INVOLVE

NHS
National Institute for
Health Research

Evidence

Bibliography 5

References on public involvement in NHS, public health and social care research

October 2014

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Acknowledgements:

Helen Hayes, Sarah Buckland and Maryrose Tarpey of the INVOLVE Coordinating Centre would like to thank all of those who have helped us develop the **Evidence** library (formally known as the invoNET library). Kristina Staley has worked with us to review articles for the Evidence library and to update the content for this 5th edition.

The first edition of the Bibliography was published in September 2007. It contained the references and a brief description of the first 85 entries of the online INVOLVE **Evidence** library. It was compiled by Kristina Staley and Bec Hanley of TwoCan Associates www.twocanassociates.co.uk

We would also like to thank Peter Beresford, Alison Faulkner, Sophie Staniszewska, and Tracey Williamson members of the INVOLVE Evidence, Knowledge and Learning working group. Thanks to John Sitzia and Vivienne Brown for advising on the initial invoNET library development and to Gill Wren and Paula Davis of the INVOLVE Coordinating Centre for their library assistance.

This publication can be referenced as:

INVOLVE (2014), Evidence Bibliography 5, INVOLVE Coordinating Centre, Eastleigh.

ISBN: 978-0-9557053-9-7

Evidence Bibliography 5

Contents

Introduction

This publication, **Bibliography 5**, contains all of the references in the online **Evidence** Library (formally known as the invoNET library) up until October 2014. New references added since the publication of **Bibliography 4** in October 2012 are highlighted in the index in grey. The index of **Bibliograpy 5** has a **new** category indicating articles and reports that have recorded members of the public, service users or carers as authors.

The **Evidence** library is an electronic library of references that is available in the **Resources Centre** of the INVOLVE website www.involve.nihr.ac.uk/resource-centre/

The Evidence library includes references (reports and articles) that cover:

- the nature and extent of public involvement in research e.g. mapping public involvement
- the impact of public involvement on research
- reflections on public involvement in research

Reports of research projects where the public have been involved are included if they contain a substantial amount of critical analysis or substantial reflection on the impact or the nature of involvement. It also includes other pieces of work that shed light or provide a new perspective on public involvement in research and evaluative case studies.

The Evidence library contains journal publications and grey literature (project reports, conference presentations, books and book chapters, theses, editorials in journals), but does not include comments and letters.

While the main focus is on public involvement in NHS, public health and social care research, studies of service user involvement in service development are included when the lessons can be generalised.

For references and resources which describe how to involve members of the public in research please visit our **Putting it into Practice database**
www.involve.nihr.ac.uk/resource-centre/putting-it-into-practice-database/

If you have any articles or reports that you think should be considered for the library please tell us about them either by completing the Library document suggestion form at www.involve.nihr.ac.uk/resource-centre/evidence-library/ or by contacting the INVOLVE Coordinating Centre admin@invo.org.uk. Please note that all suggested references will be checked before they are placed in the library to make sure they fit the criteria.

References

Abma, T. (2005) **Patient participation in health research: research with and for people with spinal cord injuries,** Qualitative Health Research, 15(10), 1310-1328.

Abstract
Aim: To develop a new research agenda for the Spinal Cord Injury Association in The Netherlands, based on the priorities of people affected by a spinal cord injury.

Methods: Three researchers, one of whom had a spinal cord injury and was a member of the Spinal Cord Injury Association, used a range of methods to listen to people's views. These included interviews, workshops and a web based discussion.

Findings/recommendations: This study was the first of its kind in The Netherlands. The involvement of a researcher with a spinal cord injury proved to be crucial for the success of the study. Priorities identified were very different to current research practice in The Netherlands.

The paper describes the barriers that researchers faced in developing a research agenda based on the views of people affected by a spinal cord injury, and reflects on how these barriers might be addressed in future. The author suggests the adoption of a 'responsive-constructivist approach', where stakeholders are seen as partners, and that much could be learnt from action research and medical anthropology.

Category: impact of public involvement, reflecting on public involvement in research

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Abma, T., Pittens, C., Visse, M., Elberse, J. and Broerse J. (2014) **Patient involvement in research programming and implementation: A responsive evaluation of the Dialogue Model for research agenda setting**, Health Expectations doi: 10.1111/hex.12213. [Epub ahead of print]

Abstract
Aim: The Dialogue Model involves multiple stakeholders in identifying and prioritising research questions. It was developed, and is now being 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.

Methods: Fifty-four different stakeholders including patients, researchers and funding agencies were interviewed, and three focus groups were held to discuss the findings.

Findings/recommendations: 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.

Category: impact of public involvement

Adams, R. & McCullough, A. (2003) **The urban practitioner and participation in research within a street work context,** Community, Work and Family, 6(3), 269-287.

Abstract

This paper tells the story of the involvement of a community worker in a research project that aimed to find out about the situation of 'detached' under 16 year olds, identify the appropriate responses and services to meet the requirements of this group and to explore the feasibility of potential projects.

At first the community worker saw his role to be opening doors for the researchers. He viewed them as the 'experts' in conducting research. As the project progressed, he realised that he had a lot more to offer to the project in terms of how best to work with this group of young people, conduct better quality interviews, gain the young people's trust, and manage complex, ethical issues like confidentiality. However, he felt his opinions were sometimes ignored, raising concerns about his involvement in the project and the moral obligations of his role.

The authors state they would like researchers to better recognise and appreciate the knowledge, values and emotions brought by community workers into research.

Category: impact of public involvement, reflecting on public involvement in research

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Ali, K., Roffe, C. & Crome, P. (2006) **What patients want: Consumer involvement in the design of a randomised controlled trial of routine oxygen supplementation after acute stroke,** Stroke, 37, 865-871.

Abstract

Aim: To involve patients and carers in the design of a study of oxygen supplementation in acute stroke.

Methods: Three focus groups were held with people affected by stroke and then participants were asked to complete questionnaires. People were asked for their views on the importance of the study, consent issues, relevance of the outcome measures and preferences for follow-up.

Findings/recommendations: Although consumer involvement helped to make the study more relevant it also led to difficult scientific and ethical conflicts in developing the trial protocol.

Consumers wanted to consider different outcome measures to those suggested by the researchers. The standard measures are based on physical health and physical recovery. However, consumers wanted to measure outcomes related to communication, mood, tiredness, cognitive function and sleep. This is because their quality of life is determined more by their cognitive and emotional problems than by their disability. But this posed a problem for the researchers because the consumer outcomes are not well represented in the standard assessment tools and are more difficult to measure.

The researchers therefore developed new tools to measure these outcomes, but were concerned that these were less scientifically rigorous.

Consumers also said they did not want their relatives to be asked to give consent on their behalf because they did not want their next of kin to experience any additional stress. They wanted to waiver the need for consent. However, asking relatives to give consent is considered to be the standard ethical practice.

Category: impact of public involvement

Allen, J., Mohatt, G., Rasmus, S., Hazel, K., Thomas, L. & Lindley, S. (2006) **The tools to understand: Community as co-researcher on culture-specific protective factors for Alaska natives,** Journal of Prevention and Intervention in the Community, 32(1-2), 41-60.

Abstract
This article reports on a collaboration between researchers and Alaska native communities in two studies about promoting sobriety.

Community members were involved as members of a co-ordinating council co-directing the project and as research staff, field workers and translators. They provided input into the design, structure and content of interview schedules, conducted a number of the interviews and helped with the data analysis.

The involvement of community members:

- gave legitimacy to the study
- led to a focus on sobriety rather than alcoholism
- helped with recruiting participants - community researchers were more successful in recruitment because they knew the community and spoke the

language
- helped engage participants - this facilitated the collection of rich, descriptive data
- gave the university researchers an enhanced and deeper understanding of the data
- ensured the interpretation of the data was culturally grounded and informed by the community's perspective thus increasing the credibility and validity of the findings
- ensured there was an immediate and tangible outcome from the research that directly benefited the community

Community co-researchers benefited personally from hearing other people's stories about how they coped with alcohol abuse. This helped one individual cope better with his own alcohol problem. They also developed and improved their research skills throughout the course of the project, which encouraged another individual to enrol at graduate school.

The university researchers benefited from learning about how to engage with native communities and about the types of research procedures that are acceptable to those communities. The project has led to the development of a new intervention that will be tested in future. The research has provided evidence that this collaborative approach is culturally relevant which will be important in future funding applications.

Category: impact of public involvement

Allsop, J., Holt, R., Levesley, M. & Bhakta, B. (2010) **The engagement of children with disabilities in health-related technology design processes: Identifying methodology**, Disability and Rehabilitation: Assistive Technology, 5(1),1-13.

Abstract

This paper summarises the findings from a literature review which aimed to identify suitable methods for involving children with disabilities in the design of healthcare technology, such as assistive technology and rehabilitation equipment. Five suitable methods were identified.

Category: reflecting on public involvement in research

Andejeski, Y., Bisceglio, I., Dickersin, K., Johnson, J., Robinson, S., Smith, H., Visco, F. & Rich, I. (2002) **Quantitative impact of including consumers in the scientific review of breast cancer research proposals,** Journal of Women's Health and Gender-Based Medicine, 11(4), 379-388.

Abstract

Aim: To assess the impact of involving consumers in scientific review panels. The study focused on the involvement of survivors of breast cancer in the review of research proposals for the US Department of Defense Breast Cancer Research Programme in 1995.

Methods: A cross-sectional analysis of the scores given to research proposals as well as analysis of the opinions of panel members obtained via questionnaires before and after panel meetings. Analysis was limited to 42 panels that reviewed 2190 proposals. Panel members included 85 consumers and 638 scientists.

Findings/recommendations: In general the average voting patterns of the consumers were very similar to that of the scientists. Final proposal scores were the same as they would have been without consumer involvement in 76% of cases, more favourable for 15% and less favourable for 9%. 84% of scientists and 98% of consumers said consumer involvement on review panels was beneficial.

While the study looked at the impact of involvement on overall voting of proposals, it did not examine the impact on how individual proposals were scored. So it is not known whether consumer input into the meeting had any impact on the scientists' scoring. Most scientists reported no effect. However, one scientist remarked that just having consumers at the table led him to consider the potential impact of each project on breast cancer more carefully.

Category: impact of public involvement

Andejeski, Y., Breslau, E., Hart, E., Lythcott, N., Alexander, L., Rich, I., Bisceglio, I., Smith, H. & Visco, F. (2002) **Benefits and drawbacks of including consumer reviewers in the scientific merit review of breast cancer research,** Journal of Women's Health and Gender-Based Medicine, 11(2), 119-136.

Abstract

Aim: To find out the views of scientists and consumers on consumer involvement in peer review. The study focused on the involvement of survivors of breast cancer in the review of research proposals for the US Department of Defense Breast Cancer Research Programme in 1995.

Methods: Members of the review panels (over 700 people in total) were sent a questionnaire before and after the panel meetings where proposals were reviewed and scored. The survey asked people about their attitudes, perceptions and beliefs about scientists and consumers working together to review research proposals.

Findings/recommendations: Both the scientists and consumers were initially concerned about whether consumers would have the necessary skills and training to take part in a scientific review. Some scientists also thought that consumers might be over-emotional and could derail the meeting. The consumers were also concerned that their views would not be taken seriously by the scientists, but were less concerned about this after the meeting. The scientists viewed the consumers as hard-working, dedicated and effective advocates after the meeting and said they were in favour of involving carefully chosen lay panel members. The scientists were initially worried that involving consumers would change the voting and scoring on proposals, but this did not happen. They were glad of the opportunity to learn about the concerns of breast cancer survivors first hand. Overall, the panel meeting appeared to have supported a spirit of teamwork and co-operation.

Category: impact of public involvement

Angell, K., Kreshka, M., McCoy, R., Donnelly, P., Turner-Cobb, J., Graddy, K., Kraemer, H. & Koopman, C. (2003) **Psychosocial intervention for rural women with breast cancer,** Journal of General Internal Medicine, 18, 499-507.

Abstract
Aim: To carry out a randomised controlled trial (RCT) to evaluate a community-based workbook-journal for improving the well-being of women with breast cancer in isolated rural areas.

Methods: Breast cancer survivors formed a partnership with academic researchers to develop and evaluate the workbook-journal. Community partners took the lead in developing the recruitment procedure, recruiting participants, conducting assessments and designing strategies to reduce women's fears about participating in a clinical trial.

Findings/recommendations: The community-focused recruitment model resulted in an 83% recruitment rate and 98% retention. The authors comment 'our rate of recruitment and retention in this pilot is unparalleled in medical research and is even remarkable for psychosocial interventions'.

They attribute their success to:

- making good use of the insights and experience of community partners
- allowing and budgeting for several meetings between recruiters and potential participants
- the high skill level of the community recruiters
- the endorsement of the study by the community

The authors conclude that barriers to recruitment can be minimised by involving community members in the design of recruitment, consent and measurement procedures. It is also important for researchers to be open to novel methods for approaching and assessing potential participants, whose culture and level of trust may be different from the people they usually work with.

Category: impact of public involvement

Arain, M., Pyne, S., Thornton, N., Palmer, S. & Sharma, R. (2013) **Consumer involvement in cancer research: example from a Cancer Network**, Health Expectations, doi: 10.1111/hex.12143. [Epub ahead of print]

Abstract
This article reports on an evaluation of the Thames Valley Cancer Network Consumer Research Partnership group which was formed in 2009. The evaluation took place between 2010 and 2011. It found that the group had been involved in:

- developing research proposals and helping with grant applications
- writing patient information sheets for clinical trials
- designing research questionnaires
- improving recruitment
- conducting interviews with other patients
- project management groups for individual research projects.

Category: impact of public involvement

Association of Medical Research Charities (2006) **Briefing Paper: Using lay reviewers in the peer review process,** London: AMRC.

Abstract
Aim: To find out the extent of lay involvement in the peer review processes carried out by AMRC members.

Methods: A survey of Association of Medical Research Charities (AMRC) members.

Findings/recommendations: 48 charities reported lay involvement in their peer review processes (53% of respondents). These have been categorised according to whether:

- lay reviewers make a full and equal contribution to the decisions of the review panel
- lay reviewers are members of a review panel but have unequal, partial or no voting rights

- lay members sit on a separate panel that makes some contribution to the review process
- lay involvement is through the contribution of Trustees or a secretariat

Examples of case studies are included to illustrate these different levels of involvement.

Category: nature and extent of public involvement in research

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Avard, D., Jean, M., Gregoire, G. & Page, M. (2010) **Public involvement in health genomics: the reality behind the policies.** International Journal of Consumer Studies, 34(5), 508-524.

Abstract
Aim: To assess how policy statements address public involvement in the context of human genetics or genomics.

Methods: A systematic review of policy documents/guidelines published between 1998 and 2009 in the area of human genomics.

Findings/recommendations: The majority of policy documents in human genomics fail to explicitly address what is meant by public involvement. Less than a third of the documents defined who the public is. When mechanisms for involvement were mentioned, they rarely explored which methods are most appropriate for different circumstances. Few documents discussed the need for evaluation. The authors conclude that policy statements should include more detail in the recommendations for public involvement. This would help with the application of the recommendations and lead to improvements in implementation.

Category: nature and extent of public involvement in research

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Bailey, S., Boddy, K., Briscoe, S. & Morris, C. (2014) **Involving disabled children and young people as partners in research: a systematic review**, Child: care, health and development, doi: 10.1111/cch.12197 [Epub ahead of print].

Abstract
Aim: To find out what impact the involvement of disabled children and young people (DCYP) has on research and on the children themselves.

Methods: A systematic literature review.

Findings/ recommendations: The positive impacts of involvement on DCYP include increased confidence, self-esteem, responsibility and independence, obtaining new skills and knowledge, feeling respected and valued, and helping others.

The negative impacts on DYCP include distress from hearing about other people's lives, feeling intimidated by the process, losing confidence and interest if overwhelmed, feeling disillusioned if involvement is tokenistic.

The positive impacts on research include better research questions, more age appropriate and accessible information, an approach that ensures the protocol and interventions are more acceptable to DCYP, enhanced data collection through peer interviews, and contributing a unique perspective to data analysis.

The negative impacts are that greater resources are required and the research takes longer.

However, overall the authors conclude that the quality of the reporting of involvement is so low, that is not possible to draw strong conclusions about the best approaches to involvement to ensure positive impacts.

Category: impact of public involvement

Barber, R., Beresford, P., Boote, J., Cooper, C. & Faulkner, A. (2011) **Evaluating the impact of service user involvement on research: a prospective study,** International Journal of Consumer Studies, 35, 609-615.

Abstract
Aim: To carry out a prospective, qualitative exploration of service user involvement in a research study.

Methods: Interviews were carried out with two service user researchers and three researchers at regular intervals during the study. These involved reflecting on the processes and outcomes of the involvement as the study progressed.

Findings/recommendations: The involvement was found to impact on the study by:

- influencing decisions about the study design
- improving the clarity of the research documents making them more accessible to a wider audience
- helping with the interpretation of data
- highlighting connections with previous and current research
- helping with dissemination to make the findings more accessible

The evaluation also highlighted the importance establishing good working relationships to ensure effective involvement. It describes how the researchers' and service users' learnt from each other and how the impact of the involvement might have been improved by involving service users earlier on.

Category: impact of public involvement, reflecting on public involvement in research

Barber, R., Boote, J., Parry, G., Cooper, C., Yeeles, P. & Cook, S. (2012) **Can the impact of public involvement on research be evaluated? A mixed methods study,** Health Expectations 15(3), 229-41.

Abstract
Aim: To assess whether it is feasible to evaluate the impact of public involvement on research.

Methods: A two-round Delphi exercise and follow-up interviews with a wide range of people with knowledge and/or experience of public involvement in health or social care research.

Findings/ recommendations: The people who took part in this study reached a consensus that it is feasible to evaluate the impact of public involvement on identifying and prioritising research topics, disseminating research findings and on key stakeholders. They also discussed the difficulties in evaluating a process that is so complex and often a highly subjective experience.

Category: reflecting on public involvement in research

Barnard, A., Carter, M., Britten, N., Purtell, R., Wyatt, K. & Ellis, A. (2005) **The PC11 Report. An evaluation of consumer involvement in the London Primary Care Studies Programme,** Exeter, UK: Peninsula Medical School.

Abstract
Aim: To evaluate the impact of consumer involvement in 11 primary care research projects in London, which were all required to involve service users or carers as a condition of funding. Training and support was made available to everyone involved. The evaluation also looked at the impact of this training.

Methods: The team looked at documents, including commissioning papers and progress reports, interviewed a range of stakeholders, sent questionnaires to everyone involved in the project, undertook two focus groups and ran a feedback day. The evaluation team was made up of researchers and a service user researcher.

Findings/recommendations: The way that people saw their own role (e.g. service user, researcher, carer, other) was not always the same as the way other people saw them. This can lead to problems and misunderstandings. Involvement took place in different ways and at different stages of the research.

In most cases, service users and researchers had not been involved in designing the research. 82% of principal investigators who responded to the survey agreed or strongly agreed that service user or carer involvement had been useful, with the same percentage saying that they believed that service user/carer involvement had had or would have a positive effect on the research outcome.

Service users and carers described many benefits and positive experiences of involvement. Common themes identified through the interviews and focus groups were:

- Empowerment
- Support and resources
- Communication
- Motivation

People's experiences of these themes varied - but many people mentioned them.

The researchers found that service user/carer involvement had the following effects:

- Changes to research questions and research tools (eg questionnaires)
- New ways of collecting and explaining data
- Wider dissemination of findings
- Better implementation and measurement of this implementation
- More service users and carers involved in research

The researchers conclude that criteria used to measure successful involvement should be specific to each project. They make a series of recommendations to researchers, research commissioners, ethics bodies and potential collaborators.

Category: impact of public involvement

Bastian, H. (2005) **Editorial: Consumer and researcher collaboration in trials: filling the gaps,** Clinical Trials, 2(1), 3-4

Abstract

This editorial reflects on the report of the collaboration between the patient organisation, the National Association for the Relief of Paget's disease, and the managers of the PRISM trial (a trial comparing two treatments for Paget's disease).

Three major issues are raised:

(1) whether the benefits of the partnership are cost-effective or need to be directly experienced to be understood
(2) whether consumer participation always improves patient information sheets - when a more informed group might increase the complexity of the information
(3) whether the views of activist consumers are the same as non-activists and whether this makes a difference to their involvement

Category: reflecting on public involvement in research

Becker, S., Sempik, J. & Bryman, A. (2010) **Advocates, agnostics and adversaries: Researchers' perceptions of service user involvement in social policy research,** Social Policy & Society, 9(3), 355-366.

Abstract
Aim: To explore social policy researchers' views of service user involvement in research.

Methods: An internet survey of 251 social policy researchers, followed by a series of discussion groups and in-depth telephone interviews.

Findings/ recommendations: The majority favoured involving service users but varied in their opinion as to how and at what stage they could/ should be involved. Some researchers questioned whether there was evidence to support involvement and whether service users had the necessary skills to be involved. The authors comment on the fact that dissenting views are hardly represented in the literature, but need to be addressed to ensure that a model of involvement is developed that is robust, sophisticated and open to challenge and debate.

Category: nature and extent of public involvement in research

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Beer, D., Keeble, P., MacInnes, D., Rees, D. & Reid, L. (2005) **Development of a questionnaire to measure service user satisfaction within in-patient forensic services - The Forensic Satisfaction Scale,** Liverpool: National Programme on Forensic Mental Health Research and Development (R&D).

Abstract
Aim: To develop a reliable and valid questionnaire to assess levels of service user satisfaction with forensic in-patient services with active service user involvement in all stages of the research.

Methods: Focus groups with service users to find out what issues are important to them in determining their level of satisfaction with services. Developing a new measure and piloting this scale in a cross-sectional survey to test its reliability and validity. Service user members of the research team were involved in developing the protocol, the study design, data collection and analysis, writing up and dissemination of results.

Findings/recommendations: The positive impact of involving service users are reported as:

Benefits for the service users:

- payment for their contribution
- greater awareness of different viewpoints
- being challenged and developing greater confidence

- developing networks
- new knowledge and skills
- making a positive contribution to research and services

Benefits for the researchers:
- service user input into the research tools
- developing clearer explanations of the research process
- access to participants who might not have otherwise been recruited
- service user input into interpreting the results
- understanding which issues are important to service users
- challenges to power structures and perceptions of health professionals

Category: impact of public involvement

Bench, S., Day, T. & Griffiths, P. (2013) **Effectiveness of critical care discharge information in supporting early recovery from critical illness,** Critical Care Nurse, 33(3), 41-52.

Abstract
When patients are discharged from critical care to a general ward, they often experience considerable distress. Providing information to patients and relatives may reduce this stress and lead to earlier recovery. This study reviewed the evidence base on giving discharge information to critical care patients and asked whether service users had been involved in developing the information. Few studies were available. Only two had involved service users, and then in only developing ideas for content. The authors conclude that future research in this area would benefit from involving service users and carers, to avoid professionals controlling the information that is provided to patients.

Category: nature and extent of public involvement in research

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Bengtsson-Tops, A. & Svensson, B. (2010) **Mental health users' experiences of being interviewed by another user in a research project. A qualitative study.** Journal of Mental Health, 19(3), 234-242.

Abstract
Aim: To describe how service users experience being interviewed by other users.

Method: 17 service users who had been interviewed by service users as part of another research project, were interviewed about their experience.

Findings/recommendations: Some users found the experience of being interviewed by another user as a positive experience particularly because they:

- were contributing to a review of care focused on the users' experience
- helped the interviewer develop their skills
- felt able to be more open and honest in the interview because of feelings of mutual understanding and trust
- felt inspired and motivated by the interviewer's story of recovery

However, some were also concerned about the experience because they felt:

- insecure and anxious about other users in general, because of previous experiences during in-patient care
- the user researchers were unprofessional or lacked the necessary social skills to be interviewers

The researchers questioned whether the user researchers in this project had received sufficient training in interviewing. They also suggested that some of the problems may be overcome by more careful matching of user researchers to interviewees.

Category: impact of public involvement

Beresford, P. (2005) **Developing the theoretical basis for service user/survivor-led research and equal involvement in research,** Epidemiologia e Psichiatria Sociale, 14(1), 4-9.

Abstract
This article is written from the perspective of a service user/survivor. It explores ideas about the value of different types of knowledge and tests the hypothesis that: the shorter the distance there is between direct experience and its interpretation, then the less distorted, inaccurate and damaging resulting knowledge is likely to be.

The author argues that this idea provides support for user-led research and challenges the traditional emphasis on positivist assumptions of 'distance', 'neutrality' and 'objectivity'. He also discusses ways in which to improve the quality of research and enable more equal involvement of service users as researchers.

Category: reflecting on public involvement in research

Beresford, P. (2007) **The role of service user research in generating knowledge-based health and social care: From conflict to contribution,** Evidence & Policy, 3(3), 329-341.

Abstract

Aim: To explore the potential contribution of service user knowledge and research to developing evidence-based policy and practice in health and social care.

Method: A review of user-controlled research.

Findings/recommendations: The authors reflect on what is understood as 'valid' knowledge and the value of service users' experiential knowledge. The benefits of users leading research were identified as:

- the research is more likely to address issues of relevance to service users because it comes from them and addresses their concerns
- it opens up new areas for research
- the research is likely to have more inclusive approach that encourages more diverse involvement
- it brings personal benefits to the people involved including greater self-confidence and a sense of empowerment
- it makes research a more positive experience for the participant
- it is committed to making change

In summary, service users describe user-controlled research as 'filling the gaps that may be left by other research approaches'.

Category: impact of public involvement, reflecting on public involvement in research

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Beresford, P. (2002) **User involvement in research and evaluation: Liberation or regulation?** Social Policy & Society, 1(2), 95-105.

Abstract

This article explores different approaches to user involvement in research and relates them to consumerist and democratic models of involvement in policy and practice, management and development. It highlights the need to approach user involvement in research critically and systematically, and to take forward user involvement in research in equal association with service user organisations and movements.

Category: reflecting on public involvement in research

Bindels, J., Baur, V., Cox, K., Heijing, S. and Abma, T. (2014) **Older people as co-researchers: A collaborative journey**, Ageing & Society, 34(6), 951-973.

Abstract

Aim: To evaluate the involvement of three older people as co-researchers, in a project which aimed to explore the experiences of frail older people living in the community in The Netherlands.

Method: Semi-structured interviews with individual members of the research team, and two reflective team meetings. The co-researchers were involved in interviewing other older people in partnership with the academic researcher and analysing the qualitative data.

Findings/recommendations: The involvement had an impact on the quality of the interviews. The co-researchers were very effective in helping the interviewees feel at ease and establishing an initial rapport. They were also better able to relate to the responses that older people gave. In some cases, the interviewees addressed all their responses to the co-researcher rather than the academic interviewer. The academic researcher concluded that the co-researchers were sometimes more successful than she was in getting to the core topic in an interview.

Category: impact of public involvement

Bird, D., Culley, L. & Lakhanpaul, M. (2013) **Why collaborate with children in health research: an analysis of the risks and benefits of collaboration with children**, Archives of Disease in Childhood: Education & Practice Edition, 98(2), 42-48.

Abstract

This article discusses collaborating with children under the age of 16 in health research. It discusses the theoretical and evidence-based risks and benefits and concludes that there is a need for:

- agreed definitions of collaboration
- better reporting of evidence of impacts
- cost-benefit evaluations
- more consideration of when collaboration with children is appropriate.

Category: reflecting on public involvement in research

Blackburn, H., Hanley, B. and Staley, K. (2010) **Turning the pyramid upside down: examples of public involvement in social care research,** Eastleigh: INVOLVE.

Abstract
This report provides real-life examples of how service users have been involved in social care research. In each of the five examples, the researcher and one or two of the service users involved report on the difference that the involvement made.

Category: nature and extent of public involvement in research, impact of involvement, reflecting on public involvement in research

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Blair, T. & Minkler, M. (2009) **Participatory action research with older adults: Key principles in practice,** The Gerontologist, 49(5), 652-662.

Abstract
This article provides a review of the literature on participatory action research with older people. It provides an overview of ten studies where older people have been involved in research, covering a broad range of research projects and a number of different contexts.

It highlights how involvement has influenced the quality of the research, improved the knowledge and understanding of the researchers and the older people involved, and increased the likelihood of change/ action following on from the research. The authors draw out the key issues for future involvement of older people in research, in terms of the factors that lead to success and the tensions that may need to be resolved.

Category: impact of public involvement, reflecting on public involvement in research

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Boaz, A., Biri, D. & McKevitt, C. (2014) **Rethinking the relationship between science and society: Has there been a shift in attitudes to patient and public involvement and public engagement in science in the United Kingdom?** Health Expectations, doi: 10.1111/hex.12295 [Epub ahead of print].

Abstract
Aim: To explore whether researchers attitudes have shifted following recent changes in policy and practice around public involvement and engagement.

Methods: Interviews with 19 researchers at three Biomedical Research Centres funded by the National Institute for Health Research.

Findings/ recommendations: The participants were clear about the distinction between engagement and involvement. There was greater support for engagement in terms of communicating research findings to the public and promoting a greater understanding of science.

