and have limited resources and support, you are welcome to join the UKCRFN PPI Theme Group – e-mail at:

[ukcrf-ppie-working-group@nihr.ac.uk](mailto:ukcrf-ppie-working-group@nihr.ac.uk)

Learn more about other UKCRFN theme groups here:

[www.ukcrfnetwork.co.uk/](http://www.ukcrfnetwork.co.uk/)

invoDIRECT is an INVOLVE directory of networks, groups and organisations that support active public involvement in NHS, public health and social care research. The searchable database allows individuals or networks, groups or organisations to be aware of and make contact with, others who are carrying out similar work:

[www.invo.org.uk/communities/invodirect/](http://www.invo.org.uk/communities/invodirect/)

Shared Learning Group for Involvement is a collection of charities, who aim to encourage shared learning about service user and carer involvement between voluntary sector organisations working in the UK. Its main Shared Learning Group looks at involvement across all areas. It also has a Shared Learning Group on involvement in research:

<http://slginvolvement.org.uk/>

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## How do I cost PPI in research projects?

The Mental Health Research Network and INVOLVE have developed a useful guide ([budgeting for Involvement](#)) that provides practical advice on how to budget for involving patients, carers and the public in research.



You can use the cost calculator to work out the costs of involvement at any stage of the research process – whether that's a planned focus group in a study underway or putting together an entire budget for a study. It may be particularly helpful when designing research studies and applying for funding.

Please see the following link: [www.involve.nihr.ac.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator](http://www.involve.nihr.ac.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator).

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## **Are there any resources on involving children and young people in research?**

Several organisations are actively involving children and young people in research and have information and resources on their websites:

**The National Institute of Health Research (NIHR) Medicines for Children Research Network (MCRN)**  
[www.mcrn.org.uk/children/design](http://www.mcrn.org.uk/children/design)

**National Children's Bureau Research Centre (NCB)**. Includes information on a 2011 conference on young people's involvement in research and projects involving children and young people:  
[www.ncb.org.uk/policy-evidence/research-centre/involving-young-people-in-research](http://www.ncb.org.uk/policy-evidence/research-centre/involving-young-people-in-research) including:

- Guidelines on research with children and young people:  
[www.participationworks.org.uk/resources/guidelines-for-research-with-children-and-young-people](http://www.participationworks.org.uk/resources/guidelines-for-research-with-children-and-young-people)

- The Pear Project – a (now completed) project involving young people in public health research, including a conference and guidance for researchers: [www.ncb.org.uk/pear](http://www.ncb.org.uk/pear)
- Viper young researchers – a project involving young disabled people in research: [www.councilfordisabledchildren.org.uk/what-we-do/work-themes/participation/viper/young-researchers](http://www.councilfordisabledchildren.org.uk/what-we-do/work-themes/participation/viper/young-researchers)

**Participation Works.** Information on children and young people's participation including downloadable versions of NCB and PEAR guidelines, 'how to' guides including 'creative methods' and 'reward and recognition', and a guide and toolkit for evaluating participation with children and young people: [www.participationworks.org.uk](http://www.participationworks.org.uk)

**Children's Research Centre.** Supports child-led research: <http://childrens-research-centre.open.ac.uk>

**Young Researcher Network.** Includes toolkit to support young people-led research [www.nya.org.uk/integrated-youth-support-services/young-researcher-network](http://www.nya.org.uk/integrated-youth-support-services/young-researcher-network)

**Children's Rights Alliance for England:** [www.crae.org.uk](http://www.crae.org.uk)

INVOLVE has published: [A guide to involving children and young people in research](#)

Visit our [Putting it into Practice library](#) and search for children and young people to find out what others have written.

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# Cost-effectiveness

A measure addressing the cost implications of achieving health benefits. To facilitate comparisons, health benefits can be quantified in terms of 'QALYs' (Quality-Adjusted Life Years), which incorporate both extra life achieved and improvements in quality of life. Knowing the cost associated with each QALY gained can help decision-makers assess whether the introduction of a treatment or service should be recommended.