

# 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.

[www.ncbi.nlm.nih.gov/pubmed/24889933](http://www.ncbi.nlm.nih.gov/pubmed/24889933)

## 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://piaf.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 Staniszewska, 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-with-psychosis-report-FINAL-221012.pdf](http://www.brunel.ac.uk/_data/assets/pdf_file/0020/277004/living-with-psychosis-report-FINAL-221012.pdf)

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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.