Views on involvement were more mixed. Some health researchers commented that involvement led to better research through asking better questions, developing more appropriate designs and outcome measures, and increasing the likelihood of the findings being implemented. However, many were disinterested, seeing involvement as a tick-box exercise only necessary to meet funding requirements. Laboratory-based researchers tended to be hostile to involvement, concluding that patients are not in a position to design and influence highly technical studies, without being researchers themselves.

The authors conclude that overall researchers’ attitudes have not shifted significantly and many are still resistant to sharing power and control.

Category: nature and extent of public involvement in research, reflecting on public involvement in research

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Boote, J., Baird, W. & Beecroft, C. (2010) **Public involvement at the design stage of primary health research: A narrative review of case examples.** Health Policy, 95(1), 10-23.

Abstract

Aim: To review published examples of public involvement in research design and explore the impact of involvement at this stage and the tensions, barriers and facilitators to involvement.

Methods: A literature review.

Findings/recommendations: The key impacts included:

- improving the quality of patient information sheets
- helping to resolve the ethical dilemmas in clinical trials where informed consent would be difficult or impossible to obtain
- identifying additional outcome measures in clinical trials
- ensuring data collection procedures are ethically acceptable
- making recommendations as to the most appropriate time to approach people to take part in clinical trials and the best time and methods for follow-up

Category: impact of public involvement, reflecting on public involvement in research

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Boote, J., Baird, W. & Sutton, A. (2011) **Public involvement in the systematic review process in health and social care: A narrative review of case examples,** Health Policy, 102(2-3), 105-116.

Abstract
This paper reports on the findings from a review of seven case studies reported in the literature where members of the public were involved in a systematic review.

It summarises the ways in which the public contributed to the process including:

- refining the scope of the review
- locating literature
- appraising the literature
- interpreting the findings
- writing up the review

Category: impact of public involvement

Boote, J., Baird, W. & Sutton, A. (2011) **Public involvement in the design and conduct of clinical trials: A review,** The International Journal of Interdisciplinary Studies, 5(11), 91-106.

Abstract: This article reports on a review of nine articles where the public were involved in the design and conduct of clinical trials. It summarises the key contributions made by the public and identifies areas for future research.

Category: impact of public involvement

Boote, J., Baird, W. & Sutton, A. (2012) **Involving the public in systematic reviews: a narrative review of organisational approaches and eight case examples**, Journal of Comparative Effectiveness Research, 1(5), 1-12.

Abstract
This paper reviews the recent literature on public involvement in systematic reviews. It includes a review of how organisations, mainly the Cochrane Network, involve the public, as well as how the public are involved in individual systematic reviews. The involvement was reported to make a difference in:

- Refining the scope of the review
- Suggesting and locating relevant literature
- Reviewing the literature
- Interpreting the findings

- Writing up the review

Category: impact of public involvement

Boote, J., Barber, R., Cooper, C. (2006) **Principles and indicators of successful consumer involvement in NHS research: Results of a Delphi study and sub-group analysis,** Health Policy, 75, 280-297.

Abstract

Aim: To see whether agreement could be reached between researchers and consumers about what it means to involve consumers successfully in research. To develop principles of successful involvement and at least one measurable indicator for each principle.

Methods: Two consensus methods were used - a workshop and a Delphi study. 3 consumers who attended the workshop were recruited as advisers to the research team.

Findings/recommendations: Consumer advisers influenced the recruitment strategy for the Delphi study and the interpretation of the findings. This paper presents a statistical analysis of the findings of the Delphi panel. It also describes a sub-group analysis, which was carried out to establish whether the 3 panel sub-groups - consumers, researchers and consumers who are also researchers - differed significantly in their views of the principles and indicators.

The researchers found that there was a significant degree of common ground between the 3 sub-groups about what successful involvement is. Consensus was reached on 8 principles, and on indicators for these principles. There were only a few significant differences between how the 3 groups rated the principles and indicators.

Category: reflecting on public involvement in research

Boote, J., Dalgleish, M., Freman, J., Jones, Z., Miles, M. & Rodgers, H. (2014) **'But is it a question worth asking?' A reflective case study describing how public involvement can lead to researchers' ideas being abandoned,** Health Expectations, 17(3), 440-51.

Abstract

This paper describes a case study in which an academic-led idea for a research project on public involvement was not supported by stroke survivors and carers who were involved at the bid development stage.

Although the idea was supported by health professionals, the stroke survivors and carers did not think it was worth pursuing. This led to the project being abandoned. The authors conclude that this meant that public money was not wasted on research that would not have been considered useful, an important benefit of patient and public involvement.

Category: impact of public involvement

Boote, J., Telford, R. & Cooper C. (2002) **Consumer involvement in health research: a review and research agenda,** Health Policy, 61(2), 213-236.

Abstract

This paper critically reviews the state of current knowledge about the effects of involving consumers in research. It discusses:

- definitions of 'the consumer'
- why consumer involvement in health research is believed to be important
- policy development in this area
- the epistemological and methodological implications of the policy
- levels of consumer involvement in research
- objections from professionals

Finally it identifies four questions that need to be addressed by further research:

- how can consumer involvement in research be further conceptualised?
- how and why does consumer involvement affect health research?
- how can the impact of consumer involvement be measured and evaluated?
- what factors are associated with successful user involvement?

Category: reflecting on public involvement in research

Boote, J., Twiddy, M., Baird, W., Birks, Y., Clarke, C. & Beever, D. (2013) **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),** Health Expectations, doi: 10.1111/hex.12130. [Epub ahead of print]

Abstract

This report describes a funding scheme to support public involvement in grant development. It includes examples of how awards have led to successful grant applications. The early public involvement in research design has 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
- improve lay summaries for the application form.

The evaluation of the scheme identified areas for improvement, in particular making sure members of the public/ patients can be rapidly reimbursed for their expenses, and enabling fast-tracking for researchers seeking grants to develop applications in response to commissioned calls from funders.

Category: impact of public involvement

Boote, J., Wong, R. & Booth, A. (2012) **'Talking the talk or walking the walk': A bibliometric review of the literature on public involvement in health research published between 1995 and 2009**, Health Expectations, doi: 10.1111/hex.12007 [Epub ahead of print]

Abstract

This report summarises the findings from a review of the literature. The analysis looked at where the papers were published, countries of lead authors, types of public involved, health topic areas and stages of research involving the public. The findings show that from 1998 onwards the number of papers reporting on examples of involvement began to outnumber papers reviewing the literature i.e. more researchers were carrying out involvement than discussing it. The authors also draw out recommendations for future reporting of involvement in research.

Category: nature and extent of public involvement in research

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Boxall, K. and Beresford, P. (2013) **Service user research in social work and disability studies in the United Kingdom**, Disability & Society 28 (5), 587-600.

Abstract

This article makes an argument in favour of greater collaboration between social work research and disabilities studies. The authors suggest that social work research would benefit from adopting a social model and working closely with service users' organisations, in the same way that the social model of disability and association with disabled people's organisations has provided a focus for disability studies. One of the direct consequences would be to prioritise service user involvement in social work research, an area which is currently underdeveloped.

Category: nature and extent of public involvement in research

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C. & Suleman, R. (2014) **Mapping the impact of patient and public involvement in health and social care research: a systematic review**, Health Expectations, 17(5), 637–650.

Abstract
This article reports on the findings from a review of the literature reporting on the impact of public involvement on health and/ or social care research. The positive impacts identified included:

- User-focused research objectives
- User-relevant research questions
- User-friendly information, questionnaires and interview schedules
- Appropriate recruitment strategies
- User focused interpretation of data
- Enhanced implementation and dissemination of study results

Some of the challenging aspects of involvement are also discussed.

Category: impact of public involvement

Brett, J., Staniszewska, S., Mockford, C., Seers, K., Herron-Marx, S. & Bayliss, H. (2010) **The PIRICOM Study: A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research.** London: UK Clinical Research Collaboration (UKCRC).

Abstract
This review synthesises the evidence on the conceptualisation, measurement, impact and outcomes of patient and public involvement in health and social care research.

It provides emerging, but important evidence of the impact of public involvement in relation to three key areas:

- making research more relevant and appropriate for users
- improving the quality of the research
- developing better relationships between researchers and communities

Based on this review, the authors have developed a series of recommendations for reporting the impact of patient and public involvement.

Category: impact of public involvement

Broad, B. & Saunders, L. (1998) **Involving young people leaving care as peer researchers in a health research project: A learning experience,** Research, Policy and Planning, 16(1), 1-9.

Abstract

Aim: To identify the met and unmet needs of young people leaving care, to explore the health experience of young care leavers and to suggest ways in which health service provision to this group may be improved. To assess the benefits and drawbacks of young people's participation for all those involved in the study.

Methods: Young people leaving care were involved as members of the research steering group. They also developed an interview schedule for use with their peers, received training as peer interviewers and carried out a survey of young people leaving care in the mid-Surrey area.

Findings/recommendations: Many of the young people involved found carrying out interviews to be a huge responsibility. They felt badly about bringing up the past with interviewees and then leaving them, and felt responsible when people became upset. They were frustrated at not being able to help people and did not know what to say to support them. The interviews also brought up emotional issues for the interviewers themselves.

The peer interviewers said they had benefited personally from being involved, could see the value of the research and felt they were contributing to changing things for the better. However, they would have liked more training and support, specifically to:

- develop interviewing skills
- address confidentiality, especially managing reports of abuse in care
- cope with the after-effects of interviews

The research team thought that the benefits of conducting peer research were:

- better quality data, because it covered a wider range of subjects and was more relevant and more reliable – 'reaches parts that other research does not meet'
- greater honesty from the interviewees
- more focus in the interviews on subjects that were of importance to young people and might otherwise been overlooked
- findings are more persuasive when presented by users at conferences or to local agencies/authorities, particularly when users feel a sense of ownership and conviction about the research

Overall the involvement of young people resulted in the research being of more use than if it had been commissioner-led and meant it placed greater emphasis on the recommendations for agencies than on the users' behaviours/lifestyles.

Category: impact of public involvement

Broerse, J., Zweekhorst, M., van Rensen, A. & de Haan, M. (2009) **Involving burn survivors in agenda setting on burn research: An added value?** Burns, 36(2), 217-231.

Abstract
This project followed a 'Dialogue Model' to identify priorities for burns research. Initially burn survivors and professionals were consulted separately about their priorities. Subsequently, the two groups met and presented and discussed their views, working together to prioritise the top 15 most important research topics.
There was a lot of overlap between the two groups, but both identified topics specific to their group. As a result of the discussions, one of the survivors' priority topics ended up as number 2 on the final list, although the topic had not been raised previously by the professionals.

The Dutch Burns Foundation has since established a pilot programme to fund the research topics that were identified as a priority, but are currently under-researched. The professionals at the meeting have also adapted their current research projects to reflect the survivors' interests. Some have also carried out further follow-up work to explore the issues in more depth. This has led to another pilot project to test a buddy system that will aim to address another of the survivors' priorities, the lack of psycho-social aftercare.

Category: impact of public involvement

Brownlie, J., Anderson, S. & Ormston, R. (2006) **Children as researchers,** Edinburgh: Scottish Executive Education Department.

Abstract
Aim: To explore the problems and possibilities of incorporating a 'children as researchers' perspective into the agenda of government social research in Scotland.

Methods: Mapping recent projects in Scotland and the UK more generally; reviewing the literature on children carrying out research; interviews with policy makers, researchers, research managers and young researchers.

Findings/recommendations: The mapping identified a range of projects involving children as researchers. These were mostly one-off projects based in community and voluntary organisations; few were funded by government and these were often limited involvement to an advisory group. Key issues were identified as ethical issues around confidentiality, risk of harm, payments and power in research partnerships; and balancing young people's involvement with the need for high quality, reliable data.

Practical concerns were raised about the resources needed to do this work in terms of staff time, training and support. It was felt that procurement processes, budgets and time-scales would act as a barrier. There were also concerns that less able and more excluded young people might not be represented.

The various stakeholders interviewed in this project shared the belief that involving young people as researchers would improve research outcomes and have greater impact on the quality of people's lives. However, they also expressed doubts as to whether such research would impact on decision-making when the general relationship between research and policy is not always clear. For this reason some people tended to focus on other ways for children's views to influence government policy e.g. through consultation.

Young people who had carried out research saw it as an opportunity to have their voice heard in important policy areas and found it empowering on a personal level.

The final recommendations are that the Scottish Executive:

- makes it clear at the procurement stage that involvement of young people in designing and carrying out research is desirable
- develops opportunities for young researchers to apply for funding, particularly in research partnerships
- develops its thinking on young researchers as part of its volunteering strategy
- develops new ways for young people to inform its research agendas
- develops a network of experienced adult and young researchers in this area to develop ideas and practice and offer support to new researchers

Category: nature and extent of public involvement in research

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Bryant, L. & Beckett, J. (2006) **The practicality and acceptability of an advocacy service in the emergency department for people attending following self-harm,** Leeds: Academic Unit of Psychiatry, University of Leeds.

Abstract
Aim: To explore the views of different stakeholders on setting up an advocacy service in the Emergency Department for people who have self-harmed and to develop practical recommendations.

Method: Interviews with service users, Emergency Department staff, mental health staff and advocates. The project team included three people with experience of self-harm who were involved at every stage of the process. They also evaluated the impact of this service user involvement.

Findings/recommendations: The evaluation assessed how well the principles of successful user involvement (Telford, 2004) had been met. By these standards, the involvement was a success. However, the authors also found that the principles did not adequately reflect the process of their involvement and therefore seemed to represent only the minimum requirements.

The evaluation also asked the team members about their personal experiences of involvement. They reported benefits for the service user researchers and for the professional researchers. They did not find that user involvement had an impact on recruitment. It had a mixed impact on the interviews. The positives were that the people being interviewed seemed to be more open about their experiences, but the negatives were that some issues were not always fully explored. They conclude that the data may not have been that different as a result of user involvement, but that the participants had a much better experience.

Category: impact of public involvement

Burrus, B., Liburd, L. & Burroughs, A. (1998) **Maximising participation by black Americans in population-based diabetes research: The project DIRECT pilot experience,** Journal of Community Health, 23(1), 15-27.

Abstract

Aim: To conduct a population survey of diabetes in Wake County, North Carolina, to reduce the burden of disease in the black community.

Methods: A community advisory board (CAB) was set up to develop the research tools, identify people to become interviewers and promote the project.

Findings/recommendations: The community advisory board had a big impact on the project by:

- checking that the community was benefiting from the research at all stages and reminding the research team to explore options for 'giving back' to the community
- shifting the emphasis of the survey (which included blood glucose measurement and blood pressure screening) so that it became more of a health service meeting people's needs than a research activity reflecting academic interests
- changing the way the project was carried out so that the people who took part received more feedback and were signposted to useful resources e.g. people with abnormal blood glucose values were followed up by phone to check that they understood the need to seek further care
- writing information for the project participants and adding their names to the recruitment brochure to give it more legitimacy
- planning mass media programs and presentations to various community groups to encourage participation

The research team attribute the high response rates to the survey (77%) to the efforts and involvement of the CAB. They also saw benefits in the relationships that developed between CAB members, the researchers and government representatives. This helped to overcome the community's general mistrust of research. The CAB have decided they want to continue to support the next stages of the project, even though there will be a delay before the second phase begins. Their ongoing dedication suggests that the pilot helped create a strong community coalition interested in taking action to address the community's problem with diabetes.

Category: impact of public involvement

Butcher, L. (2005) **No home, no job,** CareandHealth MAGAZINE, May 10- May 16, 30.

Abstract
This article summarises a research project carried out by the charity Off the Streets and into Work. The aim was to find out about homeless people's experiences of trying to find and sustain a job while being homeless.

Homeless people were involved as peer interviewers which increased the depth and richness of the information obtained in the interviews. Some of the interviewees also felt that the peer researchers were role models, inspiring them to get more involved in shaping homelessness services. The peer researchers also provided important input into the methodology and development of the questions used in interviews, surveys and focus groups. They weeded out questions that would not work and replaced them with ones that would.

The individuals involved gained personally from the project through gaining work experience, channelling their negative experiences into a positive and constructive process and feeling they had made a contribution to a significant and influential piece of research.

Category: impact of public involvement

Caldon, L., Marshall-Cook, H., Speed, G., Reed, M. & Collins, K. (2010) **Consumers as researchers - innovative experiences in UK National Health Service Research.** International Journal of Consumer Studies, 34(5), 547-550

Abstract
This paper describes the successful collaboration between professional and consumer members of a research team, who worked together on a study of surgical treatment of women with breast cancer.

The consumers were involved from the beginning and made a difference by:

- being involved in the recruitment of research staff and looking for different qualities amongst the applicants
- developing the research documentation and making it more acceptable
- advising on the recruitment of participants and ensuring the approach was ethically acceptable
- taking part in data analysis, which led to a richer interpretation than would have otherwise been possible

The research team conclude that involvement of consumers should be integral to the research process from the outset. They also recommend that researchers wishing to involve consumers seek advice from professionals and organisations with expertise in the field, to ensure good practice and optimise mutual benefit.

Category: impact of public involvement

Callard, F., Rose, D. & Wykes, T. (2012) **Close to the bench as well as at the bedside: involving service users in all phases of translational research,** Health Expectations, 15(4), 389-400.

Abstract
This paper critically reviews the literature on translational research and medicine. The authors develop a new model of translational research that describes it as an interlocking loop rather than a pipeline. They demonstrate the scientific, ethical and pragmatic benefits of involving service users in every phase.

Category: reflecting on public involvement in research

Caron-Flinterman, F. (2005) **A new voice in science: Patient participation in decision-making on biomedical research,** Zutphen: Wöhrmann Print Services.

Abstract
This book is based on a series of articles that were produced by the author while completing her PhD. It includes a review of patient participation in decision-making in biomedical research in The Netherlands, the barriers to their participation and a consideration of the contributions they do and could make.

The book also describes the findings from a pilot study of patients' research priorities and makes recommendations for a strategy to involve patients in an effective way.

Category: reflecting on public involvement in research

Caron-Flinterman, J., Broerse, J. & Bunders, J. (2005) **The experiential knowledge of patients: a new resource for biomedical research?** Social Science & Medicine, 60, 2575-2584.

Abstract
Aim: This article reflects on whether patients' experience and knowledge is of value to biomedical research. A theoretical analysis proved inconclusive. The authors therefore carried out a review of real-life examples of where patients have influenced biomedical research.

Methods: A literature review and over 60 interviews with scientists, patients, representatives of patient organisations and health professionals in The Netherlands and the UK.

Findings/recommendations: Nine concrete examples were found where patients' experiential knowledge had been translated into demands, ideas or judgements of biomedical research.

The authors therefore conclude that patients can make a valuable contribution to this type of research. However they also recommend that new structures and greater interaction between researchers and patients would be needed to make involvement more effective and more widespread. It would also require more work into finding ways of overcoming current barriers.

Category: impact of public involvement

Carter, P., Beech, R., Coxon, C., Thomas, M. & Jinks, C. (2013) **Mobilising the experiential knowledge of clinicians, patients and carers for applied health-care research**, Contemporary Social Science: Journal of the Academy of Social Sciences, 8(3), 307-320.

Abstract
This article describes three case studies where patients or members of the public were involved in applied health research. The case studies show that when patients with direct experience of the condition being studied are involved at an early stage, they help to:

- increase the likelihood of funding applications being successful
- improve ethical aspects of the research
- increase the relevance of the research for patients.

Category: impact of public involvement, reflecting on public involvement in research

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Cashman, S., Adeky, S., Allen, A., Corburn, J., Israel, B., Montano, J., Rafelito, A., Rhodes, S., Swanston, S., Wallerstein, N. & Eng, E. (2008) **The power and the promise: Working with communities to analyse data, interpret findings and get to outcomes.** American Journal of Public Health, 98(8), 1407-1417.

Abstract
This paper describes four brief case studies of community-based participatory research where community members were involved in data analysis or interpretation, or both.

The involvement of community members helped to:

- identify major research questions to ask of the data
- determine the meaning of the results and their implications for action
- expand the researchers' understanding of the issues
- identify priorities for action and strategies to address them
- identify further research questions

Overall, the community members provided an in-depth understanding of the broader community context and the implications for interpreting the quantitative results.

The researchers conclude that the involvement enriched their insights and findings and ensured that the interpretation of findings had meaning for the community.

Category: impact of public involvement

Cayton, H. & Hanley, B. (2001) **Improving research through consumer involvement,** M. Baker & S. Kirk (Eds.) Research and development for the NHS (pp 195-207). Oxford: Radcliffe Publishing Ltd.

Abstract
This chapter explores some of the reasons for involving consumers in R&D, makes recommendations about how to involve consumers and discusses the role of Consumers in NHS Research (now INVOLVE).

It includes examples of collaborations between researchers and consumers where involvement has had an impact on:

- the research topic
- priorities for research
- research design
- disseminating results

Category: impact of public involvement

Chalmers, I. (1995) **What do I want from health research and researchers when I am a patient?** British Medical Journal, 310, 1315-1318.

Abstract
The author takes on the perspective of a patient to explore what he would like from health research and researchers. He concludes that health researchers could serve the interests of the public more effectively and could be helped to do so by greater lay involvement in research.

He also reflects on his knowledge of 20 years of lay contributions to research in pregnancy and childbirth to give examples of where involvement has had an impact on:

- the research question
- outcome measures - to ensure they are of importance to patients
- trial protocols
- recruitment to trials
- interpretation of the results of a trial and their implications
- clinical practice and future research

He concludes there should be greater lay involvement more generally, and particularly in setting the research agenda and identifying which questions are worth addressing.

Category: impact of public involvement, reflecting on public involvement in research

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Chambers, R., O'Brien, L., Linnell, S. & Sharp, S. (2004) **Why don't health researchers report consumer involvement?** Quality in Primary Care, 12, 151-157.

Abstract
Aim: To find out if researchers publishing in international general medical journals had actively involved consumers in their research and to what extent they had involved consumers.

Methods: Two researchers assessed the extent of consumer involvement in 200 papers randomly selected from four international general medical journals. The corresponding authors of the papers were surveyed to find out what they thought had been the extent of that involvement.

Findings/recommendations: Consumer involvement occurred in six of the 200 papers. 132 authors replied to the survey and 54 said they had involved consumers. This mismatch occurred because some of the researchers had limited knowledge and understanding of consumer involvement and because some had not included details of consumer involvement in their original articles. A minority of the researchers were aware of the potential benefits of involving consumers.

The authors recommend that researchers and consumers need training and information about involvement as a substantial proportion of health researchers do not understand its meaning.

Category: nature and extent of public involvement in research

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Chappell, A. (2000) **Emergence of participatory methodology in learning difficulty research: Understanding the context**, British Journal of Learning Disabilities 28, 38-43.

Abstract
In this article the author reflects on the development of emancipatory and participatory approaches to research involving people with learning disabilities. She discusses why participatory approaches are gaining greater acceptance than emancipatory methodology among learning difficulty researchers.

Category: reflecting on public involvement in research

Clark, C., Scott, E., Boydell, K. & Goering, P. (1999) **Effects of client interviewers on client-reported satisfaction with mental health services**, Psychiatric Services, 50(7), 961-963.

Abstract
Aim: To compare the data collected by clients with the data collected by staff members in an evaluation of mental health services.

Methods: A questionnaire was designed with input from clients, which asked about client satisfaction with services. A total of 120 clients were then randomly assigned to be interviewed by a staff member or by a client. Both groups used the same questionnaire.

Findings/recommendations: There were no differences between the two groups in terms of the number of reports of high levels of satisfaction with services. However, clients gave a greater number of extremely negative responses when they were interviewed by client interviewers. The researchers conclude that this was because clients felt safer and were more trusting of client interviewers. They highlight the importance of involving clients in this kind of study as it results in more valid feedback. This is essential to providing relevant, effective and meaningful services.

Category: impact of public involvement

Clark, M., Glasby, J. & Lester, H. (2004) **Cases for change: User involvement in mental health services and research,** Research Policy and Planning, 22(2), 31-38.

Abstract
This paper describes the authors' experiences of involving mental health service users in research on adult mental health services. It identifies key benefits of user involvement in research in terms of:

Impact on the research: the user perspective helped shape the analysis of themes and trends as well as influence the views of the academics. The focus of the research was changed to emphasise the diversity of views on causes of mental illness, how best to deal with mental distress and how best to organise services.

Benefits for the service user researcher: using skills that were thought to have been lost; developing new skills and knowledge; greater self-esteem and confidence; social interaction; earning money; making use of users' experience and knowledge.

Impact on the academic researchers: more thought given to service users needs particularly in terms of language used in reports; assumptions, attitudes and values were challenged.

However, the pressure of work did lead to the service user researcher becoming unwell during the course of the project. This led the researchers to question whether they had provided adequate support.

Category: impact of public involvement

Collins, K., Boote, J., Ardron, D., Gath, J., Green, T., Ahmedzai, S.; on behalf of the NTCRN CRP. (2014) **Making patient and public involvement in cancer and palliative research a reality: academic support is vital for success**, BMJ Supportive & Palliative Care doi:10.1136/bmjspcare-2014-000750 [Epub ahead of print]

Abstract
This paper describes a model of public involvement in research – the North Trent Cancer Research Network Consumer Panel (NTCRN CRP) – which has 38 members. It was set up 12 years ago to provide a mechanism for patients/carers to influence the research agenda and to contribute to the research process from the outset.

The role of the Panel has since expanded. Currently, Panel members take part in public conferences and support engagement, help manage the Network's research portfolio, are involved in individual studies and contribute to overall research governance.

Over the years the challenges have been:

- Lack of time and resources
- Tensions between different stakeholders and their views of the value of involvement
- Lack of clarity of the role of Panel members at some research meetings
- Lack of clarity about how best to involve patients/carers

The authors conclude that part of the NTCRN CRP's success can be attributed to the fact that it has been supported by two local universities since the beginning and has been validated and nurtured by senior level researchers.

Category: nature and extent of public involvement in research, reflecting on public involvement in research

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Cook, T. (2012) **Where participatory approaches meet pragmatism in funded (health) research: The challenge of finding meaningful spaces,** Forum: Qualitative Social Research, 13(1), Art. 18.

Abstract

This paper highlights the confusion around the term 'participatory research' and the impact this may have on practice. It discusses some of the challenges of getting this type of research funded and reviewed, when it is so different to other approaches and cannot be judged by the same standards of 'objectivity'.

The author argues that the rationale and benefits of participatory research need to be more clearly defined, so that this approach can be embedded into research environments, funding schemes and administration in way that reflects its true nature and purpose.

Category: reflecting on public involvement in research.

Coren, E. (2007) **Collection of examples of service user and carer participation in systematic reviews,** London: SCIE.

Abstract

This report includes three different examples of user involvement in systematic reviews. Each example has used different methods of involvement and reported on different types of impact.

Example 1 is a systematic review of consumers' perspectives on electroconvulsive therapy (ECT) which was user led. User involvement had an impact on all stages of the review including the type of evidence used and the findings.

Example 2 is a review of evidence relating to HIV prevention in men who have sex with men. The lessons mainly relate to successfully involving users via an advisory group.

Example 3 is a review that contributed to developing the National Newborn Screening Programme. User involvement had an impact on the leaflets produced and led to further involvement in guideline development and research.

Category: impact of public involvement

Corneli, A., Piwoz, E., Bentley, M., Moses, A., Nkhoma, J., Adair, L., Mtimuni, B., Ahmed, Y., Duerr, A., Kazembe, P., van der Horst, C. & the UNC Project BAN study (2007) **Involving communities in the design of clinical trial protocols: The BAN study in Lilongwe, Malawi.** Contemporary Clinical Trials, 28(1), 59-67.

Abstract
Aim: To learn about the attitudes and concerns of the local community in Lilongwe, Malawi on participating in a clinical trial. The trial aimed to test antiretroviral and nutritional interventions to reduce postnatal transmission of HIV.

Methods: The views of local community members were obtained by semi-structured interviews, focus group discussions, home observations and taste trials.

Findings/recommendations: The researchers changed their trial protocol so that it would be acceptable to the local community at the same time as achieving its scientific objectives. Without this prior consultation of the community, the researchers conclude that several significant areas would have been undetected which could have jeopardised the trial. Additional research was carried out to develop a meaningful consent process.

Category: impact of public involvement

Cornes, M., Peardon, J., Manthorpe, J. & The 3YO Project Team (2008) **Wise owls and professors: the role of older researchers in the review of the National Service Framework for Older People in England,** Health Expectations, 11(4), 409-417.

Abstract
Aim: To explore the involvement of older people in the joint review of the NSF for Older People in England.

Methods: A day-long seminar was held with the user researchers and other members of the research team to capture their reflections on the user involvement in this large-scale study.

Findings/recommendations: The older researchers reported on the personal benefits of working on this project and how valuable they had found it learning from other members of the team.

One of the main learning points from the project, however, was the importance of viewing service user researchers as an integral part of a wider team.

Often service users are perceived as simply lacking experience and requiring training. This training is seen as crucial to maintaining quality standards in research. However, all individuals, whether they are researchers or service users, will have very different skills and experiences.

It is important to allow everyone in a research team to be matched to tasks accordingly.

It is also important to think about supporting the research team as a whole aiming to maximise the benefits from the diversity of skills and experiences available. This is distinct from trying to convert service users into academic researchers.

The authors conclude there is a need to move beyond the rhetoric of participation and any blanket assumptions about what it means to be a 'service user researcher' or a 'professional researcher'. This means ensuring that within any research team there are equal opportunities for individual appraisal, support and personal or professional development, at the same time as ensuring there are clear lines of accountability.

Category: impact of public involvement, reflecting on public involvement in research

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Cotterell, P. (2007) **Exploring the value of service user involvement in data analysis: 'Our interpretation is about what lies below the surface'.** Educational Action Research, 16(1), 5-17.

Abstract
This article discusses the process and outcomes of involving service users in the analysis of data from a palliative care research project. The service user group was made up of people with different life-limiting illnesses and they were involved throughout the project.

The researcher reflects on his experience of involving users in the analysis stage of the project and his initial concerns about maintaining objectivity. However, he also explains that he came to realise the value of drawing on service users' first-hand experience to interpret the data, and the usefulness of the group's insights.

The article describes how the researcher and user group identified quite different themes from the same data. The themes identified by the user group had a far greater emotional resonance and a more critical component, whilst the researcher's analysis had a more professional emphasis.

The involvement of users thus steered the analysis towards the issues of importance to service users, and a more social model of disability. This meant that some issues were raised, for example, the societal impact of living with a life-limiting condition, that might have otherwise been missed.

Category: impact of public involvement, reflecting on public involvement in research

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Cotterell, P., Clarke, P., Cowdrey, D., Kapp, J., Paine, M. & Wynn, R. (2007) **Becoming involved in research: a service user research advisory group.** Chapter 11. In: Creative Engagement in Palliative Care, (Ed: Jarrett, L.), Radcliffe Publishing Ltd.

Abstract

This chapter describes the experiences of a group of service users with different life-limiting conditions who were involved in a research project in palliative care.
The service users helped with:

- designing the project and deciding what questions to ask
- assisting with how the research data was collected
- assisting with the data analysis
- teaching and writing about the work they'd done

This chapter provides a detailed account of the service users' experiences of involvement. They describe the positive benefits including:

- being able to escape from their situation
- being able to share the lessons from their experience 'to make a smoother path on which other service users might travel'
- feeling valued and contributing so something worthwhile
- gaining understanding and developing new skills

However there were some upsetting aspects to their involvement, in particular the loss of team members through ill-health and hearing the details of what some of the interviewees had said. The support provided within the group proved an important means of coping with this upset.

Category: impact of public involvement

Coupland, H., Maher, L., Enriquez, J., Le, K., Pacheco, V., Pham, A., Carroll, C., Cheguelman, G., Freeman, D., Robinson, D. & Smith, K. (2005) **Clients or colleagues? Reflections on the process of participatory action research with young injecting drug users,** International Journal of Drug Policy, 16, 191-198.

Abstract

Aim: This paper reflects on the benefits and challenges of involving young injecting drug users (IDUs) in participatory action research.

Methods: It is based on the experiences of researchers, health workers and IDU researchers who worked on a needs assessment of young IDUs who do not access services. The research was carried out in two areas in Australia to inform local service planning.

Findings/recommendations: There were benefits for all members of the team:
The health workers gained a better understanding of the barriers to accessing services and the needs of young IDUs, a more positive attitude to young IDUs, new relationships with IDUs who don't access services i.e. better networking opportunities. The young IDU researchers benefited from increased confidence and self-esteem, a more positive attitude to future employment, a sense of having made a contribution.

The researchers gained from access to research participants that would not have been possible otherwise, faster recruitment and data collection. The wider community gained because the young IDU researchers became peer educators, disseminating information about health risks and access to services. One of the young IDU researchers has since been involved in developing an outreach service.

Category: impact of public involvement

Davies, K., Gray, M. & Webb, S. (2014) **Putting the parity into service-user participation: An integrated model of social justice**, International Journal of Social Welfare, 23(2), 119-127.

Abstract

This study examined the experiences of mental health service users and homeless people in Australia, who had been involved in decisions about their own care or been involved as representatives to inform social service development/policy. They found that neither a rights agenda nor a consumerist approach helped to support the right kind of involvement. These approaches led to tokenism and had little impact. A rights-based approach means people can simply be in the room and participation becomes an end in itself. A consumerist approach has little meaning when service users don’t have a genuine choice about the services they receive. The authors conclude that a model of involvement based on social justice – that focuses on the desired outcomes of involvement - would support better involvement processes. The goal would then be to ensure that the policy or interventions that are influenced by involvement will deliver benefits for service users - in terms of enhanced opportunities to participate more fully in society.

Category: reflecting on public involvement in research

Davies, R. & Evans, D. (2010) **Public involvement in research: How can organisations collaborate to improve involvement?** Bristol: University of the West of England.

Abstract
Aim: To undertake a scoping exercise to identify experiences and share learning on current systems and practice relating to public involvement in health and social care research.

Methods: Interviews were conducted with researchers and service user research partners from 14 stakeholder organisations in the South West region of England.

Findings: The authors identified the key issues and challenges for the organisations involved in terms of taking forward public involvement and also in terms of collaborative working. They propose five different options for future collaboration. In the course of the interviews, they also identified a range of ways in which the public have been involved in research in the region. A number of case studies describe what difference this involvement made.

Category: nature and extent of public involvement in research, impact of public involvement

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Davies, S. & Nolan, M. (2003) **Editorial: Nurturing research partnerships with older people and their carers: Learning from experience,** Quality in Ageing - Policy, Practice and Research, 4(4), 2-5.

Abstract
This edition of Quality in Ageing is devoted to the proceedings of a conference that explored research partnerships between older people, their carers and researchers. The editorial highlights some of the papers in this edition and also reports on feedback from workshops at the conference.

Workshop participants identified the following benefits of research partnerships:

- researchers focus on issues important to older people
- research focuses on real issues and is action-oriented

- challenges myths and stereotypes about ageing
- involving older people as data collectors can make it easier for some people who feel more comfortable talking to their peers

Benefits to people who are involved included: feeling of making a positive contribution; participation in new activities; opportunities to make new friends and relationships; building confidence and developing new skills; greater visibility.

Negative experiences included: feeling involvement is tokenistic; feeling let down or abandoned at the end of the research; unmet expectations of change.

Category: impact of public involvement

Davila-Seijo, P., Hernandez-Martin, A., Morcillo-Makow, E., de Lucas, R., Dominguez, E., Romero, N., Monros, E., Feito, M., Carretero, L., Aranegui, B. & Garcia-Doval, I. (2013) **Prioritisation of therapy uncertainties in Dystrophic Epidermolysis Bullosa: where should research direct to? An example of priority setting partnership in very rare disorders**, Orphanet Journal of Rare Diseases, 8, 61.

Abstract
This article summarises the outcome of a priority setting partnership that followed the James Lind Alliance method, to identify research priorities for a very rare condition.

Category: impact of public involvement

Denis, J. & Lomas, J. (2003) **Convergent evolution: the academic and policy roots of collaborative research,** Journal of Health Services Research and Policy, 8 (supplement 2), S2:1-S2:6.

Abstract
This is an editorial for a supplement to a journal, which looks at partnerships in research. In addition to briefly describing each of the papers included in the supplement, the authors define collaborative research and its benefits. They describe four streams of academic work which have contributed to the growth of collaborative research: action research, participatory action research, programme evaluation and work on knowledge utilisation.

They describe policy developments in the UK and USA which have contributed to this growth. Finally, they identify four themes from the papers in the supplement. These are:

- researchers find the additional investments of time and other resources largely worthwhile

- trust is an essential ingredient to the success of collaborative research
- the success of collaborative research depends as much on the people involved as the processes they put in place
- collaborative research is a journey without a clear destination

Category: reflecting on public involvement in research

Dewar, B.J. (2005) **Beyond tokenistic involvement of older people in research - a framework for future development and understanding,** International Journal of Older People Nursing in association with Journal of Clinical Nursing, 14(3a), 48-53.

Abstract

This paper reflects on initiatives that have been developed at the Royal Bank of Scotland Centre for the Older Person's Agenda that aim to support older people in partnership working in research and development work.

It reports on the benefits of working in partnership with older people, the challenges for researchers and issues that need to be considered in the future.

Early evaluation of the impact of involving older people in research at the centre have shown: better access to marginalised groups; more accessible information;
better dissemination of information to peers; greater empathy with other older people in interviews.

One of the key issues raised is the role of user researchers. Should they play a research assistant role (i.e. the same as the researchers) or is there something about their role which is distinct? Should the training provided be any different to the training given to research students i.e. an introduction to research methods? Or is specific training needed for user researchers?

Other issues raised include:

- the need to be critical about why it is important to involve users in research
- being clear about what involvement means
- whether older people want to control research and whether research led by older people has better outcomes than partnerships
- older people's motivation to get involved

Category: impact of public involvement, reflecting on public involvement in research

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Dickson, G. & Green, K. (2001) **Participatory action research: Lessons learned with Aboriginal grandmothers,** Health Care for Women International, 22(5), 471-482.

Abstract

This article draws out the lessons learned from a participatory action research project that involved Aboriginal women. They helped to carry out a health assessment as part of a larger health promotion project that aimed to meet the needs of older Aboriginal women.

Aboriginal women were involved as members of an Advisory Committee who guided the start-up and development of the project and as co-researchers who:

- designed interview questions and information for participants
- analysed data
- helped draft the assessment report
- took action on findings from the project

Two middle-aged Aboriginal women were also hired as research associates and conducted interviews with community members.

Their involvement changed the nature and pace of the project, linking the health needs assessment to other health promoting activities and shifting the emphasis from 'problems' to 'strengths'. Action was taken on numerous individual and social issues making a direct link between the research and community action and change.

The women involved benefited from:

- establishing new social support systems
- recognising their own strengths and values
- a raised awareness of issues they had not previously questioned , and
- growing in self-esteem and confidence

As the project became known in the community, the women were asked to receive visitors and invited to sit on committees. This gave them opportunities to speak out about issues they felt strongly about, advocating for themselves and the wider Aboriginal community. The project thus helped the women to create alliances and build the skills and organisation necessary to support ongoing health promoting activity.

Category: impact of public involvement

Dobbs, L. & Moore, C. (2002) **Engaging communities in area-based regeneration: The role of participatory evaluation,** Policy Studies, 23(3/4), 157-171.

Abstract

This paper provides an overview of a number of projects undertaken in Tyneside which employed local residents to carry out baseline and impact surveys. It explores the benefits of participation as well as the barriers to involvement and how these might be overcome.

Training and supporting community members to conduct the surveys had the following benefits:

- the researchers' knowledge of the local community meant they were better able to negotiate access to local groups as they knew the best times to visit particular areas and were skilled at engaging hard-to-reach groups
- their commitment to the local area and the project, meant they made strenuous efforts to increase the response rate at every opportunity.

The individual community researchers said they had gained a range of skills they hoped would help them find further employment in future as well as a sense of greater self-confidence and self-respect from being involved in such worthwhile work.
Members of the local community said they felt the process had allowed them to play an important role in regeneration and they enjoyed being interviewed by local people. They felt greater ownership of the outcomes and many more local people discussed the findings and recommendations.

Overall, the community centred approach to the design, administration and analysis gave the survey results and recommendations widespread credibility amongst all stakeholders. There was a general sense of agreement that the results were representative of the community. Groups and individuals were more likely to embrace the results and move forward collectively on agreed recommendations. The participatory approach to the research seemed to act as a catalyst to enhance partnership working more generally.

Category: impact of public involvement

Dona, G. (2006) **Children as research advisers: Contributions to a 'methodology of participation' in researching children in difficult circumstances,** International Journal of Migration, Health and Social Care, 2(2), 22-34.

Abstract

This article reviews the involvement of children as research advisers in two projects: a study of foster care for separated children in Rwanda and an analysis of the conditions of children outside parental care living in institutions and communities in Bangladesh.

Detailed discussions of both projects describe how the child advisory committees influenced the research topics, the selection of participants, recruitment of participants, the interpretation of findings and the recommendations proposed.

The author emphasises the importance of thinking through the method of participation, since how participation itself is conceived and carried out affects the quality of the process. If well planned, participation improves the quality of the overall research project and gives children tools to examine and discuss their lives.

Category: impact of public involvement

Donovan, J., Mills, N., Smith, M., Brindle, L., Jacoby, A., Peters, T., Frankel, S., Neal, D. & Hamdy, F. (2002) **Improving design and conduct of randomised controlled trials by embedding them in qualitative research: ProtecT (prostate testing for cancer and treatment) study,** British Medical Journal, 325, 766-770.

Abstract
Aim: To examine the impact of qualitative research on the design and conduct of a controversial randomised clinical trial for prostate cancer.

Methods: In-depth interviews were carried out with men who had been invited to join the trial to find what they had understood from the study information. Recruitment appointments were also tape recorded to find out how recruiters presented the trial. The findings were used to change the content and presentation of the study information.

Findings/recommendations: Changes to the way the information about the trial was presented and the way different elements were described increased the men's understanding of the nature and purpose of the trial. Recruitment rates increased from 40% to 70%. The authors recommend that similar approaches are used more widely, especially when a trial is thought to be difficult to carry out.

Category: impact of public involvement

Dyer, S. (2004) **Rationalising public participation in the health service: The case of research ethics committees,** Health & Place, 10, 339-348

Abstract
This paper reports on a study of lay participation on Local Research Ethics Committees based on interviews with committee members and observations of committee meetings.

It identifies a lack of understanding of the value of lay participation and the lack of a centrally defined role. This means that lay members do not possess either the authority or knowledge to challenge experts' technical assessments of research.

Category: reflecting on public involvement in research

Edwards, V., Wyatt, K., Logan, S. & Britten, N. (2011) **Consulting parents about the design of a randomised controlled trial of osteopathy for children with cerebral palsy,** Health Expectations, 14(4), 429-38.

Abstract
Aim: To demonstrate how consulting parents about the design of a study led to the successful delivery of a randomised controlled trial.

Method: Semi-structured interviews were carried out with 20 parents of children with cerebral palsy and other neurological conditions, asking them to choose between different trial designs and to talk about possible outcomes and their views about payment for trial treatment.

Findings/ recommendations: Involvement of parents helped design a trial which was acceptable to families and addressed outcomes that mattered to them. It also meant that the subsequent trial achieved excellent recruitment and retention rates.

Category: impact of public involvement

Elberse, J., Pittens, C., Buning, T. & Broerse, J. (2012) **Patient involvement in a scientific advisory process: Setting the research agenda for medical products**, Health Policy, 107(2-3), 231-42.

Abstract
This article describes a case study of the involvement of patient groups in developing advice for the Health Council of the Netherlands. The aim of the involvement was to set a research agenda for the development of medical products. The process involved four phases including interviews and focus groups with patients and patient representatives. The Advisory Board found the advice constructive and incorporated patients' input into their advice to the Minister of Health.

Category: impact of public involvement

Elliott, E., Watson, A. & Harries, U. (2002) **Harnessing expertise: involving peer interviewers in qualitative research with hard-to-reach populations,** Health Expectations, 5, 172-178.

Abstract

This paper explores a number of key issues relating to the employment of peer interviewers in a project to explore the views and experiences of people who use illegal drugs.

The authors report on training and debriefing the interviewers as well as the need to provide ongoing support. They report that employing peer reviewers had both a negative and positive impact.

Problems arose because many of the interviewees refused to have their interviews taped which left the researchers anxious about working with 'second-hand' data. Also the peer interviewers familiarity with the language and lifestyles of the people being interviewed meant that they didn't always make notes of what they perceived to be 'common knowledge' - but these were issues thought to be relevant and important by the researchers.

The researchers thought they would need to conduct the interviews themselves in future and work with users to find people to interview. The most important advantage was being able to interview people who could not have been reached in any other way. The peer interviewers were also able to collect the data quickly and from a diverse range of users.

Findings/recommendations: On reflection the authors conclude that such projects would benefit from a more flexible approach - particularly in terms of the roles of lay experts and researchers and their respective areas of control.

They recommend more joint working - during training, debriefing, and both during and after carrying out the fieldwork.

Category: impact of public involvement

Ennis, L. & Wykes, T. (2013) **Impact of patient involvement in mental health research: longitudinal study**, The British Journal of Psychiatry, 203(5), 381-6.

Abstract

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. They also showed that involvement had increased over time and some funders had more involvement in their studies than others.

Category: impact of public involvement

Entwistle, V., Renfrew, M., Yearley, S., Forrester, J. & Lamont, T. (1998) **Lay perspectives: advantages for health research,** British Medical Journal, 316, 463-466.

Abstract
This paper outlines two basic reasons for involving consumers in research and discusses some common objections.

The two reasons for involvement are that:

1. It is a political imperative - as owners of publicly funded research the public should have a say in what is done and how. Then involvement becomes a goal in its own right. The processes of decision-making become more important than the quality of those decisions.

2. It can improve the quality of research - since lay views are often different from professionals, have legitimacy and can add value.

The authors then address common objections and outline a framework for thinking about lay involvement in research.

They conclude that more work needs to be done to explore the advantages, disadvantages and resource implications of involvement in different circumstances.

Category: reflecting on public involvement in research

Evans, C. & Fisher, M. (1999) **Collaborative evaluation with service users: Moving towards user-controlled research,** Ian Shaw & Joyce Lishman (eds), Evaluation and Social Work Practice (pp101-117). London: Sage.

Abstract
The authors argue that social workers should consider how they can support service users to carry out their own research and ensure that evaluation is user-led.

The authors describe the experiences of involvement in research of the Wiltshire and Swindon Users' Network and the Leonard Cheshire Disabled People's Forum. These experiences range from being researched, where service users had a passive role, through to collaboration with researchers and ultimately to research controlled by service users.

They describe a user-controlled piece of research (an evaluation of an Independent Living Fund), how users had an impact on the research ethics and on how the research was undertaken. They also describe the training members undertook.

Finally, they outline the skills and commitment required of social workers if they are to assist service users to undertake their own research. They call for an "empowerment research agenda" which should be taken forward jointly by social workers and service users.

Category: impact of public involvement, reflecting on public involvement in research

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Evans, C. & Fisher, M. (1999) **User-controlled research and empowerment,** W. Shera and L. Wells (Eds.), Empowerment practice in social work: Developing richer conceptual foundations (pp 348-369). Toronto: Canadian Scholars Press.

Abstract

This chapter argues that empowerment of service users risks being merely collaboration unless service users define empowerment for themselves. Empowerment tends to be defined by professionals. For empowerment to improve the lives of service users it must reflect service users' experiences and issues.

In the context of research, the authors argue that the role of service users as researchers needs to be recognised as a means of achieving empowerment. They emphasise that only user-controlled research ensures that service users have power over the way their experiences are defined.

The chapter also discusses:

- the question of what counts as knowledge
- the limitations of co-operative and participatory research compared to user-controlled or emancipatory research
- an example of user-controlled research
- how to carry out user-controlled research in terms of funding, managing, designing and carrying out the research
- the benefits of user-controlled research - improving recruitment, the quality of data, and interpretation of results
- the role of academic researcher as ally and facilitator

Category: impact of public involvement, reflecting on public involvement in research

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Evans, D. (2014) **Patient and public involvement in research in the English NHS: A documentary analysis of the complex interplay of evidence and policy**, Evidence and Policy, 10(3), 361-77.

Abstract

This article reports the findings from a review of all the English health R&D policy documents published between 1991 and 2010. The aim was to find out what evidence had been used to support the policy shift towards greater PPI in health R&D over the last 20 years. The review showed that much of the policy promoting PPI was developed before evidence of the impact of PPI became available. This indicates that the policy is not truly 'evidence-based' and that another model of policy development must explain how this came about. Further research is needed to identify the factors that contributed to this development.

Category: reflecting on public involvement in research

Evans, J., Rose, D., Flach, C., Csipke, E., Glossop, H., McCrone, P., Craig, T. & Wilkes, T. (2012) **VOICE: Developing a new measure of service users' perceptions of inpatient care, using a participatory methodology,** Journal of Mental Health, 21(1), 57-71.

Abstract

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. The measure was validated by expert panels of service users and tested for its validity and reliability.

VOICE includes the issues that service users consider to be important in assessing the quality of care and is different to other measures. It places more emphasis on safety and security issues as well diversity and did not include items on the physical environment or office procedures. It provides a more in-depth assessment of users' expectations and evaluation of care, beyond a simple measure of satisfaction. It has strong psychometric properties and is suitable for use in research settings.

Category: impact of public involvement

Evans, I., Thornton, H. & Chalmers, I. (2006) **Testing treatments: Better research for better healthcare,** London: British Library (ISBN 071234909X)

Abstract

The aim of this book is to generate a wider understanding of how treatments can and should be tested fairly. It highlights issues that are fundamental to ensuring that research is designed to address the questions that matter most to patients and health professionals.

Much of the book reviews evidence that a lot of time, money and effort is wasted on research that is poor quality or unnecessary. Chapter 7 discusses how greater public involvement in research, especially in identifying research topics, could help to ensure that research better meets the needs and interests of patients. It includes a number of examples of where patient involvement has helped to define the research question and improve the quality of research.

Category: impact of public involvement

Fairbother, P., McCloughan, L., Adam, G., Brand, R., Brown, C., Watson, M., Cotter, N., Mackellaig, J. & McKinstry, B. (2013) **Involving patients in clinical research: the Telescot Patient Panel**, Health Expectations doi: 10.1111/hex.12132. [Epub ahead of print]

Abstract

The Telescot study aimed to explore the feasibility of using home telemonitoring of blood pressure for people affected by stroke. The research team set up a Patient Panel to advise on the delivery of the research. The protocol had already been agreed. The Panel made a difference by:

- improving the information given to potential participants
- commenting on the challenges for stroke patients using the technology required for telemonitoring which helped with the design of the intervention
- informing the development of the qualitative study that explored participants' experience of the telemonitoring. They also contributed to the analysis of this data.
- advising on ways to communicate the results to a wider group of stakeholders.

The research team commented on the extra demands on time and resources, which they had not built in to their original application. However, they found the input very valuable and despite some initial concerns, are planning to have more involvement in their projects in future.

Category: impact of public involvement

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

Abstract
The TRUE project was commissioned by INVOLVE to scope training provision in the UK relevant to consumer involvement in research. There were seven service users, three project supervisors and a project co-ordinator in the research team.

At the end of the project INVOLVE commissioned an extra piece of work to capture the experiences of all those who had been involved. This report is a summary of those experiences. It includes the views of the service users on the benefits of being involved. These included:

- feeling appreciated
- being stretched by new skills and new experiences
- meeting new people
- increased knowledge of mental health and research
- working in a group
- greater confidence
- further opportunities to be involved in research

Category: impact of public involvement

Faulkner, A. (2007) **Beyond our expectations: A report of the experiences of involving service users in forensic mental health research,** National Forensic Mental Health NHS Research and Development Programme.

Abstract
Aim: This report summarises the experiences of four different research projects funded by the National Forensic Mental Health NHS R&D programme which involved service users in a number of different ways.

Methods: Interviews with researchers and service users who worked on the projects.

Findings/recommendations: The report reflects on the challenges and facilitators to involvement as well as the benefits. A major benefit was that these projects contributed to challenging stigma, both within and beyond the forensic services.

Benefits for the research included:

- better quality data through engaging users to collect data from their peers
- better analysis and interpretation of the data by including the users' perspective
- more accessible information for participants to ensure fully informed consent
- more accessible and appropriate questionnaires

Benefits for the researchers included: learning to share power and control; greater knowledge and understanding of users' experiences; enjoyment and satisfaction in their work.

Benefits for the service users who were involved included: new skills and knowledge; working with others; greater confidence; a stepping-stone to work.

Category: impact of public involvement

Faulkner, A. (2010) **Changing our worlds: Examples of user-controlled research in action**, Eastleigh: INVOLVE.

Abstract
This report describes seven examples of research where service users or disabled people controlled the research process. It aims to provide a better understanding of the role and value of user-controlled research. It describes what difference it makes when the research agenda is held and directed by service users, in terms of the impact on the research, on the researchers and subsequently on policy and services.

Category: nature and extent of public involvement in research, impact of public involvement, reflecting on public involvement in research

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Fisher, M. (2002) **The role of service users in problem formulation and technical aspects of social research,** Social Work Education, 21(3), 305-312.

Abstract
This paper argues that if research is to be relevant to the issues faced by service users, they must be actively involved in this research at all stages.

Fisher draws on a range of research projects to expand on his argument. He sets out some distinctions in the meaning of user involvement in different models of social research. He argues that more traditional methods - such as consulting with service users and participatory research - are not enough to respond to the demands of service users for "genuine involvement in research design". Instead, he calls for a three-way relationship between the practitioner, research and the service user.

Fisher draws on a range of examples of user-led and user-controlled research to suggest that problem formulation benefits from user involvement. He gives illustrations that show how service users have challenged the assumptions made by researchers and research commissioners. He also argues that user involvement can help researchers to access the 'right people', giving examples of how user-controlled research can improve response rates. Fisher goes on to describe how the quality of interview data may be improved if service users act as interviewers.

Fisher moves on to consider how user perspectives can alter the research approach to outcomes, outlining three principles for user perspectives on outcome measurement.

Finally, he argues that service users can improve the analysis of qualitative data, again by drawing on a number of examples.

Category: impact of public involvement, reflecting on public involvement in research

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Forbes, L., Nicholls, C., Linsell, L., Graham, J., Tompkins, C. & Ramirez, A. (2010) **Involving users in the design of a randomised controlled trial of an intervention to promote early presentation in breast cancer: qualitative ,** BMC Medical Research Methodology, 10, 110-117.

Abstract
Aim: This paper describes the impact of user involvement in a large randomised controlled trial of an intervention that aimed to promote early presentation of breast symptoms in older women.

Method: The researchers carried out a qualitative study, involving women in focus groups and in-depth interviews to help with the design of the trial. The women involved included some who had a previous diagnosis of breast cancer and some who did not.

Findings/recommendations: The women helped with the challenges around obtaining consent, recommending an opt-out approach. They also addressed the issues around finding and contacting women who developed breast cancer, supporting the use of routine patient data.

Category: impact of public involvement

Froggatt, K., Preston, N., Turner, M. & Kerr, C. (2014) **Patient and public involvement in research and the Cancer Experiences Collaborative: Benefits and challenges**, BMJ Supportive & Palliative Care doi:10.1136/bmjspcare-2013-000548.

Abstract
Aim: To report on the experiences of eight people affected by cancer who were involved in supportive and palliative care research over a period of six years.

Methods: Their views were obtained by semi-structured interviews.

Findings/recommendations:
The main benefits of involvement 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 the practical demands. These included 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.

Category: impact of public involvement

Fudge, N., Wolfe, C. & McKevitt, C. (2007) **Involving older people in health research,** Age and Ageing Vol.36 492-500.

Abstract
Aim: To review published reports of studies which involved older people in commissioning, prioritising, designing, conducting or disseminating research.

Methods: A structured literature review of published articles of 'older people'. 2,492 articles were initially identified from the database of which 30 were included in the study.

Findings/recommendations: The authors grouped people's involvement in the research process into five stages, and listed the projects that involved people at each of them. These stages were: training of people to participate in the research, design of the research, data collection and data analysis, membership of advisory groups, and being involved throughout the process. They also report on the impact of involving people.

The paper discusses the broad range of journals from which papers were identified, and comments on the increase in literature relating to involvement over the last decade. Where comment on impact was included, papers tended to focus on impact of involvement on participants rather than on the research process itself. The many different applications of the term 'user involvement' are discussed. The authors noted that the evidence mainly focused on the impact involvement has on the people who become involved in the research process. There was little evidence on what impact involving people has on the quality of the research itself. They recommended that this issue is addressed before involving people is promoted as a policy.

Category: nature and extent of public involvement in research, reflecting on public involvement in research

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Gagnon, M., Desmartis, M., Lepage-Savary, D., Gagnon, J., St-Pierre, M., Rhainds, M., Lemieux, R., Gauvin, F., Pollender, H. & Légaré, F. (2011) **Introducing patients' and the public's perspectives to health technology assessment: A systematic review of international experiences**, International Journal of Technology Assessment in Health Care, 27(1), 31-42.

Abstract
Aim: To review international experiences of patient or public involvement in health technology assessment (HTA).

Method: A systematic review of the literature.

Findings/ recommendations: The review identified two main ways that patients/ the public are involved in HTA:

1. They participate in the research used to assess new technologies/ services. Their views, experiences and opinions are sought through interviews and focus groups.

2. They are involved in the HTA process – selecting and prioritising the technologies to be assessed, being actively involved in the design and delivery of the research used to assess new technologies, and helping with dissemination of the findings.

The authors conclude that bringing in the patient perspective could add important dimensions to the evaluation of new technologies that might otherwise be missing, for example defining outcomes for treatments that are most important and meaningful for patients. However, they also conclude that more rigorous studies of public involvement are required to identify how to expand involvement activity in HTA and to evaluate its impact.

Category: nature and extent of public involvement in research, impact of public involvement

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Gamble, C., Dudley, L., Allam, A., Bell, P., Goodare, H., Hanley, B., Preston, J., Walker, A., Williamson, P. & Young, B. (2014) **Patient and public involvement in the early stages of clinical trial development: A systematic cohort investigation**, BMJ Open, 4, e005234.

Abstract
Aim: To examine the public involvement within early development of clinical trials.

Method: A review of all the documents relating to successful applications for funding of clinical trials by the National Institute for Health Research (NIHR) Health Technology Assessment Programme 2006-10. The documents included outline and full applications and comments from funding Boards.

Findings/recommendations: Out of 110 applications that were included in this study, 29% had public involvement in the development of the outline application, 36% in the full application and 48% planned public involvement in the running of the trial. There was no evidence of an increase in public involvement over time. Blinded trials and trials with placebo arms were more likely to include public involvement. Trials recruiting people at the time of diagnosis and trials for surgical interventions were less likely to include public involvement. Board feedback rarely referred to public involvement.

Public involvement has the greatest potential to make a difference at the earliest stages of trial design but, in practice, involvement at the outline stage of funding applications is low. Funders need to request applicants to provide more detail on public involvement at this stage and more evidence of impact is required. Comments on public involvement in applications need to give direction on what further public involvement is required, rather than simply stating more is needed. Funding for public involvement at this stage needs to be made available.

Category: nature and extent of public involvement in research

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Gauvin, F., Abelson, J., Giacomini, M., Eyles, J. & Lavis J. (2011) **Moving cautiously: Public involvement and the health technology assessment community**, International Journal of Technology Assessment in Health Care, 27(1), 43-9.

Abstract
Aim: To explore the factors that may enhance or reduce the prospects for public involvement in health technology assessment (HTA) agencies.

Methods: 42 semi-structured telephone interviews with staff members in HTA agencies, academics, policy makers and members of patient and service user groups in Canada, Denmark and the UK.

Findings/ Recommendations: Four key factors appear to be influential:
1. The role of the International HTA community in disseminating and promoting practice ideas.
2. Limits on time and resources and the need for rapid and efficient processes in HTA.
3. Political leadership and the allocation of support/ resources from government.
4. Senior staff/ leaders within the HTA community championing public involvement.

The authors conclude that evidence from robust evaluation of public involvement in HTA would help to promote its practice in future.

Category: nature and extent of public involvement in research

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Gauvin, F., Abelson, J., Giacomini, M., Eyles, J. & Lavis, J. (2010) **"It all depends": Conceptualising public involvement in the context of health technology assessment agencies,** Social Science & Medicine, 70(10), 1518-1526.

Abstract
Aim: To find out how public involvement is understood in health technology assessment (HTA) agencies.

Methods: A review of the HTA literature and interviews with staff in HTA agencies in Canada, Denmark and the UK.

Findings/recommendations: The findings show that because HTA agencies sit on the boundary between research and policymaking, they struggle with the idea of public involvement. They find it difficult to be certain when 'public' versus 'patient' involvement is most appropriate.

There are three main areas of HTA work where there could be room for involvement:

- within the HTA agency to help with prioritising assessments and commissioning relevant research
- within commissioned research projects to influence research design and implementation
- finally appraising the evidence and writing reports for policymakers

There is an argument that the public should also be involved in democratic debates about the development and uptake of health technologies, but this lies outside of the sphere of influence of HTA agencies. The authors have produced a conceptual tool to help HTA agencies explore the assumptions and expectations about public involvement. The aim is to develop a common understanding of the concept of involvement and to help agencies find meaningful ways to put it into practice.

Category: nature and extent of public involvement in research, reflecting on public involvement in research

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Gillard, S., Borschmann, R., Turner, K., Goodrich-Purnell, N., Lovell, K. & Chambers, (2010) **'What difference does it make?' Finding evidence of the impact of mental health service user researchers on research into the experiences of detained psychiatric patients.** Health Expectations, 13(2), 185-194.

Abstract
This study compared the way in which service user researchers and university researchers conducted interviews and then analysed the findings. This was part of a qualitative study of the experiences of psychiatric patients who had been sectioned.

The results showed that in the interviews service user researchers were more likely to ask questions about people's experiences and feelings, whereas the university researchers were more likely to ask about medical treatments and behavioural approaches to understanding the interviewees' experiences. There were even more differences in the ways that service user and university researchers analysed the transcripts. The service users gave more weight to people's experiences and feelings about detention, while the university researchers gave more weight to practice and procedures.

The research team used these contrasting perspectives to provide different accounts of the detained patient experience. This informed the design of staff training that covered both aspects - the patient experience and procedures. They conclude that a collaborative approach can produce more complex data and analyses, and offer a more comprehensive insight into the research question.

They also suggest that a similar method is used compare the two types of researcher in a larger study involving more interviewers and more interviews. They believe this would generate more robust and rigorous evidence of the impact of service user researchers.

Category: impact of public involvement

Gillard, S., Simons, L., Turner, K., Lucock, M. & Edwards, C. (2012) **Patient and public involvement in coproduction of knowledge: Reflection on the analysis of qualitative data in a mental health study,** Qualitative Health Research, 22(8),1126-37.

Abstract
The authors reflect on the impact that service user and carer involvement had on the process of qualitative data analysis in a mental health research project.

They report that non-academic members of the team sometimes challenged academic conventions, leading to more complex findings that would otherwise have been missing. For example service users challenged some of the quantitative findings around medication, which led to a more in-depth review of the qualitative data on this issue. This revealed more complex and subtle findings about relationships between service users and clinicians and choices about medication. The authors conclude that involvement is not just about adding the service user voice to that of the academics, but about co-producing new knowledge through discussion and exploration of what the different voices mean in relation to each other.

Category: impact of public involvement, reflecting on public involvement in research

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Gillard, S. & Stacey, E. (2005) **All talk: Experiencing user-led research. A Life in the Day**, 9(2), 27-30.

Abstract

This article reports on the experiences of a user-led research project which explored the way people talk about mental health. It was carried out by Slough User-Led Consultation (SULC).

The fact that users led and conducted the research ensured that the participants had a space to explore their mental health without some of the fears, barriers and constraints that characterise many of their other experiences. The powerful findings that emerged were a direct result of the project being user-led.

The team have established training for mental health professionals that addresses the issues raised by this research and provides a far more powerful way of disseminating the findings than publishing a report. The professionals who receive the training describe the experience as eye-opening and a potential catalyst for change.

Category: impact of public involvement

Godfrey, M. (2004) **More than 'involvement'. How commissioning user interviewers in the research process begins to change the balance of power,** Practice, 16(3), 223-231

Abstract

Aim: This paper describes a small study, undertaken as part of a Masters Degree (MA), to obtain the views of social workers, service users and carers about the reconfiguration of mental health services and their experience of care in the community.

As part of this study, the author commissioned a mental health service user to undertake interviews with other users.

Methods: Four users were interviewed by one service user. She was trained and supported by an advocacy worker from a local mental health organisation.

Findings/recommendations: One of the key findings from the study was the lack of information providers to users.

The author reflects on the process of trying to recruit interviewees and recruiting a service user interviewer. He then draws on a range of other papers to consider the value of service users acting as interviewers. He argues that there is not enough evidence to demonstrate that user interviewing is more effective than 'professional' interviewing, and suggests ways that this evidence might be obtained.

He also calls for training and support to be made more readily available so that users can undertake their own research.

Category: reflecting on public involvement in research

Gooberman-Hill, R., Jinks, C., Boucsas, S., Hislop, K., Dziedzic, K., Rhodes, C., Burston, A. & Adams, J. (2013) **Designing a placebo device: Involving service users in clinical trial design**, Health Expectations, 16(4), e100-10.

Abstract
In order to improve the design of a future clinical trial of hand splints for thumb-base osteoarthritis, two groups of service users were brought together to provide advice on the selection and design of a placebo splint. The groups discussed whether the use of a placebo was acceptable and developed a potential design for a placebo splint.

Category: impact of public involvement

Goodare, H. & Lockwood, S. (1999) **Involving patients in clinical research,** British Medical Journal, 319, 724-725.

Abstract
The authors argue that patient involvement improves the quality of research. They provide three examples of involvement in breast cancer research in the UK, USA and Australia. These illustrate the impact of involvement on research quality and design, on funding decisions and the consent process.

They recommend that researchers should be asked to demonstrate that they have consulted consumers in developing their research proposals when applying for funding. They also suggest that medical journals should set new standards for consumer consultation by making involvement at all stages in research a condition for publication.

Category: reflecting on public involvement in research

Goodman, C., Mathie, E., Cowe, M., Mendoza, A., Westwood, D., Munday, D., Wilson, P., Crang, C., Froggatt, K., Illiffe, S., Manthorpe, J., Gage, H. & Barclay, S. (2011) **Talking about living and dying with the oldest old: Public involvement in a study on end of life care in care homes,** BMC Palliative Care, 10, 20.

Abstract
Aim: This paper describes the involvement of a group of older people in a study that explored the views and experiences of living and dying amongst older people living in care homes.

Findings/recommendations: The authors report that there were three main areas where the public involvement influenced the process:

- Recruitment – the group members helped to shape the whole recruitment process and introduced the study to residents and staff. They were able to take the time and care to obtain consent from older residents with sensory impairments or difficulty communicating. This resulted in greater recruitment rates than in other studies in care homes.
- Safeguarding – the group members helped provide support to interviewees if they became upset during the interviews. They also provided the team with advice for example on talking to people living with dementia.
- Interpretation of findings – the group members facilitated group meetings with residents in care homes to reflect and discuss the themes that emerged from the research. This provided different and often more reflective insights on the significance of the findings for the participants.

The authors comment on some of the challenges of the involvement, in particular around negotiating the boundaries and extent of the involvement of the group members. They conclude that future studies would benefit from developing job descriptions for group members and more formal means of setting out respective expectations.

Category: impact of public involvement

Gradinger, F., Britten, N., Wyatt, K., Froggatt, K., Gibson, A., Jacoby, A., Lobban, F., Mayes, D., Snape, D., Rawcliffe, T. & Popay, J. (2013) **Values associated with public involvement in health and social care research: a narrative review**, Health Expectations, doi: 10.1111/hex.12158. [Epub ahead of print].

Abstract
This article reports the findings from a review of the literature around the impact of public involvement on research. This review identified the values underpinning the reported involvement activity.

Three different value systems were identified:

(1) normative values – linked to ethical and/or political issues and associated with empowerment, change/action, accountability/transparency, rights and ethics.

(2) substantive values – linked to the consequences of public involvement and associated with effectiveness, quality/relevance of the research, validity/reliability, representativeness/ objectivity/generalizability and evidence.

(3) process values – linked to how public involvement is carried out and associated with partnership/equality, respect/trust, openness and honesty, independence and clarity.

The authors conclude that research teams should consider and discuss the values they attach to public involvement. This will help them find ways to manage potential tensions and maximize the benefits.

Category: reflecting on public involvement in research

Gray, B., Larsen, J. & Faulkner, A. (2013) **Third sector facilitation of lived experience in research: A case study of service user and carer involvement in the PRIMROSE project**, Journal of Mental Health Training, Education and Practice, 8(3), 141-151.

Abstract

This article reports on the impact of a Lived Experience Advisory Panel (LEAP) that was set up to inform the development of the PRIMROSE project. The project aims to improve the physical health of people with severe mental illness through a GP-practice based intervention. The LEAP is made up of 27 service users and carers with experience of mental illness. It is supported by a service user researcher employed by Rethink Mental Illness. In the first year of its activity, the LEAP has:

- identified questions for a systematic review of the literature
- informed the development of the intervention
- shaped the topic guide for focus group discussions
- convinced the project team of the value of running a separate focus group with carers
- identified real-life barriers and facilitators to implementing the intervention.

Category: impact of public involvement

Griffiths, K., Jorm, A. & Christensen, H. (2004) **Academic consumer researchers: a bridge between consumers and researchers,** Australian and New Zealand Journal of Psychiatry, 384, 191-196.

Abstract
This paper describes the contributions that consumers, particularly academic consumers, can make to mental health research. It is based on a literature review and reflection.

The authors argue that academic consumers offer all the advantages of involving lay consumers as well as extra benefits. These include:

- acceptance as equal partners by other researchers
- research skills
- access to research funding
- ability to communicate findings to the research community
- ability to influence research policy and culture
- potential to facilitate lay involvement

They conclude that academic consumers could therefore help to bridge the gap between researchers and consumers as well as reducing the stigma of mental health problems.

Category: reflecting on public involvement in research

Guarino, P., Elbourne, D., Carpenter, J. & Peduzzi, P. (2006) **Consumer involvement in consent document development: a multicenter cluster randomized trial to assess study participants' understanding,** Clinical Trials, 3(1), 19-30.

Abstract
Aim: To compare an informed consent document (participant information sheet) developed by consumers with one developed by researchers.

Methods: The two documents were tested in a clinical trial for Gulf War veterans in the US. Different trial centres were randomised to either the researcher-developed or the consumer-developed information sheet. The researchers measured whether there was any effect on:
- participants' satisfaction with the information sheet
- how well people said they understood the information
- whether people refused to take part in the clinical trial
- whether the people who did take part in the trial did everything they were asked to do and stayed to the end

Findings/recommendations: The results showed that asking service users to develop the information sheet made no difference in this trial. The researchers suggest this might be because the consumers didn't make dramatic changes to the information sheet. The trial participants were also used to reading complicated documents as part of their military training. It is also possible that the conversation between researchers and potential trial participants is a more important part of the consent process than the written information.

Category: impact of public involvement

Hall, V. (2009) **Reflections on engaging in participatory research.** Evidence Based Midwifery, 7(2), 40-45.

Abstract

This paper describes the development of involvement in research and the shift from a consumerist approach to a more democratic model. It discusses the criticisms of involvement and the nature of evidence.

It concludes that working in this way requires the researcher to personally address power differences and embrace the challenges to their role as a researcher.

Category: reflecting on public involvement in research

Hamilton, S., Pinfold, V., Rose, D., Henderson, C., Lewis-Holmes, E., Flach, C. & Thornicroft, G. (2011) **The effect of disclosure of mental illness by interviewers on reports of discrimination experienced by service users: A randomised study**, International Review of Psychiatry, 23(1), 47-54.

Abstract

Aim: To test the hypothesis that when an interviewer discloses their mental health service user status, participants in a survey about discrimination will be more likely to share their experience.

Methods: The participants in this study took part in a quantitative telephone survey. They were assigned to one of three groups:

1. The interviewer was a service user and was open about this.
2. The interviewer was a service user but did not disclose.
3. The interviewer was not a service user.

All groups were asked the same questions and their responses were compared.

Findings/ recommendations: No differences were found in the levels of discrimination reported to any of the interviewers. Fewer people agreed to take part in the study when told they would be interviewed by a service user. However, fewer questions were left unanswered by the group that were interviewed by a peer.

The authors conclude that the peer status of an interviewer does not have a broad impact on quantitative data collected by a structured questionnaire. There may be more of an impact during in-depth qualitative interviews, when the rapport between the interviewer and interviewee makes a significant difference.

Category: impact of public involvement

Hanley, B., Morris, C. and Staley, K. (2009) **An evaluation of the process and impact of patient and public involvement in the advisory groups of the UK Clinical Research Collaboration,** London: UK Clinical Research Collaboration.

Abstract
This report summarises the findings from an evaluation of the process and impact of patient and public involvement in the advisory groups of the UK Clinical Research Collaboration. These groups played a role in developing high level strategic thinking for the UKCRC.

The impact of involvement varied but included:

- asking questions that are simple but fundamental to the groups' debates
- keeping discussions grounded
- monitoring performance
- promoting issues of importance to the public or patients
- acting as a reminder of patient/public accountability
- bringing in knowledge from other related experiences
- contributing to practical decisions
- promoting the use of plain English
- lobbying for more public involvement

Category: impact of public involvement

Hanley, B., Truesdale, A., King, A., Elbourne, D. & Chalmers, I. (2001) **Involving consumers in designing, conducting and interpreting randomised controlled trials: questionnaire survey,** British Medical Journal, 322, 519-523.

Abstract
Aim: To assess the nature and extent of consumer involvement in clinical trials managed by clinical trial co-ordinating centres in the UK.

Methods: Survey of 103 UK clinical trial co-ordinating centres and investigators in 60 clinical trials.

Findings/recommendations: 23 of the 62 eligible centres reported they were involving consumers in their work and were positive about the involvement. Another 17 were planning to involve consumers. 15 did not plan to involve consumers and 4 of these did not think involvement was relevant. Of the 48 trial investigators who responded, many were positive about consumer involvement and reported that consumers had helped to:

- refine research questions
- improve the quality of patient information
- make the trial more relevant to the needs of patients

The authors conclude that consumer involvement in clinical trials seems to be growing and welcomed by most researchers.

Category: nature and extent of public involvement in research, impact of public involvement

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Happell, B. & Roper, C. (2007) **Consumer participation in mental health research: articulating a model to guide practice.** Australasian Psychiatry, 15(3), 237-241

Abstract
The authors undertook a review of the literature relating to consumer involvement in mental health research. They identified a number of benefits of and barriers to consumer participation. Based on these findings, they have developed a model for consumer involvement in mental health research, which they hope will improve understanding and help avoid tokenistic involvement.

Category: reflecting on public involvement in research

Harding, E., Brown, D., Hayward, M, & Pettinari, C. (2010) **Service user perceptions of involvement in developing NICE mental health guidelines: A grounded theory study.** Journal of Mental Health, 19(3), 249-257.

Abstract
Aim: This study aimed to find out what service users thought about their involvement in the National Institute of Health and Clinical Excellence's (NICE) guideline development.

Methods: 10 interviews were carried out with guideline development group (GDG) representatives. The interviewer was a service user representative on an early GDG.

Findings/recommendations: Part of the work of the GDGs involves identifying the research needed to fill any gaps in the evidence base. The service users involved reported having influenced research questions and having identified priorities for outcomes for treatment. They described how they were able to see the whole person, not only the 'small points' that research often addresses and so were able to judge and elaborate on the evidence used in debate. They were thus able to ensure transparency, as well as influencing GDG decisions.

Category: impact of public involvement

Heritage N., Barnes, E., Perry, B., Nelson, B., Shaw M. & Matata, B. (2010) **Evaluation of the Liverpool Cardiac Phase-4 Rehabilitation Programme: A service user-led community-based investigation**, International Journal of Medicine and Medical Sciences, 2(6), 178–183.

Abstract
This article reports on a service-user led evaluation of Cardiac Rehabilitation Programme. The authors reflect on some of the issues that limited the quality of the findings.

Category: reflecting on public involvement in research

Hewlett, S., de Wit, M., Richards, P., Quest, E., Hughes, R., Heiberg, T., Kirwan, J. (2006) **Patients and professionals as research partners: Challenges, practicalities and benefits,** Arthritis & Rheumatism, 55(4), 676-680.

Abstract
This paper describes the experiences of a group of researchers and 'patient research partners' who have collaborated in a series of arthritis research projects. It describes the challenges they faced, outlines a practical model for involvement and lists some outcomes of involvement.

The authors describe 4 main challenges to involvement - access and communication, relationships, tokenism and the anxieties of taking on a new role. Their solution to these challenges is a model called FIRST. This acronym describes the approach patient research partners and professionals need to adopt if involvement is to be successful: Facilitate (inclusions and contribution), Identify (projects, patients and roles), Respect, Support and Training.

Finally, the authors describe the impact of this involvement on:

- research - e.g. a fresh insight into issues, novel outcomes and altered study design
- patient research partners - e.g. improved confidence and being able to give something back
- professionals - e.g. greater understanding of rheumatoid arthritis and its impact

Category: impact of public involvement, reflecting on public involvement in research

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Hofmann, D., Ibrahim, F., Rose, D., Scott, D., Cope, A., Wykes, T. & Lempp, H. (2013) **Expectations of new treatment in rheumatoid arthritis: developing a patient-generated questionnaire**, Health Expectations doi: 10.1111/hex.12073. [Epub ahead of print]

Abstract

This article reports on a project which involved patients with rheumatoid arthritis (RA) in developing a new outcomes measure for measuring patients' expectations prior to treatment. Such a measure can identify what individual patients think is most important for their healthcare and so help tailor treatment to their needs. A patient researcher with experience of a similar long-term condition helped to run focus groups with rheumatoid arthritis patients and to consult two expert panels with patients. The new measure was tested with patients receiving outpatient treatment for RA. The final draft version is being tested to see how reliable it is and will then be piloted in a clinical trial.

Category: impact of public involvement

Holmes, W., Stewart, P., Garrow, A., Anderson, I. and Thorpe, L. (2002) **Researching Aboriginal health: Experience from a study of urban young people's health and well-being,** Social Science & Medicine, 54(8), 1267-1279

Abstract

This paper describes the first stage of a study of the health and well-being of urban young Aboriginal people carried out by a community organisation. The goal was to enable Aboriginal people to direct and own the research, in contrast to historical poor practice.

Aboriginal health workers contributed to the study design, helping to ensure that the project would work in practice and to overcome the natural mistrust of research in the community. Community members helped to facilitate focus groups with young people and interpret the results. This proved important to the group discussions and subsequent understanding of what had been said.

The focus groups helped shape the next stages of the project, determining how a survey of young people's health should be carried out and what kind of health tests would be included.

The ethical issues were considered by a newly established group of representatives from the Aboriginal community rather than the university's ethics committee. This made an important contribution to the community's ownership of the project.

Young people were trained and recruited to conduct the survey as peer interviewers. This helped to raise awareness of the study.
The authors suggest that the interviewers were more sensitive to subtle signs of a lack of willingness to take part in the project and so less likely to pressurise people into taking part. However, it also seemed that young people were more willing to take part because they had been asked by a peer.

The peer interviewers benefited from learning new skills and increased confidence. They have gone on to play important advocacy and management roles in other community organisations.

The presence of young people at the health service also increased and it seems that more young people feel more comfortable in using the services available.

The authors conclude that involving community members improved the quality of the research by:

- increasing the representativeness of the people who took part via access to extensive community networks
- validity of the findings because the questionnaires were developed and checked by Aboriginal people and because the participants were more likely to trust the research team and therefore more willing to give honest answers

Category: impact of public involvement

Howe, A., Delaney, S., Romero, J., Tinsley, A. & Vicary, P. (2010) **Public involvement in health research: a case study of one NHS project over 5 years,** Primary Health Care Research & Development, 11(1), 17-28.

Abstract

This study reports on an evaluation of the Patient and Public Involvement in Research (PPIRes) project. PPIRes consists of a panel of approx. 50 volunteers that has existed since 2003 and is supported by the Norfolk and Waveney R&D consortium.

The evaluation involved an analysis of volunteer activity, interviews with key stakeholders, and questionnaires to volunteers followed by a focus group with a small number of the respondents.

The researchers who had worked with the panel reported that the volunteers had helped with:

- developing successful bids for funding
- developing lay summaries
- reviewing patient information sheets
- managing research through membership of steering groups
- developing successful approaches to target possible study participants
- disseminating study findings to relevant sections of the community

PPIRes was thought to have enhanced the R&D consortium's profile and made it more competitive in terms of getting funding.

The evaluation concluded that more work needs to be done to:

- raise the profile of PPIRes with the local research community to increase its use by researchers
- monitor the activity of volunteers and provide feedback on their impact to all involved
- engage the agencies and communities that are currently under-represented in the panel membership

Category: impact of public involvement

Hull, D., Barton, D., Guo, K., Russell, C., Aucott, B. & Wiles, D. (2012), **Patient and public involvement to support liver disease research**, British Journal of Nursing, 21(16), 972-976.

Abstract

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

- improve patient information and informed consent for study participants
- improve the design of clinical studies
- promote public engagement and education activities – helping to raise awareness of liver disease and the importance of research and clinical trials.

Category: impact of public involvement

Hutton, E. & Coxon, K. (2008) **Involving parents as service users in an interprofessional research project.** Journal of Interprofessional Care, 22(6), 661-663.

Abstract

This report describes the process of involving parents in the development of a research study.

A team of academics and therapists began the process of designing a study which aimed to improve postural management for children with physical disabilities attending mainstream schools. They presented their ideas to a group of parents of children with physical disabilities.

In response to parents' feedback, the research team adapted their study to:

- expand the settings to include both mainstream and specialist schools
- move away from a professional concept of 'postural management' towards considering understanding the barriers to the children's physical, social and emotional development in the school setting
- place greater emphasis on including the perspectives of the teaching staff

This involvement helped to keep the researchers focused on the issues most relevant and important to the parents and their children.

The researchers therefore had to redesign their study. They comment on how this delayed the submission of their research proposal but how the benefits in terms of strengthening the proposal, far outweighed any delays in timing.

Category: impact of public involvement

Iliffe, S., McGrath, T. & Mitchell, D. (2013) **The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies,** Health Expectations,16(4), 351-61.

Abstract

This article reports on three case studies where patient and public involvement has made a difference to DeNDRoN research projects.

In the first case study the involvement seemed to boost recruitment rates in a project that was not recruiting to target. In the second, involvement in writing the patient information sheet helped with finding the right language to describe the complexity and sensitivity of the research project. In the third, a patient reference panel contributed to many different aspects of the study, from the design through to dissemination.

Category: impact of public involvement

INVOLVE (2013) **Exploring public involvement in research funding applications**, Eastleigh: INVOLVE.

Abstract

This report provides 10 examples of projects where members of the public were involved in the development of National Institute for Health Research (NIHR) funding applications. The lead researchers were interviewed in each case, and asked to describe the impact of public involvement on their research.

Overall, the public involvement helped to:

- Identify the research question
- Influence the outcome measures
- Refine the methods used
- Maintain a focus on the interests of patients/ the public
- Keep the research grounded and meaningful
- Make participation easier for the research participants
- Improve the accessibility of the information produced for participants
- Shape the plans for public involvement in the project
- Define the most useful project outputs
- Promote multidisciplinary working across teams
- Develop a dissemination strategy

Category: impact of public involvement

INVOLVE (2013) **Exploring the impact of public involvement on the quality of research: examples**, Eastleigh: INVOLVE.

Abstract
This project aimed to explore the views and experiences of researchers in relation to the impact that public involvement has on the quality of research. The report includes an overview of the different ways that involvement influences research quality as well as six different stories of involvement.

Category: impact of public involvement

INVOLVE (2012), **Public involvement in research: impact on ethical aspects of research**, Eastleigh: INVOLVE.

Abstract
This resource provides examples of the impact of public involvement in the ethical design and conduct of research. Drawing on findings from three reviews (Brett et al. 2010; Staley 2009; Smith et al. 2008) and more recent literature, this supplement illustrates how public involvement throughout a study can help to make research more ethical.

Category: impact of public involvement

Ives, J., Damery, S. & Redwood, S. (2012) PPI, paradoxes and Plato: **Who's sailing the ship?** Journal of Medical Ethics doi:10.1136/medethics-2011-100150 [Epub ahead of print]

Abstract
In this article, the authors unpick a 'paradox' within public involvement. They suggest that the benefits of involvement derive from the patient/ member of the public bringing a lay perspective to the research. However, they also suggest that through formal training and 'on the job' familiarisation with research, the patient/ member of the public becomes professionalised. As a result, their ability to act as a lay person is undermined, which may mean that they no longer bring the benefits of 'layness' to the project. The authors therefore conclude that we should not seek to train lay people in research and that patients/ members of the public should not be actively involved in carrying out research. Involvement should be limited to the non-research stages, including making funding decisions, prioritising research agendas, overseeing research governance and ethical review.

Category: reflecting on public involvement in research

Jagosh, J., Macaulay, A., Pluye, P., Salsberg, J., Bush, P., Henderson, J., Sirett, E., Wong, G., Cargo, M., Herbert, C., Seifer, S., Green, L. & Greenhalgh, T. (2012) **Uncovering the benefits of participatory research: implications of a realist review for health research and practice,** Millbank Quarterly, 90(2), 311-46.

Abstract
Aim: To identify the ways in which collaborative partnerships between researchers and community members may add value to the research process, taking into account the many different approaches and the complex nature of such partnerships.

Methods: A review of the literature using a realist theory, which looks at how different contexts and methods lead to different outcomes.

Findings/recommendations: The reviewers looked at 23 partnerships between researchers and communities working on health-related research. The contexts were too varied to draw any conclusions about how context relates to outcomes. However, the review did find links between processes and outcome. When partnerships were working well, i.e. when the community members had equal status and meaningful influence on the research, then this led to better outcomes. The effects were synergistic, in that a positive outcome at one stage created a better context for the next. For example, when researchers showed willing in listening to the community views in setting the research question, this enhanced the partnership, which led to more effective collaboration and greater influence on the outcomes at later stages.

The main positive outcomes were:

- Culturally relevant research
- Making participation in the research easier for the research subjects
- Boosting recruitment
- Increasing research capacity in the community
- Productive conflict between partners followed by useful negotiation leading to more productive research
- Sustained activity beyond the life of the project and during gaps in funding
- Creating system changes and unanticipated projects and activities

There were some negative outcomes to collaborative working that could sometimes be explained by aspects of the context, and sometimes a lack of genuine partnership.

Category: impact of public involvement, reflecting on public involvement in research

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Johns, T., Miller, P., Kopp, K., Carter, Z., Cooper, G., Johnston, J., Nicholas, Z. & Wright, N. (2004) **Equal lives? Disabled people evaluate an independent living strategy for Essex Social Services,** Research Policy and Planning, 22(2), 51-57.

Abstract

Aim: To evaluate the impact of the Equal Lives strategy in facilitating disabled service users to lead more independent lives and to identify signs of improvement in services and opportunities to improve services further.

Methods: A telephone survey of 250 disabled service users and qualitative interviews. Disabled service users were recruited, trained and paid as co-research consultants.

Findings/recommendations: The paper discusses the impact of including service users as equal partners in the research. The service user researchers also report on their experiences of being involved. These include:

Positive impact on the research:

- enhanced validity of research evidence because research participants felt more comfortable being interviewed by their peers and were more willing to share their experiences
- added dimension to the analysis and interpretation of the data based on service users' experiences
- dissemination of the findings - hearing directly from service users improves the validity and weight of the findings

Negative impact on the research: there were also occasions where research participants appeared to over-identify with their interviewers and 'expected' them to understand their situation. The interviewers had been trained to recognise and respond to this.

Benefits for the service user researchers: new social contacts; work and training leading to new employment opportunities; feeling of making a positive and valued contribution to improving services; increased confidence; broadened outlook and experience.

The research team as a whole also benefited from the wealth of interpersonal and other skills that the service user researchers brought to the project.

Category: impact of public involvement

Jones, E., Williams-Yesson, B., Hackett, C., Staniszewska, S., Evans, D. & Francis, N. (2014) **Quality of reporting on patient and public involvement within surgical research: A systematic review**, Annals of Surgery, [Epub ahead of print].

Abstract
Aim: To find out the extent of public involvement within surgical research.

Methods: A systematic literature review. The quality of reporting was assessed using the GRIPP checklist and guidelines for assessing the quality of public involvement.

Findings/ recommendations: Eight articles were identified. They reported the following impacts of the involvement:

- Identification of research topics
- Influencing study design
- Improving recruitment and retention in surgical trials
- Helping with data collection

Some studies worked with research participants, using interviews and group discussions to find out about their experience of participation, subsequently using this information to shape consent procedures and study design. Others involved patients/ carers who did not take part in the research, and adopted a more collaborative approach for example in a systematic review of surgical literature.

Overall, the quality of the reporting was suboptimal, according to the checklists used. For example, none described how patients/ carers were trained prior to involvement.

The authors conclude that involvement in surgical research is currently limited, but this may reflect limited reporting as well as limited activity.

Category: nature and extent of public involvement in research, impact of public involvement

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Kara, H. (2013) **Mental health service user involvement in research: where have we come from, where are we going?** Journal of Public Mental Health, 12(3), 122-135.

Abstract
Aim: To assess the extent and value of mental health service user (MHSU) involvement in research in England.

Method: A review of the academic and grey literature from 2002. Findings: Involvement of MHSU adds value to research, also benefiting everyone involved. Four gaps in the literature were identified:

1. Lack of evidence of researchers' experience of involvement of MHSUs.
2. Lack of recognition that many people involved in research may hold more than one role, for example many researchers are carers and MHSUs but may not disclose this information.
3. Carers are not identified separately from MHSUs, if they are included at all.
4. MHSU researchers could contribute to research that is not about mental health.

Findings/recommendations: Recognising the multiple roles and identities that exist for everyone involved in research has the potential to help with the redistribution of power necessary for effective involvement. Without this recognition, people tend to categorise themselves as belonging to one or other group (researchers, or researched) and the power struggle between the groups continues.

Category: impact of public involvement, reflecting on public involvement in research

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Katz, M., Archer, L., Peppercorn, J., Kereakoglow, S., Collyar, D., Burstein, H., Schilsky, R. & Partridge, A. (2012) **Patient advocates' role in clinical trials,** Cancer, 118(19), 4801-5.

Abstract
Aim: To evaluate the role and value of patient advocates in cancer clinical trials.

Method: An online survey was sent to current and past advocates and investigators working in cancer research in the US.

Findings/ recommendations: The advocates reported greater impact than the investigators, including influencing trial protocols, helping with recruitment and dissemination of trial findings to the wider community. All respondents commented on how involvement could be improved. Strategies to improve advocate training and advocate-investigator communications may enhance the role of patient advocates.

Category: impact of involvement

Kellett, M. (2006) **Children as researchers: Exploring the impact on education and empowerment,** childRight, 226 (May), 11-13.

Abstract
This article discusses the role of children as active researchers, why it is necessary for children to engage in their own research and the benefits for child researchers.

The benefits for children participating in active research include:

- raised self-esteem and self-worth

- increased confidence
- development of transferable study skills
- sharpening of critical thinking skills
- heightened ethical awareness
- enhanced problem solving ability
- more effective communication
- independent learning

Children’s research is distinct from adults' research because:

- children succeed in getting responses from their peer group in ways that would not be possible for adult researchers
- it reflects children’s experiences from a genuine children’s perspective
- it is an important vehicle for children’s voices
- it is an empowering process for children

Category: impact of public involvement

Kellett, M., Forrest, R., Dent, N. & Ward, S. (2004) **'Just teach us the skills please, we'll do the rest': Empowering ten-year-olds as active researchers,** Children & Society, 18(5), 329-343.

Abstract
This paper discusses the outcomes of an initiative to empower ten-year-olds as active researchers. It discusses some of the perceived barriers to children taking ownership of research and challenges the status quo. Reports from two research projects led by children are included.

Category: reflecting on public involvement in research

Kennedy, S. in association with involved carers (2011) **Older carers involvement in research: Why, what and when?** Nottingham: University of Nottingham and London: Macmillan Cancer Support.

Abstract
This report describes the views and experiences of six older carers who were involved in a research project exploring the support needs of older carers. The report describes in people’s own words, why they got involved, how they were involved at the different stages, the benefits to them and their plans for further involvement.

Category: reflecting on public involvement in research.

Kernick, D. & Mitchell, A. (2010) **Working with lay people in health service research: A model of co-evolution based on complexity theory.** Journal of Interprofessional Care, 24(1), 31-40.

Abstract
The authors describe their experience of working with patients as co-producers of research relating to migraine. Based on this experience and drawing on insights from complexity theory, they have developed some principles for a successful research partnership and a model they describe as consensual qualitative research.

They conclude that their approach does not sit easily within the current academic research structure - which sees research as a linear process achieving defined objectives. Instead the process involves a non-linear ecosystem of co-evolving elements that are united by a shared vision.

They also conclude that the process requires considerable resources in terms of time and effort, but offers the potential to make research more relevant and acceptable to end users.

Category: nature and extent of public involvement in research, reflecting on public involvement in research

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Kirwan, J., Newman, S., Tugwell, P. & Wells, G. (2009) **Patient perspective on outcomes in rheumatology - A position paper for OMERACT 9,** Journal of Rheumatology, 36(9), 2067-2070

Abstract
This paper discusses the work done in preparation for OMERACT 9, an international consensus conference on outcome measures used in rheumatology clinical trials, which was held in 2008.

At OMERACT 6 in 2002, the patient perspective was included for the first time. This led to the recognition that there were outcomes of importance to patients that had not been previously measured. These included a sense of well-being, fatigue and disturbed sleep.

In the first instance a lot of work was put into developing new ways of measuring fatigue. As a result, fatigue is now routinely assessed in all studies of rheumatoid arthritis.

This paper summarises the work that has been done since to develop ways of measuring sleep disturbance. In addition, it discusses the development of an Effective Consumer Scale which will assess patients ability to manage their own healthcare, patients' evaluation of educational and psychological interventions and the concept of a 'core set' of patient outcomes, that could become a requirement for all clinical trials in rheumatology. These topics were discussed at the Patient Perspective Workshop at the conference in 2008.

Category: impact of public involvement

Koops, L., Lindley, R. (2002) **Thrombolysis for acute ischaemic stroke: consumer involvement in design of new randomised controlled trial,** British Medical Journal, 325, 415-418.

Abstract
Aim: To determine whether consumer involvement could help to address some of the ethical issues associated with research into thrombolysis for acute ischaemic stroke.

Methods: One of the researchers attended three meetings of older people in Edinburgh to discuss stroke and thrombolysis. Older people who attended these meetings were also asked to complete a questionnaire. Two focus groups were then held to explore the issues raised in the discussions and questionnaires. This led to a revision of patient information leaflets. These leaflets were then tested with six patients and carers in a stroke rehabilitation unit.

Findings/recommendations: Most people who completed the questionnaire were prepared to accept the risks of thrombolytic treatment in a clinical trial. Participants in the focus groups were comfortable with the concept of risk, and recognised the ethical dilemmas involved in obtaining valid consent. They suggested some solutions to these dilemmas.

The researchers made many changes to their information leaflet as a result of this consultation process. They report that "despite the potential ethical barriers to our planned trial, our trial material was accepted after only one cycle of amendments with the national ethics committee, an important achievement." They call for consumer involvement in trial development to become the norm.

Category: impact of public involvement

Kreis, J., Puhan, M., Schunemann, H. & Dickersin, K. (2013) **Consumer involvement in systematic reviews of comparative effectiveness research,**
Health Expectations, 16(4), 323-37.

Abstract
Aim: To explore current approaches to consumer involvement in US and international organisations commissioning systematic reviews.

Methods: Interviews with staff and review of organisations' websites.

Findings/ recommendations: Seven of the 17 organisations included in this study involved consumers either at a programme level within the organisation or in individual reviews. A variety of approaches are used and different kinds of consumers are recruited. However, there has been little formal evaluation of the impact of this involvement.

Category: nature and extent of public involvement

Krieger, J., Allen, C., Cheadle, A., Ciske, S., Schier, J., Senturia, K. & Sullivan, M. (2002) **Using community-based participatory research to address social determinants of health: Lessons learned from Seattle Partners for Healthy Communities,** Health Education & Behaviour, 29(3), 361-38.

Abstract
This article describes three projects from the Seattle Partners for Healthy Communities Research Center that used participatory approaches. Two demonstrate the impact of involving community members:

(1) Healthy Homes project (a randomised controlled trial of an outreach programme to reduce the incidence of asthma): Community members first identified the topic and then as members of a parent advisory group helped shape the project to:

- increase its benefit to the community, respect community values and avoid doing harm
- ensure the research was sensitive to the issues faced by local tenants
- address the general problem of mistrust of government research when recruiting participants
- ensure the questionnaires were culturally appropriate and relevant

Community members were hired as outreach workers. The participants reported that working with local people gave them confidence in the project. The individual community researchers benefited directly from learning new skills. They have also gone on to assist other organisations with asthma education and community work.

A problem arose at the beginning because community members would not accept that a control group would receive less interventions than the experimental group. This led to a change in the protocol.

At later stages, people realised that the trial was less convincing because it did not have the usual-care control group. Funding was sought for a Phase II of the project to carry out this comparison.

(2) Study of ethnic and sexual minority women's experience of domestic violence, satisfaction with services and service needs: Representatives from community agencies serving the different groups joined the research team. They helped with all stages of research. Their involvement proved crucial to recruiting women to discuss such a sensitive topic. They also ensured the safety of participants in ways that the researchers would not have considered. Community advocates helped with facilitation and interviews. They also brought expertise and experience to the analysis of data that the researchers lacked. Their involvement also gave credibility to the project encouraging women to take part.

In summary participatory approaches have:

- increased community acceptance and participation in research
- improved data collection and interpretation
- improved implementation of changes and their cultural relevance
- enhanced the capacity of community based organisations
- increased the benefits received by community members

Category: impact of public involvement

Lammers, J. & Happell, B. (2004) **Research involving mental health consumers and carers: a reference group approach.** International Journal of Mental Health Nursing, 13(4), 262-266.

Abstract

This paper describes how a reference group of service users and carers was set up to help with a research project that examined people's experiences of using psychiatric support services.

The group spent a considerable amount of time reviewing the initial research proposal. They changed a lot of the wording to make it more user/carer friendly. This improved the researchers' understanding of how users see themselves and how this contrasts with the way they are described in policy documents and by service providers.

The researchers conclude that the reference group's changes to the proposal, in particular the use of more user/carer friendly language, helped to develop greater rapport and trust with the research participants. This ultimately influenced the participants' willingness to share their opinions and experiences in a more open and honest way.

The users and carers involved in the reference group reported that taking part in the project helped them to improve their own understanding and knowledge of current issues, so that they became better informants for other service users and carers.

Category: impact of public involvement

Langston, A.L., McCallum, M., Campbell, M.K., Robertson, C. & Ralston, S.H. (2005) **An integrated approach to consumer representation and involvement in a multicentre randomised controlled trial,** Clinical Trials, 2(1), 80-87.

Abstract
Aim: To work closely with the National Association for the Relief of Paget's Disease (NARPD) in the PRISM trial (a randomised trial of intensive versus symptomatic management).

Methods: The PRISM trial management group worked in partnership with the patient organisation NARPD in designing, conducting and delivering the trial. The NAPRD were involved in peer-review, the trial steering committee, giving advice to participants and promoting the trial to people with Paget's disease.

Findings/recommendations: There were many advantages to working in partnership with NARPD. Most importantly all the participants gained a sense of ownership of the trial. This led to very high response rates to questionnaires which improved the quality of the trial data. The partnership also helped to improve recruitment and the quality of patient information sheets.

The authors recommend this approach is used in other trials as a way of improving the information for participants and recruitment. However, there are resource implications for both parties.

Category: impact of public involvement

Leamy, N. & Clough, R. (2006) **How older people became researchers: Training, guidance and practice in action,** York: Joseph Rowntree Foundation. (ISBN 1 85935 435 1)

Abstract

This report describes how a group of older people became involved in a three-year large-scale research project on housing.

It gives an account of how the older people were trained and the experiences of the people involved. It also provides practical guidance.

The researchers found they had to rethink their roles and find the right balance between their 'expert' role and 'empowering or facilitative role'. There was always a tension between enabling the older people to develop their research skills at their own pace and needing to complete the research on time. The older people gained from a wider appreciation and understanding of research and from developing marketable research skills. They are now using these skills in other areas.

Involving the older people as researchers also affected the quality of the interview data in both positive and negative ways. It appears that interviewees talked more freely and disclosed more information to their peers. However, the interviewers then found it difficult to keep the interview focused on the research topic and to be sure whether the discussion was relevant.

Category: impact of public involvement

Lindenmeyer, A., Hearnshaw, H., Sturt, J., Ormerod, R. & Aitchison, G. (2007) **Assessment of the benefits of user involvement in health research from the Warwick Diabetes Care Research User Group: A qualitative case study,** Health Expectations, 10, 268-277.

Abstract
Aim: To assess the benefits of involving health-care users in diabetes research by evaluating the impact of the Warwick Diabetes Care Research User Group.

Methods: Semi-structured interviews were conducted with researchers who had worked with the Group. Group members also discussed their views of the group's effectiveness at a number of their regular meetings.

Findings/recommendations: The study showed the feasibility, acceptability and effectiveness of this longstanding, experienced group. Its impact largely stems from the continuing interaction between researchers and users, and the general ethos of learning from each other in an ongoing process.
Specific benefits of the group's involvement were identified as:

- adding value by forcing researchers to address why they want to conduct their research in the first place and focusing their minds on making a difference to service users
- adding credibility to proposals (usually) making them more likely to be funded
- making changes to research protocols, questionnaires and patient information to

make them more practical, relevant and accessible

The authors conclude that the greatest benefit of involving the User Group was being able to make continued use of their experiential knowledge throughout all stages of research.

Category: impact of public involvement

Lindow, V. & Morris, J. (1995) **Service user involvement: Synthesis of findings and experience in the field of community care,** York: York Publishing Services (ISBN 1 899987 00 2)

Abstract
This report summarises a range of work commissioned by the Joseph Rowntree Foundation (JRF) to explore different aspects of service user involvement. There is a short section on involvement in research.

Each section makes suggestions about topics for future research. The authors begin by considering the theme of unequal power relationships, which was common in much of the work commissioned by JRF.
Section 2 deals with the involvement of individuals in decisions which affect their lives, and considers some of the barriers to involvement and the opportunities for people to influence decisions.

Section 3 looks at collective involvement. Again there is a discussion about barriers to involvement, and then a look at what service users need organisations to do to make involvement possible. This section also looks at user-controlled organisations and services.

Section 4 reflects on involvement in professional education and staff development.

Section 5 considers research about user involvement, and user involvement in research. It looks at the challenges of involving marginalised groups in research, and briefly reflects on the impact of involving service users on the research process.

This includes:

- Changing the focus of research
- Changing the nature of the research
- Changing how reports are written
- Enabling researchers to access a wider range of people

Category: impact of public involvement, reflecting on public involvement in research

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Lloyd, K., Rose, D. & Fenton, M. (2006) **Identifying uncertainties about the effects of treatments for schizophrenia,** Journal of Mental Health, 15(3), 263-268.

Abstract

This article discusses the problem of treatment uncertainties and the value of involving service users in the development of clinical trials to ensure that trials measure the outcomes that matter to participants. It also describes the establishment of the Database of Uncertainty about the Effects of Treatments (DUETs) and how this could help.

Category: reflecting on public involvement in research

Lowes, L. & Hulatt, I. (Eds.) (2005) **Involving service users in health and social care research,** London: Routledge

This book is a collection of papers written by service user and professional researchers. The titles of the chapters are:

1. Theory and practice of user involvement in research: making the connection with public policy and practice.
2. Actively involving marginalised and vulnerable people in research
3. Supporting people with learning difficulties to do their own research
4. A hard fight: the involvement of mental health service users in research
5. Translating health policy into research practice
6. Foster carers undertake research into birth family contact: using the social action approach
7. From recruitment to dissemination: the experience of working together from service user and professional perspectives
8. Consumer led research? Parents as researchers: the child health surveillance project
9. Consumer involvement in cancer research in the UK: benefits and challenges
10. Community action to housing and health needs
11. Helping older people to share the research journey
12. Really making it happen in Wiltshire: the experience of service users evaluating social care
13. Research with children who use NHS services: sharing the experience
14. From rhetoric to reality: the involvement of children and young people with mental ill health in research
15. Strategies for involving service users in outcomes focused research
16. Working with older women in research: benefits and challenges of involvement
17. Service user involvement at all stages of the research process
18. Working together to undertake research

Category: impact of public involvement, nature and extent of public involvement in research, reflecting on public involvement in research

Lowes, L., Robling, M., Bennert, K., Crawley, C., Hambly, H., Hawthorne, K., Gregory, J. & the DEPICTED Study Team (2010) **Involving lay and professional stakeholders in the development of a research intervention for the DEPICTED study**, Health Expectations 14(3), 250-260.

Abstract
This paper describes the involvement of both lay and professional stakeholders in developing a complex therapeutic intervention for teenagers with diabetes. This intervention included a training course for paediatric diabetes teams, an agenda setting tool and a questionnaire too assess patient preferences for consultation style. These were subsequently trialled in the DEPICTED study. The authors describe how a Stakeholder Action Group that included teenagers with diabetes and their parents contributed to the initial development stage.

Category: reflecting on public involvement in research

Lucas, P., Allnock, A. & Jessiman, T. (2013), **How are European birth-cohort studies engaging and consulting with young cohort members?** BMC Medical Research Methodology, 13, 56.

Abstract
This study involved contacting the research groups running 84 different cohort studies to ask about their practice in engaging and involving study participants. The authors were particularly interested in the question of seeking consent for participation from young cohort members as they grow older. The findings showed that most cohorts make an effort to keep participants in engaged, for example through sending newsletters, birthday cards and summaries of findings. Much smaller numbers consult their participants and usually on a one-off basis. The barriers to consultation were reported to be:

- concerns about the impact on the quality of research
- ethical constraints
- resource limitations
- attitudes to involvement – lack of importance
- previous adverse experience.

Category: nature and extent of public involvement in research

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Marias, F. (2007) **Toward the improvement of tuberculosis control and participatory research,** London: Department of Primary Care and Social Medicine, Imperial College.

Abstract

Aim: To investigate the social, economic, legal, political and organisational factors influencing the emergence and control of tuberculosis (TB) in migrant African communities in Westminster, London.

Methods: Surveys, interviews, community consultations with migrant Africans and key stakeholders from multiple sectors. Members of the community were engaged as research partners from the beginning and involved in all stages of the research process. They were recruited to a Community Advisory Panel overseeing the research as well as being employed as Community Research Fieldworkers.

Findings/recommendations: The involvement of community members was formally evaluated through questionnaires and feedback forms. The evaluation of the Community Advisory Panel showed that it:

- achieved co-ownership of the entire research
- members ensured the study was culturally appropriate and sensitive
- broke down barriers between different communities and sectors
- enabled the study to respond to recommendations from community and achieved a focus on the needs of communities rather than organisations
- provided a rich and empowering learning experience for its members
- developed into a resource of information and access to migrant African communities for outside agencies

The evaluation of the Community Research Fieldworkers showed that some had been able to engage a diverse range of communities, but language barriers and limited access prevented them from engaging with communities other than their own. They helped the wider community by providing information about TB and its control. The community members who were involved said they benefited from: increased knowledge about TB, greater confidence, self-esteem and motivation, new skills, improved cross-cultural awareness and understanding, enhanced employment potential.

Category: impact of public involvement

Marsden, J. & Bradburn, J. (2004) **Patient and clinician collaboration in the design of a national randomized breast cancer trial,** Health Expectations, 7, 6-17.

Abstract

Aim: To find out if breast cancer patient involvement in the design of a randomised controlled trial of hormone replacement therapy (HRT) in symptomatic patients will increase recruitment rates.

Methods: Nine focus groups were held with breast cancer patients to identify the issues they thought relevant to the trial. A consensus on the focus group recommendations was reached at a one-day workshop with focus group representatives and research stakeholders. Patient representatives joined the trial steering committee and commented on the resulting trial design.

Findings/recommendations: There was some concern about this trial because of the potential for HRT to have an adverse effect on breast cancer survival. However, the issues relating to trial participation raised by the women in the focus groups were much broader than just the research topic. They also commented on more complex aspects of the trial design and the significance of the trial. This led to further negotiation between the patients and the clinicians to agree priorities for the final trial protocol. The patients also highlighted the lack of information available about breast cancer and HRT in general which led to the production of an information booklet. This was written with the input of patients. Given the need to give more background information to trial participants, consent interviews were extended. This may have reduced recruitment rates, but overall the quality of the consent process was greatly improved. The authors conclude that measuring recruitment rates is too simple a measure to assess the impact of patient involvement.

Category: impact of public involvement

Marston, C. & Renedo, A. (2013) **Understanding and measuring the effects of patient and public involvement: an ethnographic study**, The Lancet, 382, S69.

Abstract

This conference abstract provides an overview of a four-year ethnographic study of public involvement activities run by the Northwest London Collaboration for Leadership in Applied Health Research and Care (CLAHRC). One of the main findings was that health professionals tended to view involvement as an intervention, wanting to see evidence of cost-effectiveness and improved health outcomes, as well as tending to look for the difference that individual participants made. The authors suggest that the effect of public involvement cannot be captured in this way. Instead, they highlight the importance of looking at the dynamic social processes and networks through which involvement contributes to change. They present a framework for future assessment of public involvement based on this approach.

Category: impact of public involvement

Mathie, E., Wilson, P., Poland, F., McNeilly, E., Howe, A., Staniszewska, S., Cowe, M., Munday, D. & Goodman, C. (2014) **Consumer involvement in health research: A UK scoping and survey**, International Journal of Consumer Studies, 38, 35-44.

Abstract
Aim: To provide an overview of the current extent and variation of public involvement in research in the UK.

Method: Six research topics were selected to include a range of types of research and public involvement approaches. 838 studies on these topics (non-commercial studies, less than two years old) were contacted. They were asked to forward research documents (e.g. funding bids and protocols) for the scoping exercise, and also to take part in a survey about public involvement.

Findings/recommendations: The most common involvement activity was membership of steering committees and reviewing patient information leaflets. However, there was very limited information about involvement in publicly available research documents. This makes it very difficult to know whether any plans for public involvement are followed through, and how different approaches might lead to different impacts. More routine recording of how public involvement is carried out and what difference it makes is essential to develop the evidence base.

Category: nature and extent of public involvement in research

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Mayer, M. (2012) **Seeking what matters: Patients as research partners**, Patient, 5(2), 71-74.

Abstract
This is an editorial written by a patient advocate working in cancer research in the US. The author reflects on what patients bring to the research process, in particular their views on what outcomes matter to other patients.

Category: reflecting on public involvement in research

McClimens, A., Grant, G. & Ramcharan, P. (2007) **Looking in a fairground mirror: reflections on partnerships in learning disability research.** In: M. Nolan, E. Hanson, G. Grant & J. Keady (Eds.) User participation in health and social care research: voices, values and evaluation (pp104-119). Maidenhead: Open University Press

Abstract

The authors (all researchers) reflect on the difficulties and dilemmas experienced when working with people with a learning disability as research partners. They discuss some of the practical difficulties and the problems caused by others outside of the research team, not working inclusively. They describe how developing the process of partnership working was an intensive and time-consuming process and how they found it difficult to maintain an emancipatory approach, given the demands of the project.

Category: reflecting on public involvement in research

McCormick, S., Brody J., Brown, P. & Polk, R. (2004) **Public involvement in breast cancer research: An analysis and model for future research,** International Journal of Health Services, 34(4), 625-646.

Abstract

Aim: This paper reviews the development of public involvement in health research; describes three research studies where breast cancer activists became actively involved and outlines a model of lay involvement in research based on this analysis.

Methods: In addition to reviewing the literature, the authors interviewed a range of stakeholders in order to understand the obstacles, processes and benefits of public involvement in research. These stakeholders were all involved in environmental breast cancer research in three areas of the USA.

Findings/recommendations: The authors suggest that the potential challenges to public involvement in research fall into three categories: relationship issues, methodological issues and social, political and cultural issues.

They describe how women affected by breast cancer had an impact on research commissioning through:

- using political connections and activism to campaign for and secure government funding for research
- influencing the research agenda
- influencing how the research was carried out.

The authors describe the impact on activists:

- their understanding of environmental causation and research methods increased
- their feelings about researchers changed from fear to respect

Both activists and researchers described a feeling of empowerment that resulted from the collaboration. Both groups felt that public involvement pushed the research forward more quickly. The authors reflect that "public involvement created an articulated value structure that made research relevant to women with breast cancer." They argue that public involvement reduces distrust of science on the part of the public and increases public accountability.

Collaboration between researchers and activists led to the establishment of Project LEAD, a National Breast Cancer Coalition project that trains activists in breast cancer research. They go on to describe a model for public involvement in research, which covers principles (e.g. openness), tasks (e.g. training activists) and structure (e.g. lay people in positions of governance).

Category: impact of public involvement, nature and extent of public involvement in research, reflecting on public involvement in research

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Mckeown, M., Malihi-Shoja, L., Hogarth, R., Jones, F., Holt, K., Sullivan, P., Lunt, J., Vella, J., Hough, G., Rawcliffe, L., Mather, M. & CIT. (2012) **The value of involvement from the perspective of service users and carers engaged in practitioner education: Not just a cash nexus**, Nurse Education Today, 32(2), 178-84.

Abstract

This paper summarises the findings from a participatory action research study which aimed to develop service user and carer involvement in a university setting, in particular in practitioner education. The study explored what value service users and carers obtained from their involvement. Three main themes emerged:

- a more positive sense of self
- expanding social networks and growing friendships
- changing things for the better – altruism in activism.

The authors reflect on the implications for supporting and resourcing involvement and the issue of payment.

Category: impact of public involvement, reflecting on public involvement in research

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McKevitt, C., Fudge, N. & Wolfe, C. (2009) **What is involvement in research and what does it achieve? Reflections on a pilot study of the personal costs of stroke.** Health Expectations, 13(1), 86-94

Abstract

This paper reports on the experience of involving users in a pilot study to investigate the costs of illness to stroke survivors and their families. A standing forum of stroke survivors/family members associated with the King's College London Stroke Research Program identified the need for the study.

The forum was also involved in choosing the methods, developing and piloting the questionnaire, and analysing the results of the pilot survey.

The authors reflect on their experience of working with service users and the nature of the involvement. They also describe the reactions of their academic colleagues to the concept of involvement.

They conclude that the involvement made a difference to the research in three ways:

1. It led to the identification of questions regarded as relevant and important by service users as opposed to professionals.
2. It helped to refine the methods.
3. It helped to reconceptualise the problem of the economic costs of disease in a way that incorporated the views of service users.

Category: impact of public involvement, reflecting on public involvement in research

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McLaughlin, H. (2010) **Keeping service user involvement in research honest.** British Journal of Social Work, 40(5), 1591-1608.

Abstract
This article critically examines the development of service user involvement in research. It aims to identify ways in which service user research can retain its honesty.

The author discusses:

- top-down and bottom up approaches to the development of service user involvement in research
- the nature of service users
- different levels of involvement
- benefits and costs of involvement
- the knowledge claims of service user researchers and co-researchers

Category: reflecting on public involvement in research

McLaughlin, H. (2006) **Involving young service users as co-researchers: Possibilities, benefits and costs,** British Journal of Social Work, 36, 1395-1410.

Abstract
This paper explores the benefits and costs of involving young service users in research in terms of the impact on:

- developing and delivering research
- dissemination and service development
- young people
- adult researchers

The author concludes that these benefits and costs cannot be summed up to decide whether or how to involve young people in any particular research project. He argues that this decision is more likely to be influenced by political, ethical and practical considerations. Further work is needed to determine when it is best to involve young people in different parts of the research process and where this involvement is most likely to result in service improvements and better service outcomes.

Category: impact of public involvement

McLaughlin, H. (2005) **Young service users as co-researchers. Methodological problems and possibilities,** Qualitative Social Work, 4(2), 211-228

Abstract
This paper explores the challenges in working with young service users as co-researchers. It also highlights some of the benefits including:

- young co-researchers are better able to understand the language of young people and to create rapport in an interview. This gives them access to information that may not be obtained by adult researchers.
- young co-researchers have distinct insights which can inform the analysis of interviews in a different way to adults.

However, the author notes that it is not always true that young researchers are better able to engage with other young people and provides examples of where this has not been the case. He concludes that the benefits of working with young people need to be weighed up against the extra effort and resources required to equip young co-researchers and enable them to benefit from the experience.

Category: impact of involvement

Meyer, M., Torres, S., Cereno, N., MacLean, L. & Monzon, R. (2003) **Immigrant women implementing participatory research in health promotion,** Western Journal of Nursing Research, 25(7), 815-834.

Abstract
This report describes the experience of using participatory research methods with Hispanic women to collect information about community needs and provide health education. The authors were particularly interested to explore combining participatory research with health promotion activities.

The participatory researchers from the community reported that:

- their new interviewing skills helped them to develop closer contacts with other community members and helped to strengthen previously established links
- they learnt a lot about the community in terms of their health needs and barriers to accessing health services
- they gained confidence and a sense of personal satisfaction

The researchers reported that this approach:

- enhanced the professional credibility of the team in the community
- helped improve explanations of confidentiality to participants, which in turn generated greater levels of trust, and made it easier to discuss personal health issues with the women
- is very resource intensive and requires a lot of time and commitment from all involved

They concluded that the combination of approaches worked well as it made it possible to give something back to the women who took part in the study. The women received relevant health information as well as being asked about their needs. However, this did create some problems for the participatory researchers. They sometimes felt overwhelmed by high expectations and greater than anticipated levels of need.

Category: impact of public involvement

Miller, E., Cook, A., Alexander, H., Cooper, S., Hubbard, G. Morrison, J. & Petch, A. (2006) **Challenges and strategies in collaborative working with service user researchers: Reflections from the academic researcher,** Research Policy and Planning, 24(3), 197-208.

Abstract
Aim: To develop a collaborative approach to finding out the views of users of services provided by health and social services partnerships.

Methods: Academic researchers worked with three user research organisations to design a research tool and interview service users

Findings/recommendations: The input of the user researchers was significant in developing the research tool and changed its final form and content. This helped ensure the tool more closely reflected the issues important to users. They also influenced the data collection and analysis by contributing their thoughts and reflections after completing the interviews.

However, the academic researchers also highlight the difficulties that arose because some of the user researchers did not possess or develop the necessary skills to carry out in-depth interviews. It proved difficult to address this problem within the constraints of the grant award. They believe this compromised the quality of the research and the well-being of the interviewees. They recommend that in future projects, user researchers are not only offered training but also offered alternative tasks to match their skills and levels of confidence. It might also be appropriate to interview people for specific research roles.

Category: impact of public involvement

Miller, E., Morrison, J. & Cook, A. (2006) **Brief encounter: Collaborative research between academic researchers and older researchers,** Generations Review, 16(3/4), 39-41.

Abstract

This article describes a two-year research collaboration between university researchers and older researchers and reflects their views on how involving older people added value to the project.

The collaboration involved designing a research tool and conducting interviews with users of services for older people provided by health and social services partnerships.

From the perspective of the university researchers involving older researchers was helpful at the early stages because:

- it challenged the university researchers to be clear about their aims and to explain these clearly to interviewees
- it shaped the development of the interview schedule

At later stages, the older people's reflections on the sites where they conducted the research helped to enrich the analysis and writing from the project.

The older researchers felt their awareness of the social impacts of aging helped them have an increased empathy with interviewees.

All the researchers learnt that involvement at only one stage of a project can limit its effectiveness. For example, it was only after being involved in discussions around analysing the data that the older researchers became aware of the key questions to ask in the interviews. Prior to this involvement, the older researchers tended to ask the key questions less often and were unaware of the emergence of new themes. This suggests that better results are obtained when user researchers are involved in all stages of a project.

Category: impact of public involvement

Minkler, M., Fadem, P., Perry, M., Blum, K., Moore, L. & Rogers, J. (2002) **Ethical dilemmas in participatory action research: A case study from the disability community,** Health Education & Behaviour, 29(1), 14-29.

Abstract
Aim: To use a participatory action research approach working with people with disabilities to explore the views of the disabled community on dying with dignity and physician-assisted suicide legislation.

Methods: A Community Advisory Group was formed at the beginning of the project and involved in all aspects of the research. They helped with:

- defining the sample and identifying potential participants
- developing the interview questions
- conducting interviews and analysing data
- preparing the final report and presenting the findings to participants
- meeting with local policy makers and other stakeholders

Findings/recommendations: The paper reports on the benefits and ethical dilemmas raised by this example of participatory research. The project benefited from the involvement of people with disabilities through:

- the use of the right language
- better research tools
- access to a highly diverse group of participants
- better reporting back to the community in ways that stimulated further dialogue as well as plans for education and action

The community researchers benefited from learning new skills, particularly research skills. The academic researchers benefited from learning about the experiences of people with disabilities which helped strengthen the identification of relevant themes in the interview data.

Category: impact of public involvement

Minkler, M., Vasquez, V., Warner, J., Steyssey, H. & Facente, S. (2006) **Sowing the seeds for sustainable change: A community-based participatory research partnership for health promotion in Indiana, USA, and its aftermath,** Health Promotion International, 21(4), 293-300.

Abstract
Aim: To examine the long-term impact of community-based participatory research (CBPR) on communities via a case study of a partnership involving the Indiana University School of Nursing and the Healthy Cities Committee in New Castle, USA.

Methods: A review of the partnership's archived documents, interviews with academics, community partners and policy-makers and focus groups with community members.

Findings/recommendations: The original study involved a survey of the local community. Community members helped shape the questionnaire, collected data and interpreted the findings. The almost 50% response rate was attributed to the work of the community partners in gaining advance publicity for the study.
A community meeting was held to look at the findings. This allowed the community to compare itself (unfavourably) to national norms and become informed about their level of health. Other sessions involved members of the City council, the newspaper editor, fire chief and other key stakeholders which helped move the community into the action phase.

In the 10 years since this research a number of heath initiatives got under way including a ban on indoor smoking, developing plans for walking trails, funding and building a new playground. Community members took a leading role in all of these efforts.

The CBPR therefore played an important part in catalysing long-term change as a strong and dynamic community partner proved willing to continue to work for change long after the initial project had ended.

Category: impact of public involvement

Minogue, V., Boness, J., Brown, A. & Girdlestone, J. (2005) **The impact of service user involvement in research,** International Journal of Health Care Quality Assurance, 18(2-3), 103-112.

Abstract
Aim: To examine the development of one service user and carer research group in a mental health Trust.

Methods: A literature review, a review of user involvement in research in the Trust, a survey of consumers and NHS staff in the Trust, a skills audit and training needs analysis of consumers. Service users and carers worked on the project.

Findings/recommendations: The benefits for consumers were found to be:

- gaining knowledge and experience
- improved sense of well-being, self-esteem and confidence

The Trust gained from hearing the service user perspective and maintaining a user focus. They reported changes in research design and methods as a result of user involvement and the following changes to services:

- changes in information packs and leaflets given to service users
- continuation of a service
- continuing to the next stage of an evaluation

Category: impact of public involvement

Mockford, C., Staniszewska, S., Griffiths, F., & Herron-Marx, S. (2012) **The impact of patient and public involvement on UK NHS health care: a systematic review**, International Journal for Quality in Health Care, 24(1), 28-38.

Abstract

This articles reports on the findings from a literature review that aimed to identify the impact of public involvement on NHS healthcare services. The review found a broad range of impacts that can be broadly divided into impact on service planning and development, on information development and dissemination and on the attitudes of service users and providers. The authors also highlight the limits of the evidence available, in particular a lack of economic analysis on the costs involved and the poor quality of reporting. They argue that the evidence based needs to be significantly strengthened.

Category: impact of public involvement

Morris, M., Nadkarni, M., Ward, F. & Nelson, R. (2004) **Exception from informed consent for pediatric resuscitation research: Community consultation for a trial of brain cooling after in-hospital cardiac arrest,** Pediatrics, 114(3), 776-781

Abstract

The researchers in this study carried out a consultation of healthcare professionals and parents of current and past patients at a children's hospital. The aim was to explore the ethical dilemmas around obtaining consent for their clinical trial. They were hoping to conduct a trial to find out if brain cooling would be beneficial for children as part of the treatment following a cardiac arrest in hospital. The cooling needs to begin within 30 minutes of the cardiac arrest.

The parents and health professionals all agreed it would be unethical to try to obtain consent from parents at this traumatic time. The parents also concluded that it would be unethical to ask all parents about the possibility of their child entering the trial at the time of admission. They suggested that the best solution would be to ensure that all families were made aware of the study via posters and leaflets in the hospital, and that parents were given at an opportunity to opt out of the study in the 30 minutes before starting treatment. The consultation thus identified a way of conducting the trial, without the need to obtain informed consent, in a way that was likely to be acceptable to families, health professionals and the institution.

Category: impact of public involvement

Morrow, E., Cotterell, P., Robert, G., Grocott, P. & Ross F. (2013) **Mechanisms can help to use patients' experiences of chronic disease in research and practice: An interpretative synthesis**, Journal of Clinical Epidemiology, 66(8), 856-864.

Abstract
This article reports the findings from a literature review that aimed to identify the mechanisms by which patients' experiences of chronic disease can be used to improve outcomes, health care costs and quality of life for individuals. Ten different mechanisms were identified, including involving patients as co-researchers in healthcare research and participative action research. The different mechanisms were compared and their strengths and weaknesses described as far as possible. Information about their impact is limited. The authors suggest that a greater understanding of these mechanisms could help determine which mechanism works best in different contexts, and also help find ways to link the learning across them.

Category: reflecting on public involvement in research

Morrow, E., Ross, F., Grocott, P. & Bennett, J. (2010) **A model and measure for quality service user involvement in health research.** International Journal of Consumer Studies, 34(5), 532-539.

Abstract
The authors identify a need for a more critical and consistent assessment of what constitutes quality involvement. However, they also recognise that there are many different ways of defining quality and that ideas about quality involvement are highly subjective.

They have reviewed a range of philosophical and social theories of power and empowerment to develop a model of quality involvement. They have turned this into a questionnaire which they hope could be used by service users and researchers to reflect and report on their experiences. The questionnaire asks questions about the service user's views of their involvement experience and the research context.

Category: reflecting on public involvement in research

Mosavel, M., Simon, C., van Stade, D. & Buchbinder, M. (2005) **Community-based participatory research (CBPR) in South Africa: Engaging multiple constituents to shape the research question,** Social Science & Medicine, 61(12), 2577-2587.

Abstract
Aim: To address the (perceived) need for cervical cancer screening in an under-resourced community in Cape Town, South Africa, by exploring the local context for a new health promotion programme.

Methods: A CBPR approach was taken to developing the project including field visits and informal interviews and focus groups with community members. Local people were trained and employed as focus group moderators and outreach workers. They were also involved in data analysis.

Findings/recommendations: One important outcome of the community visits was the formation of a community-based reference team that helped shape the rest of the project. This ensured that community stakeholders were involved at all stages. The major impact of involving community members was to shift the emphasis of the whole project from the researchers' narrow interest in cervical cancer to a much broader consideration of young women's 'cervical health'. This took into account a much wider range of problems affecting sexual health in the community. As a result the health promotion programme is now more likely to address the multiple anxieties and lived experiences of the target group.

Category: impact of public involvement

Muir, D. (2011) **Patient and public involvement in pressure ulcer research**, Journal of Tissue Viability, 20, 132-133.

Abstract
This article reports on the development of the Pressure Ulcer Research Service User Network UK (PURSUN UK). The network is supported by the University of Leeds to provide input into a large scale National Institute for Health Research (NIHR) funded programme based at the university. The network has contributed to: developing a pressure ulcer risk assessment framework; analysis of data from research related to severe pressure ulcers; and developing new research ideas.

Category: impact of public involvement

Nacif, A. (2005) **Young researchers: Can I ask you some questions?** Children & Young People Now, 29 March 2005.

Abstract

This article reports on research projects carried out by children working with the Open University Children's Research Centre. It describes how children taking part in research will often answer questions from their peers more easily than those from adults.

Because young researchers are experts in the views and feelings of children, they can also find out what their peers think in a way that is not open to adults. The children who have been involved have gained personally from the experience. They have not only acquired research skills but also social and communication skills.

Category: impact of public involvement

Newell, C. & South, J. (2009) **Participating in community research: exploring the experiences of lay researchers in Bradford,** Community, Work & Family, 12(1), 75-89.

Abstract

Aim: To investigate the experiences of young Asian women who undertook a community needs assessment in a neighbourhood in Bradford.

Methods: Semi-structured interviews were carried out with six of the women who became community researchers.

Findings/recommendations: Being involved had a positive impact on the women themselves. It increased their confidence and self-esteem and gave them a greater understanding of research. It also deepened their understanding of the issues affecting their community and inspired a determination to work towards making positive changes. However the women were also concerned that by conducting the research, they had raised community expectations, and that they would personally be held accountable if the research didn’t deliver any benefits.

This raises important questions about providing ongoing support for community researchers and the responsibilities of the commissioning authorities to act upon the findings.

Category: impact of public involvement

Niba, M. & Green, J. (2005) **The impact of participatory and non-participatory evaluations on meeting project objectives,** African Journal of AIDS Research, 4(2), 103-113.

Abstract

Aim: To assess the effects of participation on the outcomes of a health project's objectives. This was done by comparing similar HIV/AIDS projects with and without participation.

Methods: The overall outcomes of six HIV/AIDS projects (3 participatory and 3 non-participatory) were compared in terms of how well they met their common objectives. This involved reviewing documents and interview data from the project evaluations. The participatory evaluations were carried out in parallel with the implementation of the projects and included reflection time, focus groups and feedback sessions.

Findings/recommendations: The projects with participatory evaluations were high performing in terms of meeting their objectives. The non-participatory projects registered only an average performance. Awareness, knowledge, attitudes, skill acquisition, effective functioning and sustainability within the health projects were improved and supported through a participatory approach. The authors conclude that participation is important in both the implementation and evaluation stages of a project.

Category: impact of public involvement

Nierse, C., Schipper,K., van Zadelhoff, E., van de Griendt, J. & Abma, A. (2012) **Collaboration and co-ownership in research: dynamics and dialogues between patient research partners and professional researchers in a research team,** Health Expectations, 15(3), 242-54.

Abstract

This article describes how two patient researchers worked with academics on a project to develop a research agenda for social-science research in the area of chronic kidney disease (CKD). The patient researchers helped with carrying out interviews with patients with CKD and parents of children with CKD, conducting focus groups and observing people in a dialysis centre. They also helped to analyse and write up the data.

The article describes the mutual learning that took place at all stages of the project. The researchers conclude that involving the patients in the team improved the quality of the findings because the patients ensured diversity amongst the people interviewed, carried out more in-depth interviews and brought more insights to the analysis of the data. This resulted in new perspectives on the social aspects of living with CKD, laying the groundwork for a research programme that will better meet patients' needs.

Category: impact of public involvement

Nilsen, E., Myrhaug, H., Johansen, N., Oliver, S. & Oxman, A. (2006) **Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Review),** Cochrane Database of Systematic Reviews, Issue 3, Art. No. CD004563.

Abstract

Aim: To assess the effects of consumer involvement and compare different methods of involvement in developing healthcare policy and research, clinical practice guidelines and patient information material.

Methods: Systematic review of published trials and controlled studies assessing methods for involving consumers.

Findings/recommendations: Five randomised controlled trials were included in the review. These showed that involving consumers in the development of patient information materials results in material that is more relevant, readable and understandable to patients, without affecting their anxiety. This material can also improve patients' knowledge.

There is also some evidence that using consumer interviewers instead of staff interviewers in satisfaction surveys can have a small influence on survey results.

The authors conclude that there is a huge gap in the evidence from comparative studies about the desirable and adverse effects of consumer involvement. People making decisions about how best to involve consumers may therefore wish to rely on advice based on practical experience and common sense. What the evidence does suggest is that in future, randomised controlled trials of consumer involvement would be feasible and relevant.

Category: impact of public involvement

Noonan Walsh, P. (2003) **A courtly welcome: observations on the research initiative,** British Journal of Learning Disabilities, 31, 190-193.

Abstract

This short paper reflects on the author's involvement in commissioning and overseeing a series of learning disabilities research projects. The author argues that because self advocates were involved in this process, presentations about the research projects were more concise and more interesting. The author compares the involvement of self advocates in research in England with that in Ireland, where self advocates are not involved in commissioning policy research at a national level.

Noonan Walsh raises several questions about what policy research is, who should do it, and how results should be disseminated. In particular, she asks:

- Who should set research priorities?
- Who should be included in the research process?
- How inclusive should dissemination processes be?

She argues that future research in this area should look at the experiences of more diverse groups - for example older people with a learning disability.

Category: reflecting on public involvement in research

O'Connel, D. & Mosconi, P. (2006) **An Active Role for Patients in Clinical Research?** Drug Development Research, 67, 188-192.

Abstract
Aim: To review the trend towards greater public involvement in clinical research in the UK and internationally.

Methods: Based on their own experiences as Board members of EUROPA DONNA (The European Breast Cancer Coalition), the authors review the trend towards greater involvement of patients and patient groups as research subjects, as partners in the research process and as supporters of research.

Findings/recommendations:

- involvement in research as subjects: examples of research promotion by patient groups and partnerships involving patient organisations are given
- involvement in the research process: national and international examples of involvement are given, particularly from the field of breast cancer research
- supporting research: for example, the need for patient involvement in outcome research is highlighted

Category: nature and extent of public involvement in research, reflecting on public involvement in research

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O'Donnell, M. & Entwistle, V. (2004) **Consumer involvement in decisions about what health-related research is funded,** Health Policy, 70, 281-290.

Abstract
Aim: To find out whether, why and how research funders involve consumers in decisions about what health-related research is funded.

Methods: A survey and telephone interviews with staff working for UK funders of health-related research.
Findings/recommendations: 69 organisations responded to the survey and 17 agreed to follow-up interviews. They gave different reasons for why they involved consumers in funding decisions, but the most common was that their involvement ensures that research is more relevant and important to consumers. Different organisations have different structures and processes for making funding decisions and therefore involve consumers in a variety of ways. Little is known about what impact this involvement has. The authors conclude that the future development of consumer involvement in research agenda setting needs to consider not only when and how best to involve consumers, but also needs to critically assess the whole system and the roles of other stakeholders.

Category: nature and extent of public involvement in research

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O'Donnell, M. & Entwistle, V. (2004) **Consumer involvement in research projects: the activities of research funders,** Health Policy, 69(2), 229-238

Abstract
Aim: To find out whether, why and how UK funders of health-related research promote consumer involvement in research projects.

Methods: Postal survey and telephone interviews with UK funders of health research.

Findings/recommendations: Many UK funders of health research are encouraging researchers to involve consumers in their work. Many recognise that different forms of consumer involvement will be appropriate for different types of research project. There is no standard way of judging the quality of proposals for involving consumers in a research project. Given the variation in involvement, any criteria used to make judgements about quality will need to be flexibly and fairly applied. Researchers also need to be made aware of funders' requirements.

Category: nature and extent of public involvement in research

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Oliver, S. (1996) **The progress of lay involvement in the NHS Research and Development Programme,** Journal of Evaluation in Clinical Practice 2(4), 273-280.

Abstract
This paper describes the nature and extent of lay involvement in the NHS R&D Programme.

Lay involvement is described in the following stages of research:

- setting the research agenda
- funding research
- designing and conducting research
- implementation of research

The author summarises the findings of 3 discussion groups to listen to lay people's views on involvement in research and how this work might be evaluated. The barriers to involvement are described and discussed. There is also a call for clarity about the role(s) lay people are required to play, and for resources, training and support to be made available to lay people who become involved in research.

Finally, the author calls for research into evidence of the effectiveness of involvement, and outlines some of the questions such research might address.

Category: nature and extent of public involvement in research

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Oliver, S., Armes, D. & Gyte, G. (2009) **Public involvement in setting a national research agenda,** Patient, 2(3), 179-190.

Abstract
This article reports the findings from a mixed-methods evaluation of public involvement in the National Health Service Health Technology Assessment program. The focus was on the nature and influence of patients and public on research topics.

Their influence was found to include:

- Making patient and carer perspectives explicit
- Changing the focus of research
- Adding new outcomes
- Refuting the need for planned research
- Providing up-to-date prevalence data
- Providing plain English background text

Category: impact of public involvement

Oliver, S., Clarke-Jones, L., Rees, R., Milne, R., Buchanan, P., Gabbay, J., Gyte, G., Oakley, A. & Stein, K. (2004) **Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach,** Health Technology Assessment, 8(15).

Abstract
Aim: To look at the processes and outcomes of involving consumers in identifying and prioritising research topics. This included involvement in national and regional R&D programmes in health and other areas. The goal was to find out what helps or hinders consumer involvement in agenda setting.

Methods: The authors carried out a systematic literature review and interviews with consumers and research managers in the UK.

Findings/recommendations: Successful consumer involvement in research agenda setting requires appropriate skills, resources and time. Consumers are best placed to advise on how to work with them. Research programmes are advised to work with well-networked consumers and provide them with information, resources and support to consult their peers to prioritise topics. This is best done through repeated and facilitated debate.

The authors found little evidence of the impact of consumers on the research agenda. This is because records are rarely kept and the contributions made by consumers are not identified in reports from panels/committees.

Further research is required on:

- the best training and support for consumers
- how to tackle the barriers to involvement
- comparing different methods of involvement
- evaluation and identifying best practice
- processes and outcomes of developing consensus with the involvement of consumers

Category: nature and extent of public involvement in research

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Oliver, S. & Gray, J. (2006) **A bibliography of research reports about patients', clinicians' and researchers' priorities for research,** London: James Lind Alliance.

Abstract
Aim: To describe the scope of the literature addressing patients' and clinicians' priorities for research and outcomes for assessing treatments.

Methods: Literature review.

Findings/recommendations: The study identified a substantial literature addressing patients' and clinicians' research priorities. These references are listed in the report. Further work is required to evaluate this evidence in terms of methods used to find out about people's priorities in different contexts, who was involved and how their views were analysed.

Category: nature and extent of public involvement in research

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Oliver, S., Liabo, K., Stewart, R. & Rees, R. (2014) **Public involvement in research: Making sense of the diversity**, Journal of Health Services Research & Policy, doi: 10.1177/1355819614551848. [Epub ahead of print]

Abstract
This paper presents a framework for designing and evaluating public involvement in research, which is based on findings from the literature and the authors' experience. The framework consists of three elements:

- Drivers for involvement – who gets involved and why, which researchers involve people and why, and the wider research context
- Processes of involvement – bringing people together and supporting debate/ decision-making and how people interact
- Impact – on people, research, policy & practice and personal decisions

The authors hope that better planning, reporting and evaluation of involvement may result from using this framework.

Category: reflecting on public involvement in research

Owens, C., Farrand, P., Darvill, R., Emmens, T., Hewis, E. & Aitken, P. (2011) **Involving service users in intervention design: A participatory approach to developing a text-messaging intervention to reduce repetition of self-harm**, Health Expectations, 14(3), 285-95.

Abstract
Aim: To involve people with relevant lived experience in the development of a text-messaging intervention to reduce repetition of self-harm.

Methods: Six participatory workshops were held with service-users and clinicians to help develop the intervention.

Findings/recommendations: Service users rejected the researchers' original plans for the intervention. This resulted in a new approach that was much more tailored to the individual. Developing a more complex intervention had serious implications for the pilot trial design. The researchers concluded that involving people at the development stage requires openness, flexibility and a readiness to abandon or radically revise initial plans. While this was acceptable for the research team, they wondered if it would be tolerated by all funders, given that they often require very formulated research proposals.

Category: impact of public involvement

Palmer, R. & Paterson, G. (2013) **To what extent can people with communication difficulties contribute to health research?** Nurse Researcher, 20 (3), 12-16.

Abstract
This paper presents a model of involvement for people with aphasia, a communication problem commonly experienced after a stroke. The researchers set up an advisory group for people with aphasia and their carers. The group was involved at every stage of a project to assess the cost-effectiveness of computer-based treatment for aphasia. The group's involvement made a difference to the:

- recruitment process and materials
- training guide on the use of the computer therapy
- dissemination of the results of the study to people with aphasia.

The group members reported that their involvement had: increased their confidence in communicating; provided a source of peer support; been motivating and stimulating; led to feelings of empowerment in being able to influence future treatment for others.

Category: impact of public involvement

Parker, E., Israel, B., Williams, M., Brakefield-Caldwell, W., Lewis, T., Robins, T., Ramirez, E., Rowe, Z. & Keeler, G. (2003) **Community action against asthma: Examining the partnership process of a community-based participatory research project,** Journal of General Internal Medicine, 18(7), 558-567.

Abstract
Aim: To evaluate the Community Action Against Asthma (CAAA) participatory research project.

Methods: In-depth interviews were conducted with members of the CAAA Steering Committee.

Findings/recommendations: Community partners proved to be crucial to the success of the research and to the implementation of the intervention. Their input helped to tailor the research to be more sensitive, acceptable, locally relevant and beneficial to the participating families.

Benefits to the researchers included:

- publicity and recognition for doing community work
- recognition within their department for doing community based participatory research
- career advancement and recognition for individuals

The community based organisations who were involved benefited from:

- gaining credibility for the activities they had been working on
- increased knowledge and understanding of asthma
- recognition for their participation at conferences
- their involvement in disseminating information to the community

Category: impact of public involvement

Paterson, C. (2003) **Consumer involvement in research into complementary therapies,** Bristol: Medical Research Council Health Services Research Collaboration.

Abstract
Aim: To find out about the extent and range of consumer involvement in UK complementary medicine research and explore the perceptions and experiences of researchers and consumers.

Methods: The author carried out a literature review and interviewed consumers who had been involved in complementary medicine research and researchers by phone or face-to-face.

Findings/recommendations: Some people thought that consumer involvement was particularly important in the field of complementary medicine research as consumers can be useful and powerful allies for such marginalised disciplines. However consumer involvement in this area is not commonplace.
The benefits of consumer involvement were identified particularly in:

- priority setting and protocol development
- doing the research
- the review and dissemination of results

Consumers described several positive ways in which they had benefited from being involved:

- turning an illness into a positive contribution
- feeling encouraged that something was being done
- new social opportunities

Negative experiences included: frustration at not being able to influence the establishment; financial or health restrictions; surprise at the cost of research.

Category: impact of public involvement, nature and extent of public involvement in research

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Paterson, C. (2004) **'Take small steps to go a long way': consumer involvement in research into complementary and alternative therapies,** Complementary Therapies in Nursing & Midwifery, 10, 150-161.

Abstract
Aim: To find out about consumer involvement in complementary medicine research from people with experience in this area.

Methods: Literature review, contact with relevant organisations in the UK and interviews with consumers and researchers.

Findings/recommendations: The overall level of consumer involvement was low. However several examples were found where consumers had had an impact on:

- priority setting
- protocol development
- recruitment to research and tackling ethical problems
- producing written information for participants

Researchers gained from the added energy and enthusiasm to the team and from practical and personal support from consumers.

Consumers benefited in the following ways: they were able to turn a bad experience of illness into a positive contribution to the common good; new social opportunities; knowing that something was being done. However they also expressed frustration and not being able to influence the medical research establishment and surprise and anxiety about the costs of research.

Category: impact of public involvement

Paterson, C., Allen, J., Browning, M., Barlow, G. & Ewings, P. (2005) **A pilot study of therapeutic massage for people with Parkinson's disease: the added value of user involvement,** Complementary Therapies in Clinical Practice, 1(3), 161-171.

Abstract
Aim: To carry out a pilot study of therapeutic massage for people with Parkinson's disease, particularly looking at outcome measures.

Methods: Observation and interviews with service users receiving massage therapy.

Findings/recommendations: The participants in this study discussed their experience of being in the study and also analysed the results in order to make recommendations for the design of any future clinical trial.

They commented on a number of aspects of the research design including:

- how to describe the treatment
- the design of the quality of life questionnaires - difficulties in completing them and relevance of the outcomes being measured
- the importance of the timing of the massage - since symptoms vary during the day and depend on medication
- how to administer questionnaires to people with disabilities

The researchers commented that the users had highlighted important issues in the study design that otherwise would have been ignored.

Category: impact of public involvement

Patterson, S., Trite, J. & Weaver, T. (2014) **Activity and views of service users involved in mental health research: UK survey**, British Journal of Psychiatry, 205(1), 68-75.

Abstract
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 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 had found their involvement to be very positive. It had provided them with a sense of purpose and belonging, and enhanced their self-respect. However,

a small minority felt involvement had 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.

Category: impact of public involvement, reflecting on public involvement in research

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Pearson, M., Monks, T., Gibson, A., Allen, M., Komashie, A., Fordyce, A., Harris-Golesworthy, F., Pitt, M., Brailsford, S. & Stein, K. (2013) **Involving patients and the public in healthcare operational research: The challenges and opportunities**, Operations Research for Health Care, 2(4), 86–89.

Abstract
This authors argue that public involvement could make a valuable contribution to operational healthcare research, which involves testing new models of providing health services. The authors suggest that the arguments for public involvement are ethical and economic as well as ensuring relevant outcomes for patients. They provide two case studies where involvement has contributed to developing and refining models of care. The potential benefits and barriers to public involvement in operational research are discussed, and an outline approach to its implementation is proposed.

Category: nature and extent of public involvement in research, impact of public involvement, reflecting on public involvement in research

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Pennisi, E. (2000) **Patients help track down disease gene,** Science, 288(5471), 1565-1567.

Abstract
This news article describes how a patient advocacy group has helped further biomedical research.

The group was set up by a family with a rare genetic condition. They established a blood bank, persuaded families from all over the world to sign up and held meetings with researchers to encourage them to use this resource. Their efforts have helped the successful identification of the gene responsible for this condition.

Category: impact of public involvement

Petit-Zeman, S., Philpots, L. & Denegri, S. (2010) **"Natural Ground" for medical research charities: Patient and public involvement in research funding,** Journal of Ambulatory Care Management, 33(3), 249-256.

Abstract: This article reports on the Association of Medical Research Charities' Natural Ground project which brought together a learning set of staff and volunteers from member organisations to discuss current involvement activities and share best practice. The article describes five areas where medical research charities involve patients and discusses some of the methods used.

Category: nature and extent of public involvement in research

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Petit-Zemen, S. & Locock, L. (2013) **Bring on the evidence**, Nature, 501, 160-161.

Abstract

The authors comment on the need for better quality evidence to support patient and public involvement in research. It highlights 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.

Category: reflecting on public involvement in research

Petrie, S., Fiorelli, L. & O'Donnell, K. (2006) **If we help you what will change? Participatory research and young people,** Journal of Social Welfare and Family Law, 28(1), 31-45.

Abstract

This paper describes a participatory research project about teenage pregnancy and young parenthood, where a number of young people were actively involved. It considers the impact of this involvement, both on the young people and on the research itself.

The research involved peer group interviews, which took place in a number of towns across the UK. There was a Young People's Advisory Group at each of the research sites. These groups undertook some interviewing and looked at preliminary research findings. A range of young people were involved for all or part of the project.

In their reflections on being involved in the project, two young women discuss some of the unwelcome and negative press attention they received, and how they challenged this. They comment that "we have gained confidence, friends and pride (in ourselves and our children)."

The authors conclude that it is possible to involve young people in research in a meaningful way, and that this involvement enhances the research process. They consider the financial and other costs of this involvement, and talk about what they have learnt. They also consider how young people enabled the researcher to gain understanding about the culture of young people and to interpret the research findings.

Category: impact of public involvement

Phillips, W. & Grams, G. (2003) **Involving patients in primary care research meeting worked well,** British Medical Journal, 326 (7402), 1329.

Abstract
Aim: To explore involving patients who had not previously been involved in health research, services or advocacy in a primary care research meeting.

Methods: Six patients were invited to participate in the annual meeting of the North American primary care research group. Patients and professionals were asked to evaluate research presentations using 5-point Likert scales. Patients also took part in a focus group discussion and completed open-ended questionnaires.

Findings/recommendations: Patients participated enthusiastically in the meeting. Patients and professionals rated research presentations similarly. The only difference in ratings was on validity of conclusions, where patients were more positive than professionals.

Patients felt that primary care was important and that research was relevant to their lives. Professionals cited worthwhile questions and comments from patients and appreciated their influence on the atmosphere of the meeting. The authors encourage others to involve patients in their meetings.

Category: impact of public involvement

Philpot, M., Collins, C., Trivedi, P., Treloar, A., Gallacher, S. & Rose, D. (2004) **Eliciting users' views of ECT in two mental health trusts with a user-designed questionnaire,** Journal of Mental Health, 13(4), 403-413.

Abstract
Aim:

- to determine whether a user-designed questionnaire could be used to measure user satisfaction with electroconvulsive treatment (ECT)
- to find out users' views of ECT as a treatment
- to compare findings from two mental health trusts

Methods: A mental health service user group designed a self-report questionnaire and sent this to every patient who received ECT during the period of the study.

Findings/recommendations: This is the first prospective study of users' experiences of ECT which is based on a questionnaire designed by users.

(Other studies with user-involvement have asked about people's past experience of ECT, whereas the study asked everyone who received treatment as the study went along.) This overcomes criticisms of previous user-led studies, where the methods used to survey users may have led to an unusually high level of negative responses.

This study confirmed that there is a difference between clinician-led and consumer-led studies in terms of the reported benefits of ECT. As has been found with other user-led studies, fewer users said that ECT had helped them and fewer people would consider having ECT again.

Category: impact of public involvement

Pizzo, E., Doyle, C., Matthews, R. and Barlow, J. (2014) **Patient and public involvement: how much do we spend and what are the benefits?** Health Expectations doi: 10.1111/hex.12204. [Epub ahead of print]

Abstract
Aim: To assess the benefits and costs of involvement and the challenges in carrying out an economic evaluation.

Methods: A literature review.

Findings/recommendations: The benefits of public involvement include effects on the design and development of research and new services, on NHS governance and on citizenship and equity. Very few studies have assessed the economic impact.

The authors have developed a framework to help identify the costs associated with involvement, including hidden costs, such as the costs to patients. They suggest that greater clarity on the costs and benefits of different approaches to public involvement will help with making a business case for involvement.

Category: impact of public involvement

Plumb, M., Price, W. & Kavanaugh-Lynch, M. (2004) **Funding community-based participatory research: lessons learned,** Journal of Interprofessional Care, 18(4), 428-439.

Abstract
Aim: To evaluate the California Breast Cancer Research Program (CBCRP) to measure success and identify areas for improvement.

Methods: Review of grant applications to the program and telephone interviews with consumer and academic researchers working on CBCRP funded projects.

Findings/recommendations: As well as drawing out lessons for improving the funding program the project has also identified how consumer involvement has had an impact on:

- identifying research questions, to ensure they are relevant to consumers
- recruitment and retention and the involvement of underserved communities

The paper also recommends that the funders change their funding processes so as to better support researchers working collaboratively with consumers.

Category: impact of public involvement

Poland, F., Mapes, S., Pinnock, H., Katona, C., Sorensen, S., Fox, C. & Maidment, I. (2014) **Perspectives of carers on medication management in dementia: lessons from collaboratively developing a research proposal**, BMC Research Notes, 7, 463.

Abstract
This article reports on the outcomes of a workshop held with carers of people with dementia from the Alzheimer's Society Research Network. The workshop brought together carers, health professionals and researchers with the aim of understanding the issues that carers face in managing medication related problems. The workshop identified the key issues for carers that were then used to inform the development of a future research proposal. The carers' perspectives ensured that the research would address carers' priorities and focus on the areas of most relevance to them.

Category: impact of public involvement

Purtell, R. & Wyatt, K. (2011) **Measuring something real and useful in consumer involvement in health and social care research,** International Journal of Consumer Studies, 35(6), 605-608.

Abstract
This article critiques the current debate around measuring the impact of patient and public involvement.

The authors highlight that the purpose of involvement is not clearly defined or being considered. They also suggest that there needs to be wider discussion about why impact needs to be measured and who benefits from this process. They recommend that a wider debate also needs to be held around the criteria to be used for reporting involvement and when any assessment of impact should be made.

Category: reflecting on public involvement in research.

Ramon, S. (2000) **Participative mental health research: Users and professional researchers working together,** Mental Health Care, 31(7), 224-228.

Abstract
This paper describes two research projects that involved mental heath service users in research. The first was an evaluation of a user-run information and support organisation. The second aimed to explore the experiences of people with personality disorders.

Involvement in the projects helped service users to:

- become familiar with research and learn the skills for themselves
- gain confidence
- enjoy the creative elements of the project
- feel like they were contributing again, being socially useful and acknowledged

The researchers benefited from:

- a better understanding of the lives of service users and lay perceptions of research that allowed them greater reflection and a more critical perspective
- more truthful information from the research participants than would have otherwise been possible

Category: impact of public involvement

Reed, J., Weiner, R. & Cook, G. (2004) **Partnership research with older people - moving towards making the rhetoric a reality.** International Journal of Older People Nursing, 13(3a), 3-10.

Abstract

This paper is a reflection on the issues that have arisen in three projects where older people were involved in the research at different levels, from sources of data to independent researchers.

The authors conclude that there is a need to develop a model of involvement that is shaped by philosophical, ethical and professional debates about partnership. This model could then be translated into practice, particularly in terms of how involvement is facilitated.

Category: reflecting on public involvement in research

Reeve, P., Cornell, S., D'Costa, B., Janzen, R. & Ochocka, J. (2002) **From our perspective: Consumer researchers speak about their experience in a community mental health research project,** Psychiatric Rehabilitation Journal, 25(4), 403-408.

Abstract

In this article, consumer researchers share their experiences of being involved in a mental health project. The project followed the changes in three local community mental health organisations over two years.

The consumers were involved in conducting focus groups and interviews, analysing the data and writing-up and presenting the results.

The consumer researchers said they personally benefited from being involved. It helped their recovery to be working again. They gained new skills and greater self-esteem. They gained support from their peers, learned to have more compassion for other consumers, and became more aware of the kinds of changes needed in the mental health system.

They thought that their involvement contributed to the research findings and processes by:

- making it easier for the interviewees to talk about the problems they have faced
- changing the direction of the project and the way the research methods were carried out

Category: impact of public involvement, reflecting on public involvement in research

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Renedo, A. & Marston, C. (2011) **Healthcare professionals' representations of 'Patient and Public Involvement' and creation of 'Public Participant' Identities: Implications for the development of inclusive and bottom-up community participation initiatives**, Journal of Community and Applied Social Psychology, 21, 268-180.

Abstract
This article draws on an example of involvement in healthcare delivery to examine key socio-psychological elements at the heart of community engagement with participatory processes. The authors explore the link between public participant identities and social representations of public involvement among healthcare professionals, and examine the role they play in supporting or undermining inclusive and bottom-up forms of public involvement.

Category: reflecting on public involvement in research

Restall, G. (2013) **Conceptualising the outcomes of involving people who use mental health services in policy development**, Health Expectations, doi: 10.1111/hex.12091. [Epub ahead of print]

Abstract
This study explored the outcomes of the involvement of mental health service users in the development of health and social housing policy in Manitoba, Canada. It involved interviewing a range of different stakeholders. The author developed a conceptual framework to describe the different kinds of outcomes.

These include:

- personal outcomes – in terms of increased empowerment and self-confidence, but also greater vulnerability - these affect the individuals involved
- substantive outcomes – which result in better policy decisions that achieve the intended goals - these impact organisations and communities
- instrumental outcomes – which give policy decisions greater legitimacy, through greater transparency and accountability in the decision-making process – these again impact on organisations and communities
- normative outcomes – which further the values of a democratic society and have a wider impact on social and political institutions.

The author concludes that having a clear idea of the purpose of involvement, in terms of the type of outcome expected, is critical to developing the process and deciding how best to evaluate it.

Category: reflecting on public involvement in research

Rhodes, P., Nocon, A., Booth, M., Chowdrey, M., Fabian, A., Lambert, N., Mohammed, F. & Walgrove, T. (2002) **A service users' research advisory group from the perspectives of both service users and researchers,** Health and Social Care in the Community, 10(5), 402-409.

Abstract
This paper, written by service users and researchers, is about the experience of a service user advisory group that was set up to advise an evaluation of diabetes services in Bradford.

Advisory group members became key communication links between the research team and the wider community passing information in both directions. This gave the project greater credibility as well as access to different networks.

Service user members of the group reported the following benefits:
- greater confidence and feeling of making a contribution
- better knowledge of diabetes and diabetes services that they were also able to pass on to others

Researchers describe the benefits in terms of:
- being able to test the appropriateness and effectiveness of their research tools e.g. questionnaires developing appropriate recruitment strategies - how to contact potential participants and address payment issues
- greater knowledge of the experience of diabetes and using diabetes services.

The researchers reported that service users suggested topics and research questions they had not considered and challenged some of the background assumptions and aims of the research. They also stated that there were costs in terms of time and resources and that careful attention had to be paid to the role of the group, so they didn't stray off task or weren't used like a focus group by the researchers.

Category: impact of public involvement

Rickard, W. & Purtell, R. (2011) **Finding a way to pay in the UK: methods and mechanisms for paying service users involved in research**, Disability & Society, 26(1), 33-48.

Abstract
This article critically examines the policy context, policy guidance, payment mechanisms, advice and suggested solutions to existing payment problems. The authors conclude that mechanisms for paying people are a core problem and that focusing on mechanisms should be the key next step to improve opportunities for disabled people (and other service users) to be involved in research.

Category: reflecting on public involvement in research

Rose, D. (2014) **Patient and public involvement in health research: Ethical imperative and/or radical challenge?** Journal of Health Psychology, 19(1), 149-158.

Abstract
The author discusses the different reasons for promoting public involvement in research. One argument is that it is a moral imperative and therefore best considered as a way of democratising science. Another is that involvement contributes to new and different forms of knowledge. The author concludes that a political conceptualisation best captures the new knowledge that marginalised health groups can produce.

Category: reflecting on public involvement in research

Rose, D. (2004) **Telling different stories: user involvement in mental health research,** Research and Policy Planning, 22(2), 23-30.

Abstract
This paper describes the work of the Service User Research Enterprise (SURE) at the Institute of Psychiatry in London. It describes:

- user involvement in research committees and the impact on research priorities at the Institute
- an example of collaboration where user researchers had an impact on the quality of the research and subsequent health policy - the user researchers relied on their experience of receiving electroconvulsive therapy (ECT) to improve the assessment of users' satisfaction with the treatment. They showed that previous studies had overestimated the levels of user satisfaction. This research was used by NICE in its appraisal of ECT and the criteria for this treatment are now much more restrictive
- the model of participatory research used in the research at SURE

The author also reflects on the experiences of SURE to discuss the issue of power differences between user researchers and professionals and the problems this creates in terms of achieving full 'partnership' in research. She also considers the criticisms of user-focused or collaborative research and the theoretical basis for evaluating different kinds of knowledge - knowledge based on science and knowledge based on experience.

Category: impact of public involvement, reflecting on public involvement in research

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Rose, D. (2003) **Collaborative research between users and professionals: peaks and pitfalls,** Psychiatric Bulletin, 27, 404-406

Abstract

This paper defines and gives an overview of collaborative research between mental health clinical academics and service users; gives some examples of different collaborations, and summarises some of the obstacles to collaborative research in mental health.

Rose describes a range of examples drawn from the Service User Research Enterprise (SURE) at the Institute of Psychiatry in London. These include:

- Service users suggesting changes to the outcome measures for a clinical trial
- Service users undertaking a user-led piece of research as part of a larger research project
- Service users becoming involved in research management structures

Key obstacles identified are scepticism about the value of user involvement in research, and power differentials. Rose argues that collaborative research needs to "deliver" and that research capacity should be developed amongst service users with an interest in this area. Service users can provide fresh insights. Their involvement can therefore lead to the development of services which are more acceptable to service users.

Category: nature and extent of public involvement in research, reflecting on public involvement in research

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Rose, D., Leese, M., Oliver, D., Sidhu, R., Bennewith, O., Priebe, S. & Wykes, T. (2011) **A comparison of participant information elicited by service user and non-service user researchers,** Psychiatric Services 62(2), 210-3.

Abstract

Aim: This study examined whether the data collected by service user researchers was different to data collected by non-service user researchers in a wider study of mental health service users' perceived coercion in their treatment.

Methods: Mental health service users were interviewed during their first week of compulsory admission at three different provider settings. Each site had one service user and one non-service user researcher. They used two standard quantitative scales to measure service users' perceived levels of control and freedom in the admission process.

Findings/recommendations: The authors hypothesised that inpatients would express a higher degree of perceived coercion to service user researchers. In fact no difference was found. The authors have a number of suggestions as to why this was the case (e.g.

the nature of the training, levels of interaction between service user and non-service user researchers) which they recommend are explored through further research.

Category: impact of public involvement

Rosenbaum, P. (2005) **From research to clinical practice: Considerations in moving research into people's hands. Personal reflections that may be useful to others,** Developmental Neurorehabilitation, 8(3), 165-171.

Abstract

The purpose of this personal reflection is to consider some of the common challenges and opportunities in trying to 'get the important messages' out to people who could benefit from the information.

The author identifies two important strategies as:

- ensuring the research is relevant to end users and asks the questions they think are important by seeking their input at an early stage of developing the material. This ensures the information is accessible and useful;
- involving service users in reviewing and commenting on written summaries of research.

He also considers whether it is necessary to produce different materials for different audiences and concludes that when information is produced in plain English, it is usually judged equally accessible by all audiences.

Category: reflecting on public involvement

Ross, F., Donovan, S., Brearley, S., Victor, C., Cottee, M., Crowther, P. & Clark, E. (2005) **Involving older people in research: methodological issues,** Health and Social Care in the Community, 13(3), 268-275.

Abstract

As well as discussing the methods of involving older people, the paper also discusses the impact of involvement on research quality and local service development.

Working with an advisory panel of older people benefited the following stages of the project:

- developing the interview agenda
- developing and validating methods e.g. through independent observation of focus groups
- early analysis of the interview data

By the end of the project, the panel had developed into a 'cohort of advocates' who continued to contribute to ongoing policy development on falls prevention. The panel members had developed links with other local stakeholders and continued to strengthen these relationships independently. They also started to work with groups developing patient and public involvement strategies for older people in the area. Their influence was therefore felt more widely than within the boundaries of the research.

The researchers reflect on working with older people in this way and comment on the need to accept that timeframes and agendas will change as a result.

They also note that researchers' and funders' notions of power, status and accountability are challenged by involvement.

Category: impact of public involvement

Ross, F., Smith, P., Byng, R., Christian, S., Allan, H., Price, L. & Brearley, S. (2014) **Learning from people with long-term conditions: new insights for governance in primary care**, Health and Social Care in the Community 22(4), 405-416.

Abstract
This article reports 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 (e.g. 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
- Helping to disseminate the findings locally.

Category: impact of public involvement

Rowe, A. (2006) **The effect of involvement in participatory research on parent researchers in a Sure Start Programme,** Health and Social Care in the Community, 14(6), 465-473.

Abstract

Aim: To investigate the experiences of parent researchers involved in a community survey within a Sure Start programme.

Methods: The parent researchers were involved in the development, data collection, analysis and report writing phases of the survey and the dissemination of the findings. Their experiences were captured by questionnaires before and after the study, by a focus group at the end of data collection and via personal diaries.

Findings/recommendations: The parent researchers felt they had developed new skills through the project including listening skills, improved confidence, the ability to communicate with a range of people, research skills and telephone skills. As a result, a number of the parent researchers have taken up further courses to increase their employment prospects and continue work in the Sure Start programme.

The fact that they were local parents helped the participants in the survey to share a great deal of personal information that was at times accompanied by considerable emotion. The parent researchers felt this had helped to achieve their objective of 'doing good' for the community. Through their visits they were able to listen and support people who were isolated and also pass on information about a range of local services.

However, they were frustrated by some parts of the project, in particular:

- not being able to respond immediately to the concerns of the people they interviewed
- not being able to shape the study as much as they would have liked because the direction and nature of the project had already been set by the commissioners

The researcher found the involvement of parent researchers to be challenging because they needed to adopt a different role - one of facilitator and occasional adviser rather than the more usual and familiar role of directive leader. This required a different set of skills. However, they also felt that the input of local knowledge informed the work and increased the acceptability of the research to the participants. The parent researchers also improved the design of the research tool to make it more accessible. The enthusiasm and commitment they brought to the project also ensured that local agencies were aware of the findings.

Category: impact of public involvement

Royle, J. & Oliver, S. (2001) **Consumers are helping to prioritise research,** British Medical Journal, 323, 48-49.

Abstract
The authors report on the impact of consumer involvement in the prioritisation of research topics at the National Co-ordinating Centre for Health Technology Assessment. They report that consumers refereeing research reports have:

- suggested changes as well as providing positive support
- raised issues not previously mentioned
- helped rank recommendations for research
- identified how reports could be made more accessible and informative
- provided constructive criticism e.g. questioning outcome measures

Category: impact of public involvement

Savage, C., Xu, Y., Lee, R., Rose, B., Kappesser, M. & Anthony, J. (2006) **A case study in the use of community-based participatory research in public health nursing,** Public Health Nursing, 23(5), 472-478.

Abstract
Aim: To explore the culture of pregnancy and infant health in an African American community via an ethnographic study.

Methods: The researchers set up a community partnership with the help of two community nurses. The core group overseeing the project included nurse researchers, public health nurses from the stakeholder organisations and women who lived in the community.

Findings/recommendations: The involvement of community members helped to improve the design and conduct of the research by:

- shaping the recruitment strategy using local knowledge
- checking the research tools were culturally relevant
- helping the researchers gain entrance to the community
- analysing the data and helping to draw out relevant themes

The researchers comment on the benefits of the participatory approach and also explain how they had to change the way they worked to ensure genuine collaboration.

This project helped the group to form a strong partnership which has helped them to continue this work, conducting a survey based on the findings of this study and developing a new intervention that was relevant to the community and had complete community support.

Category: impact of public involvement

Schneider, B., Scissons, H., Arney, L., Benson, G., Derry, J., Misurelli, N., Nickerson, D. & Sunderland, M. (2004) **Communication between people with schizophrenia and their medical professionals: A participatory research project**, Qualitative Health Research, 14(4) 562-577.

Abstract

Aim: To undertake a participatory research project with a group of people with schizophrenia under the guidance of a university researcher.

Methods: Members of the research group participated in all stages. They chose the topic – experiences with medical professionals – and the method of data collection – in-depth interviews with each other. They also developed and performed a drama presentation of the results and recommendations for how they would like to be treated by professionals.

Findings/recommendations: Taking part in this research was a transforming experience for the people involved. It made an enormous contribution to their quality of life and sense of self. They were proud to have been members of the group and to have investigated what they thought was an important topic.

The user researchers had all been subjects of research and at the beginning of the project did not believe they were people who could do research. By the end they had a strong sense of themselves as researchers. They saw that they could identify problems, come up with ways to investigate them and produce solutions. This experience increased their awareness of themselves as people who could make significant contributions to society.

The project also made an important contribution to healthcare practice by influencing the psychiatrists and other professionals who came to their performances. One professional commented on how they had changed how they interact with their patients as a direct result of hearing the group members speak about the project.

Category: impact of public involvement

Schulz, A., Israel, B., Parker, E., Lockett, M., Hill, Y. & Willis, R. (2001) **The East Side Village Health Worker Partnership: Integrating research with action to reduce disabilities,** Public Health Reports 116, 548-557.

Abstract

Aim: This article describes the findings from an evaluation of the East Side Village Health Worker Partnership. The aim of the Partnership was to address the social determinants of health on Detroit's east side using lay health advisers.

Methods: Community partners were involved in all stages of the ongoing research and evaluation process, including designing the study, interpreting the results and integrating the findings into the work of the Partnership.

Findings/recommendations: A major part of the evaluation assessed whether the Partnership had made any difference to the research carried out to inform the development and implementation of the project. It showed that the collaboration between community members and researchers had improved research methods and the implementation of the findings.

Community members helped to develop a locally relevant model of stress and health which helped to shape an initial survey of the community. They developed the questionnaire and were also hired as interviewers. The survey had an 81% response rate, attributed to the efforts of the community researchers. They helped address local people's mistrust of research and increased the community's understanding and support for the survey. Working together to interpret and disseminate the results helped to increase the clarity and depth of the findings and led to a shared vision of priorities for change.

Category: impact of public involvement

Scotton, W., Kolias, A., Shen Ban, V., Crick, S., Sinha, R., Gardner, A., Massey, K., Minett, T., Santarius, T. & Hutchinson, P. (2013) **Community consultation in emergency neurosurgical research: lessons from a proposed trial for patients with chronic subdural haematomas**, British Journal of Neurosurgery, 27(5), 590-594.

Abstract

Chronic subdural haematoma (CSDH) affects mostly older people and requires neurosurgical treatment. Researchers are interested in developing a new type of surgery which would be much less invasive. However a clinical trial is needed to test whether this approach is safe and effective. People with CSDH are sometimes neurologically impaired which would make it difficult to obtain their consent to take part in such a trial. In order to assess potential participants' willingness to take part in the research, the clinicians carried out a survey of 215 patients, family members and carers, recruited from neurosurgical waiting rooms and clinics. This article reports on the findings, which showed that most people would be willing to participate in the proposed trial and would be happy for either the next of kin or an independent doctor to give consent on their behalf when necessary. The authors conclude that this kind of community consultation enables researchers to develop trial designs that are ethically acceptable to potential participants.

Category: impact of public involvement

Shah, S. & Robinson, I. (2007) **Benefits of and barriers to involving users in medical device technology development and evaluation.** International Journal of Technology Assessment in Health Care, 23(1), 131-137.

Abstract

Aim: To investigate the benefits of and barriers to user involvement in medical device technology development and evaluation.

Methods: Literature review.

Findings/recommendations: The main benefits of user involvement are increased information about users' needs, experiences and ideas.

Users generate ideas for both new and innovative products. Involvement also leads to improvements in the design, interface, function, usefulness and quality of medical devices. It is more useful if users are involved in the early stages, such as concept and idea generation, as well as the development, prototype testing and trials stages, rather than just in the late stages of product testing.

The main barriers to involvement are lack of resources, particularly time and money.

Category: impact of public involvement

Shippee, N., Garces, J., Lopez, G. et al. (2013) **Patient and service user engagement in research: a systematic review and synthesised framework**, Health Expectations doi: 10.1111/hex.12090. [Epub ahead of print].

Abstract

This article reports on the findings from a systematic review of the literature on patient and service user engagement in research. The authors have developed a two-part framework. The first part describes four components of involvement:

- patient and service user initiation
- building reciprocal relationships
- co-learning
- re-assessment and feedback.

The second part describes involvement during three phases of research: preparatory, execution and translational phases. The authors comment on the poor quality of the evidence and inconsistency in reporting on involvement.

Category: impact of public involvement

Simpson, A., Jones, J., Barlow, S., Cox, L. and SUGAR (2014) **Service user and carer collaboration in mental health nursing research**, Journal of Psychosocial Nursing and Mental Health Services, 52(1), 22-30.

Abstract
The Service User and carer Group Advising on Research (SUGAR) was set up in 2009 to support a five-year research programme. This article reflects on their experience and reports on the findings from a survey of the group's members. SUGAR has had an impact on the researchers, the group members and the programme of research. The services users and carers report that their involvement has helped them to feel included and empowered, it has offered meaningful activity leading to employment for some, and provided friendship, support and opportunities for personal growth.

The impact on the research has been to:

- improve and refine projects and activities
- extend the meaning of research findings
- produce outcomes and interventions that service users and carers find more useful.

The researchers report that working with SUGAR has helped them to express their ideas more clearly, to learn about service user and carer experiences and to develop new ideas and new ways of thinking.

Category: impact of public involvement

Sims, S., Brearly, S., Hewitt, G., Greenwood, N., Jones, F., Ross, F. & Harris, R. (2013) **How to develop a patient and carer advisory group in stroke care research**, Nurse Researcher, 20(3), 6-11.

Abstract
This study explored the effect of interprofessional teamworking on the experiences of patients and carers following a stroke. The research team established an advisory group of patients and carers. The group had a positive impact on the research by:

- improving the information given to participants
- making the interview questions easier to understand
- providing alternative interpretations of the data from interviews with patients and carers.

However, the advisory group strongly disagreed with the views of one of patients interviewed in the project, which proved to be a challenge for the research team. They describe how they managed this issue. They also report on the benefits of the involvement for everyone involved.

Category: impact of public involvement

Slade, M., Bird, V., Chandler, R., Fox, J., Larsen, M (2010) **The contribution of advisory committees and public involvement to large studies: case study,** BMC Health Services Research, 10, 323.

Abstract

This paper reports on an assessment of the impact of advisory committees on a large five-year study funded by the National Institute of Health Research. In particular the authors looked at the impact of public involvement. They conclude that the benefits experienced by the research team were improved quality and confidence in their study design. However, there were costs in terms of increased demands on researchers having to think through and come to a decision about each issue. This meant it took longer to finalise the study protocol and progress was slower.

Category: impact of public involvement

Smith, E., Manthorpe, J., Brearley, S., Ross, F., Donovan, S., Sitzia, J. & Beresford, P. (2005) **User involvement in the design and undertaking of nursing, midwifery and health visiting research,** London: National Co-ordinating Centre for NHS Service Delivery and Organisation.

Abstract

Aim: To find out what is known about user involvement in nursing, midwifery and health visiting research.

Methods: The authors carried out a systematic review of published and grey literature and a survey of current activity and practice. A service user reference group provided advice throughout the project.

Findings/recommendations: The report discusses:

- the context and drivers of user involvement
- the best ways of involving users in these three areas of research
- the outcomes of involving users
- the capacity of researchers and research organisations to involve service users

Some of the main conclusions are:

- there is little evidence of benefits of involvement and more work is needed to explore the meaning and importance of user involvement in research in different circumstances
- different approaches need to be tested to understand what works best and when
- measuring the impact of user involvement on the relevance and appropriateness of research can be problematic as it depends on who exactly decides whether research is relevant and appropriate

- user involvement is different in every research project – no one size fits all. So there is no single ‘how to do it’ model. The report recommends that a better way forward would be to identify triggers for decision-making to guide researchers in nursing, midwifery and health-visiting in the various stages of user involvement in research

Category: nature and extent of public involvement in research

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Smith, E., Ross, F., Donovan, S., Manthorpe, J., Brearley, S., Sitzia, J. & Beresford, P. (2008) **Service user involvement in nursing, midwifery and health visiting research: A review of evidence and practice**, International Journal of Nursing Studies, 45(2), 298-315.

Abstract
Aim: To review the evidence and practice relating to service user involvement in nursing, midwifery and health visiting research.

Method: The researchers undertook a literature review as well as telephone interviews with researchers and service users with experience of involvement. A service user reference group worked with the research team throughout the project.

Findings/recommendations: The authors describe the social and political ideas that have shaped involvement in research and the different ways in which it has been understood and developed. They identify the ways in which user involvement has had an impact at different stages of research and the practical challenges in taking involvement forward. They conclude that it is not possible to say that involving service users should always be undertaken in the same way to achieve the same benefits. The strength of user involvement depends on its unique purpose within any particular research project.

Category: impact of public involvement, reflecting on public involvement in research

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Snape, D., Kirkham, J., Britten, N., Gradinger, F., Looban, F., Popay, J., Wyatt, K. & Jacoby, A. (2014) **Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research: A modified Delphi study**, BMJ Open, 4:e004943.

Abstract
Aim: To explore people’s views on the barriers and drivers of public involvement (PI) in research, its impact and ways to evaluate the outcomes.

Methods: A Delphi consultation exercise with researchers, members of the public, research managers, commissioners and funders.

Findings/recommendations: There was a lot of agreement about the barriers and drivers to PI, with drivers tending to be the opposite of barriers. Common barriers included lack of funding for PI and work-time pressures on researchers. Team-building, training for all involved and openness to the perspectives of others were agreed to be essential factors for effective PI. There was also lot of agreement about how PI impacts on research, but no consensus on whether it necessarily improves quality and relevance. Although PI was thought to be of value in itself, the majority of participants still thought it important to evaluate its impact. This was recognised to be difficult, when much of current practice tends to be tokenistic, and the quality of the PI process has a major influence on its impact.

The authors conclude that addressing tokenism and related barriers remains a priority for all stakeholders with an interest of PI.

Category: reflecting on public involvement in research

Snape, D., Kirkham, J., Preston, J., Popay, J., Britten, N., Froggatt, K., Gibson, A., Lobban, F., Wyatt, K. & Jacoby, A. (2014) **Exploring areas of consensus and conflict around values underpinning public involvement in health and social care research: A modified Delphi study**, BMJ Open, 4, e004217.

Abstract
Aim: To explore areas of consensus and conflict around the values underpinning public involvement.

Methods: A modified Delphi exercise with researchers, members of the public, research managers, commissioners and funders.

Findings/recommendations: There were high levels of consensus on many of the issues including for example the argument that members of the public have unique knowledge and expertise that is complementary to researchers and that members of the public should be involved in publicly-funded research and health-related research. However, there were also areas of conflict, for example on the issues of bias and representativeness, and divided opinion on whether public involvement makes research more ethical.

The authors conclude there is a need for more training and support infrastructure to help researchers implement involvement, and for ‘best practice’ standards to help all stakeholders understand and evaluate different approaches.

Category: reflecting on public involvement

Stack, R., Mallen, C., Deighton, C., Kiely, P., Shaw, K., Booth, A., Kumar, K., Thomas, S., Rowan, I., Horne, R., Nightingale, P., Herron-Marx, S., Jinks, C., DELAY Study Syndicate, Raza, K. (2014) **The development and initial validation of a questionnaire to measure help-seeking behaviour in patients with new onset rheumatoid arthritis**, Health Expectations doi: 10.1111/hex.12203. [Epub ahead of print]

Abstract
This article reports on the involvement of people with rheumatoid arthritis (RA) in the development of a questionnaire to explore why patients delay seeking help at the onset of RA. The patients were involved through focus groups. They rephrased questions, added questions and removed irrelevant items. They also divided the questions into key themes relevant to patients. The questionnaire was also reviewed by health professionals. Overall, the involvement helped to increase the relevance of the questionnaire, so that it measured what patients thought was important to measure. The questionnaire is now being used in a study that will inform the development of tailored health promotion interventions that will aim to reduce the delay in people with RA seeking help.

Category: impact of public involvement

Staley, K. (2013) **Lay REC members – patient or public?** Journal of Medical Ethics, 39(12), 780-2.

Abstract
This article considers the role of lay members of Research Ethics Committees and describes how in practice this is very similar to that of patients who are actively involved in research. The author argues that patients with direct experience of the topic being investigated are best placed to advise on the ethical aspects of research design in a way that ensures the interests of potential participants are protected. A process of patient involvement prior to ethical review would be the most effective way to enable patients’ views to influence research. This has implications for the role of lay REC members and their recruitment.

Category: reflecting on public involvement in research

Staley, K. (2013) **A series of case studies illustrating the impact of service user and carer involvement on research**, Mental Health Research Network: London.

Abstract
This series of case studies describes how service user and carer involvement has an impact on mental health research. These examples were selected from the Mental

Health Research Network's portfolio to include projects that illustrate the wide range of impacts that service user and carer involvement has on mental health research. Involvement was found to influence all stages of a project, from developing a research question through to implementing the findings. It is hoped these examples will encourage other mental health researchers to involve service users and carers in their work.

Category: impact of public involvement

Staley, K. (2013) **There is no paradox with PPI in research**, Journal of Medical Ethics, 39, 186-187.

Abstract
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, for example in the case of peer interviewers. The author concludes that therefore the proposed paradox does not exist in practice.

Category: reflecting on public involvement in research

Staley, K. (2012) **An evaluation of service user involvement in studies adopted by the Mental Health Research Network,** London: Mental Health Research Network.

Abstract
Aim: This report summarises the findings from an evaluation of 45 studies selected at random from the MHRN portfolio.

Methods: The lead researchers from these studies were interviewed to find out how they had involved service users in their research and what difference this had made.

Findings/recommendations: The majority of researchers (40%) had involved service users on steering groups with variable success. In some cases the involvement had influenced key aspects of the study design and delivery, whereas in others the impact had been minimal. About 20% of the researchers had involved service users throughout their project, so that all aspects of the research had been influenced by the service user perspective. About 20% had involved service users at the design stage. Most often this led to changes in the practical arrangements for participants, but occasionally service users had influenced important aspects of the study design including the research question and choice of outcome measures.

Category: impact of public involvement

Staley, K. (2009) **Exploring impact: Public involvement in NHS, public health and social care** Eastleigh, INVOLVE.

Abstract
This report summarises the findings from a literature review that aimed to increase our knowledge of the evidence of impact of public involvement on health and social care research. It identifies a wide range of ways in which public involvement impacts on the research process and outcomes, on researchers, on participants, on the public involved, on the wider community and on subsequent implementation of research findings.

Category: impact of public involvement, reflecting on public involvement in research

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Staley, K., Buckland, S., Hayes, H. & Tarpey, M. (2014) **'The missing links': Understanding how context and mechanism influence the impact of public involvement in research**, Health Expectations, 17(6), 755–764.

Abstract
This article reflects on the ways in which the impact of public involvement in research has been assessed. The vast majority of reports of impact are based on observational studies or case studies. These are often purely descriptive. They describe the context and how the involvement was carried out and the impact – but they do not make the links between context, mechanism and outcome. They have therefore contributed to our understanding of general good practice, but have not helped to explain when and how a particular approach to involvement works well. The authors argue that using an approach based on realistic evaluation would provide a more in-depth understanding of these links. This would involve designing studies of involvement to test out theories of how involvement makes a difference. The findings from such studies would support a more strategic approach to involvement.

Category: reflecting on public involvement in research

Staley, K. & Minogue, V. (2006) **User involvement leads to more ethically sound research,** Clinical Ethics, 1, 95-100.

Abstract

The authors reflect on the general benefits of user involvement in research and in particular how user involvement can improve the ethical conduct of research. They describe how research projects with user involvement have experienced difficulties in receiving ethical approval. They explore the barriers to user involvement within the current system of ethical review and suggest how these barriers might be overcome.

Category: reflecting on public involvement in research

Staniszewska, S., Adebajo. A., Barber, B., Beresford, P., Brady, L., Brett, J., Elliott, J., Evans, D., Haywood, K., Jones, D., Mockford, C., Nettle, M., Rose, D. & Williamson, T. (2011) **Developing the evidence base of patient and public involvement in health and social care research: the case for measuring impact**, International Journal of Consumer Studies, 35(6), 628-632.

Abstract

This paper argues that one of the difficulties with developing an evidence base for public involvement is that there is currently no mechanism to quantify its impact. They suggest that robust measurement of the impact of public involvement is needed and should be developed collaboratively with service users.

Category: reflecting on public involvement in research

Staniszewska, S., Brett, J., Mockford, C. & Barber, R. (2011) **The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research,** International Journal of Technology Assessment in Health Care, 27(4), 391-399.

Abstract

This paper presents a checklist for people writing journal articles about patient and public involvement in health research. It has been developed through an analysis of two different literature reviews in this field. The aim is to enhance the quality of reporting of public involvement.

Category: reflecting on public involvement in research

Staniszewska, S. & Denegri, S. (2013) **Patient and public involvement in research: Future challenges**, Evidence Based Nursing, 16 (3), 69.

Abstract
This editorial highlights the following challenges for public involvement in research:

- Improving the evidence base through better reporting of involvement
- Training and support for researchers
- Developing community capacity for involvement
- Raising the status of public involvement

Category: reflecting on public involvement in research

Staniszewska, S., Jones, N., Marshall, S. & Newburn, M. (2007) **User involvement in the development of a research bid: barriers, enablers and impact,** Health Expectations, 10(2), 173-183.

Abstract
This paper describes the process of user involvement in the development of a research bid.

The idea for the research came from a group of parents of pre-term babies. This group had been set up as a support group for parents who felt that aspects of their care had been very poor. They hoped that their involvement in research would help to improve services and make things better for future parents.

A chance meeting between the organiser of the support group and a researcher from the RCN Institute led to a partnership being established to develop the bid. The process involved many meetings, a literature search and consultation with an advisory group. This helped to narrow down the parents' broad interests to a clearly defined research question. A key challenge was to keep the parents' ideas central to the bid, at the same time as ensuring it would be viewed as high quality research.

As well as shaping the research question, group members also helped with refining the methods and advising on ethical issues. The researcher concludes that the involvement had a clear impact on the project's aims, methods, ethical acceptability and dissemination plans. They believe that as a result they developed a bid that was more grounded in parents' experience, had more relevant research questions, used more appropriate and sensitive methods and had a strong dissemination strategy to reach out to healthcare professionals.

Category: impact of public involvement

Staniszewska, S., Thomas, V. & Seers, K. (2013) **Patient and public involvement in the implementation of evidence into practice**, Evidence Based Nursing 16(4), 97.

Abstract
This editorial highlights the potential value of involving patients and the public in research about how to implement best-practice evidence into healthcare. Similarly the authors argue for a role for patients and the public in implementing clinical guidelines.

Category: reflecting on public involvement in research

Stevens, T., Wilde, D., Hunt, J. & Ahmedzai, S. (2003) **Overcoming the challenges to consumer involvement in cancer research,** Health Expectations, 6(1), 81-88.

Abstract
This paper describes how people affected by cancer have influenced the cancer research agenda in the North Trent Cancer Research Network (NTCRN).

Researchers used a range of methods to recruit consumers. These included local radio and newspapers, posters and leaflets in law centres, supermarkets, using clinical trial databases and clinicians approaching patients directly. The NTCRN has worked to formalise the process of consumer involvement and incorporate it into the organisational infrastructure. This means that consumers are represented on key committees and have been involved in organising the annual Consumer Involvement Conference.

Consumers have identified research topics that have been taken forward. They have become involved in research advisory groups and in analysis and dissemination. A Consumer Research Panel has been set up to increase involvement across the NTCRN. The authors call for opportunities for involvement at all stages of the research process, and for this involvement to be co-ordinated.

Category: nature and extent of public involvement in research, impact of public involvement

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Stewart, R., Caird, J., Oliver, K. & Oliver, S. (2011) **Patients' and clinicians' research priorities,** Health Expectations, 14(4), 439-48.

Abstract
This paper summarises the findings from a review of the literature reporting on patients' and clinicians' priorities for research. It shows that activity in this area has grown over the last decade and that methods have advanced over time. The authors recommend that research funders and researchers draw on this literature to identify topics for research.

Category: nature and extent of public involvement in research

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Stewart, R. & Liabo, K. (2012) **Involvement in research without compromising research quality,** Journal of Health Service Research & Policy, 17(4), 248-51.

Abstract
The authors present an alternative model for public involvement which emphasises the expertise that different stakeholders bring to different stages of research.

Category: reflecting on public involvement in research

Stickley, T. (2006) **Should service user involvement be consigned to history? A critical realist perspective,** Journal of Psychiatric and Mental Health Nursing, 13, 570-577

Abstract
The author suggests that critical realist theory provides an alternative way of understanding the complex relationships between service users and professionals. He argues that while service user involvement is controlled by service providers it only serves to reinforce existing power imbalances. So it does not achieve empowerment. Service users are given power rather than taking it. In contrast, a critical realist model recognises that service users now possess power, because they can provide services that service providers now require. The author therefore concludes that service user involvement can be considered a historical concept.

Category: reflecting on public involvement in research

Stiffman, A., Freedenthal, S., Brown, E., Ostmann, E. & Hibbeler, P. (2005) **Field research with underserved minorities: The ideal and the real,** Journal of Urban Health, 82 (2, Suppl 3), iii56-iii66

Abstract

Aim: This article describes the realities of doing field research with high-risk, minority populations. It reports on the problems that researchers faced when working on a study of American Indian youth.

Methods: The researchers initially set up a Research Implementation Team (RIT) composed of tribal elders, council members, parents and youth from the community. They asked that the study specifically look at risk of abuse, HIV risk related behaviour, gay and lesbian activity, drug abuse and mental health issues. They also helped develop the protocol. However there was then a three year delay while the researchers sought funding. When the study was finally funded, the RIT members had changed. The new members raised many concerns about the study, for example cultural sensitivities around the discussion of topics such as sexual behaviour. The protocol was therefore changed considerably.

The focus was directed towards community strengths rather than problems and youth participants were given the option to 'skip out' certain sections of the survey. The RIT also wanted to offer services to youths who were identified in the interview as having problems. This required developing a clear process to help the researchers know when to intervene and how best to encourage uptake of services and record the outcome of this discussion. A surprisingly large number of the interviewees were found to have a problem that required directing them to services (90%).

Findings/recommendations: The researchers emphasise that making all these changes to the design in no way compromised the collection of data or participation in a follow-up study three years later. So while there were challenges in responding to the requests from the community in a way that would not compromise the research, ultimately this balancing act accelerated the end goal of the project - to translate the findings into practice and action.

Category: impact of public involvement

Stockdale, S., Mendel, P., Jones, L., Arroyo, W. & Gilmore, J. (2006) **Assessing organisational readiness and change in community intervention research: Framework for participatory evaluation,** Ethnicity & Disease, 16(1 Suppl 1), S1 136-S1 145.

Abstract
Aim: To use a collaborative approach to assess the capacity of organisations to form partnerships around mental health and substance abuse.

Methods: Representatives of leading community mental health and substance abuse agencies worked with university based researchers to develop and plan this project. They will also collect and analyse data and disseminate the results.

Findings/recommendations: This report from the first year of the project describes how the project goals have shifted substantially to match the interests and concerns of the community agencies. This will help increase the rigour and relevance of the assessment framework so that it is likely to produce useful information for community organisations as well as robust research findings.

To date, the community co-investigators have helped to identify:

- what questions to ask community organisations
- which agencies to include in the study
- which local communities to include and how to work with them
- how to manage the study to maximise cross-learning across communities
- recruitment strategies

Their involvement has helped to recruit participants who might otherwise have been ‘under the radar’ of traditional research or reluctant to be involved.

The collaboration has worked well because it has recognised and made good use of the researchers’ academic knowledge and the experiential knowledge of the community co-investigators. In particular it has helped the planned assessment of organisational capacity to reflect the ‘real-world’ rather than be limited by an academic approach.

Category: impact of public involvement

Sutton, J. & Weiss, M. (2008) **Involving patients as advisers in pharmacy practice research: What are the benefits?** International Journal of Pharmacy Practice, 16(4), 231-238.

Abstract

Aim: To describe how people with a chronic condition were involved as advisers to a research project exploring prescribing by pharmacists.

Methods: 10 people with a chronic condition attended six meetings with researchers over the course of a year. The researchers took an ethnographic approach to reflect on these meetings and the impact of user involvement.

Findings/recommendations: The patient advisers helped to maintain a strong patient focus and kept the project grounded in the patient's perspective. They made a significant contribution to the content and direction of the project. They helped to shape the interview schedules and offered comments on interview transcripts.

Their conclusions were incorporated into the final report. The researchers report that at first it was difficult to shift from being in control to taking a more participative role, but by the end of the project they felt more confident of their skills as facilitators.

Category: impact of public involvement

Tanner, D. (2012) **Co-research with older people with dementia: Experience and reflections**, Journal of Mental Health, 21(3), 296-306.

Abstract

This paper reports on the involvement of people with dementia in a project investigating older people's experiences of transitions between care services. The people with dementia were involved as co-researchers and carried out interviews of older people jointly with the researcher. Involving people with dementia in this way helped to establish trust and credibility with the interviewees and also enabled them to be open about their difficulties.

The co-researchers reported that their involvement gave them a sense of purpose and value, countering the feelings of powerlessness more usually associated with dementia.

Category: impact of public involvement

Tarpey M. (2011) **Public involvement in research applications to the National Research Ethics Service**, Eastleigh: INVOLVE.

Abstract

Aim: A study to provide baseline data on the extent and nature of reported public involvement in health and social care research by analysing information routinely collected by National Research Ethics Service (NRES) as part of the applications process for ethical approval of research projects.

Methods: The study was based on a sample of applications submitted to NRES in 2010. It focused on responses to the two-part question NRES asks applicants about how they will involve the public in their research. The question has a tick-box list of public involvement activities, and then a free-text box asking researchers to describe the involvement they have ticked.

Findings/ recommendations: The study found that researchers often appeared not to understand the involvement question, with many referring to engagement rather than involvement activities. Analysis of the free-text responses showed that while engagement and involvement are clearly linked activities and complement each other, they are also distinct, in that one does not describe the other. The study makes a number of specific recommendations for funders, researchers, Research Ethics Committees and NRES.

Category: nature and extent of public involvement in research

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Tarpey, M. (2006) **Why people get involved in health and social care research: a working paper,** Eastleigh: INVOLVE.

Abstract
Aim: To explore what is known about people's reasons for getting involved in health and social care research.

Methods: A review of the literature (including grey literature) as well as personal accounts from people who have been involved in research. These accounts were obtained from people responding to an advertisement in the INVOLVE newsletter.

Findings/recommendations: The paper discusses what motivates people to get involved in research; who gets involved and ways they are involved; what factors influence motivation; how to motivate people.

The conclusions are:

- people have varied reasons for getting involved
- people need to be made more aware of involvement opportunities
- researchers need to be flexible when involving people in order to meet their preferences for involvement
- people need to be convinced their involvement will make a difference
- people need training and support to be involved
- researchers need to be more proactive in engaging diverse groups

Category: reflecting on public involvement in research

Taylor, S. (2006) **A new approach to empowering older people's forums: Identifying barriers to encourage participation,** Practice, 18(2), 117-128.

Abstract
Aim: This paper reports on a study to identify the research training, support and information needs of 10 Older People's Forums in the UK.

Methods: Focus groups were undertaken with older men and women from a range of backgrounds. All were aged over 50. Most had not been involved in research to date.

Findings/recommendations: Most forums asked for user-friendly, non-accredited research training and support to enable them to get involved in research. Some groups wanted training to support them to undertake their own research. None of the groups wanted accredited research training.

Category: reflecting on public involvement in research

Telford, R., Boote, J.D. & Cooper, C.L. (2004) **What does it mean to involve consumers successfully in NHS research? A consensus study,** Health Expectations 2004, 7(3), 209-220.

Abstract
Aim: To reach a consensus on the principles and indicators of successful user involvement in research.

Methods: An expert workshop was held with researchers and consumers and the nominal group technique used to generate possible principles and indicators. A consensus was reached on these via a two-round Delphi process.

Findings/recommendations: Eight principles were agreed and at least one indicator identified to measure each principle. There was more agreement between researchers and consumers than in previous studies.

The authors hope these principles and indicators will be used by commissioners, researchers and consumers to guide good practice.

Category: nature and extent of public involvement in research

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Telford, R. & Faulkner, A. (2004) **Learning about service user involvement in mental health research,** Journal of Mental Health, 13(6), 549-559.

Abstract
Aim: To investigate how far service user involvement in mental health research appears to have been understood, how far it is happening, reasons why service users get involved and barriers to involvement.

Methods: A literature review looking at user involvement in mental health research and how users are carrying out research.

Findings/recommendations: There is little empirical research in this area but a lot more information in the grey literature. However, there is increasing evidence of user involvement in mental health research and at all stages of the research cycle.

Category: nature and extent of public involvement in research

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Terry, S., Terry, P., Rauen K., Uitto J. & Bercovitch, L. (2007) **Advocacy groups as research organisations: the PXE International example,** Nature Reviews Genetics, 8(2), 157-164.

Abstract
Aim: This paper describes the experience of a number of advocacy organisations in the USA which have become actively involved in research. The paper concentrates on one advocacy organisation, called PXE International (PXE is a rare genetic condition), but also describes the experiences of a number of other organisations which support people with a rare condition.

Methods: PXE International has initiated, funded and carried out research on PXE. It has also brought together researchers and people affected by PXE, and developed new clinical trials.

Findings/recommendations: The authors state that the involvement of PXE (and other similar advocacy organisations) in research has led to:

- An increase in the amount of research undertaken in a particular area
- An increase in funding available for research and number of biological samples donated
- Recruitment being quicker and easier
- The establishment of a blood and tissue bank
- The discovery of genes and the development of new diagnostic tests

PXE has shared its experience with other organisations. This has led to the sharing of protocols, procedures and the establishment of a Genetic Alliance Biobank.

Category: impact of public involvement

Tetley, J., Haynes, L., Hawthorne, M., Odeyemi, J., Skinner, J., Smith, J. & Wilson, D. (2003) **Older people and research partnerships,** Quality in Ageing - Policy, Practice and Research, 4(4), 18-23

Abstract
This paper describes the experiences of researchers and older people working together on a research project to explore people's involvement in decision-making processes when using care services in later life.

An advisory group of seven older people made valuable contributions throughout the project.

The paper describes in detail how the advisory group helped to improve the consent process for people taking part in the study.

It also reports that the advisory group:

- helped the researcher to work effectively and sensitively with different community groups
- contributed their experiences to the research
- benefited personally from being involved
- were able to link with a wider range of initiatives in their local community through their involvement in the group

The individual group members describe the personal impact of their involvement in their own words.

Category: impact of public involvement

The Learning Difficulties Research Team with assistance from Bewley, C. & McCulloch, L. (2006) **Let me in - I'm a researcher! Getting involved in research,** London: Department of Health

Abstract

Aim: This research aimed to find out what 12 research teams, funded by the Department of Health as part of the Learning Disability Research Initiative, had done to actively involve people with learning difficulties in their research. The research and management was undertaken by a team of people with learning difficulties.

Methods: Team members undertook semi-structured interviews with the research teams and with people with learning difficulties who had been involved in the research. They also kept diaries to reflect on their experience as researchers.

Findings/recommendations: Of the 12 research projects, only two employed people with learning difficulties. The report identifies a number of barriers to the employment of people with learning difficulties as researchers. All but one of the projects had advisory groups which included people with learning difficulties. Some of the advisory groups were more successful than others in effectively involving these people.

The authors of this report found examples of "really excellent involvement" and of accessible information. But they also found that people with learning difficulties were usually involved in research in limited, traditional and unimaginative ways. To involve people more effectively, they conclude that research has to be done over a longer period and resourced effectively - in terms of money, support and team working.

Reflecting on doing the research, the authors remarked that being user researchers improved the quality of the project by covering different questions and getting different information. However, they identify two issues for people with learning difficulties acting as interviewers:

- they were concerned that they might know someone they interviewed
- they might get their own experience mixed up with that of the people they were interviewing.

The authors reflect that they have learnt a lot and gained from their involvement, even though at times it was difficult. They call for more opportunities for people with learning difficulties to do research.

Category: nature and extent of public involvement in research, reflecting on public involvement in research

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Thompson, J., Barber, R., Ward, P., Boote, J., Cooper, C., Armitage, C. & Jones, G. (2009) **Health researchers' attitudes towards public involvement in health research,** Health Expectations, 12(2), 209-220.

Abstract
Aim: To investigate health researchers' attitudes to involving the public in research.

Methods: Semi-structured telephone interviews with 15 UK-based University health researchers.

Findings/recommendations: The researchers expressed different views of the meaning of public involvement in research, ranging from 'partnership in research', 'offering the public information about research' through to 'participation in a clinical trial'.

Some gave arguments in favour of involvement based on political and moral principles. Others suggested the motivation for involvement was the positive impact on research. However, some participants expressed some feelings of apprehension, suggesting that some researchers are still uncomfortable with involving the public. This may be a barrier to involvement.

Category: nature and extent of public involvement in research

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Thompson, J., Bissell, P., Cooper, C., Armitage, C. & Barber, R. (2012) **Credibility and the ‘professionalized’ lay expert: Reflections on the dilemmas and opportunities of public involvement in health research,** Health, 16(6), 602-18.

Abstract
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 that they brought to their involvement role, which were above and beyond their experience of the condition. They thought these additional areas of expertise gave them credibility and legitimacy to be involved. Some interviewees also seemed to have become professionalised in public involvement. The authors reflect on the implications for involvement.

Category: reflecting on public involvement in research

Thompson, J., Bissell, P., Cooper, C., Armitage, C. and Barber, R. (2014) **Exploring the impact of patient and public involvement in a cancer research setting**, Qualitative Health Research, 24(1), 46-54.

Abstract
Aim: To find out about the experiences of patients/ members of the public involved in research.

Methods: This study formed part of a larger ethnographic study of public involvement in the National Cancer Research Network in England. Interviews were conducted with lay members of six clinical studies groups and a local patient and public involvement panel. They were asked about why they had got involved and what their experience had been.

Findings/ recommendations: The majority of the patients/ members of the public involved were highly educated with professional or managerial backgrounds. They reported that being involved was part of being a ‘good citizen’ and seemed a natural extension to their involvement in other areas of civic life (for example through volunteering or being involved in cancer service improvement). They often wanted to improve health care for the benefit of others or to repay health services and staff for the care they (or a loved one) had received.

For many, being involved provided a means of redefining their professional lives, developing new skills and knowledge, and enabling them to recover aspects of their lives that had often been lost through illness.

The authors conclude that these findings represent important impacts of involvement, which are not given as much attention as the impacts on the research process. They would welcome research that explores whether people from different social backgrounds are able to make use of such opportunities for career and identity development.

Category: impact of public involvement

Thornton, H., Edwards, A., Elwyn, G. (2003) **Evolving the multiple roles of ‘patients’ in health-care research: reflections after involvement in a trial of shared decision-making,** Health Expectations 6, 189-197.

Abstract
Aim: This paper sets out some "consumer-led" reflections on a study which looked at shared decision-making in general practice.

Methods: The study used a systematic review, evaluation of outcome measures, and quantitative, qualitative and health economic analyses of a cluster randomised trial. This paper reflects on the involvement and its impact and does not describe the research in detail.

Findings/recommendations: Consumers and patients were involved in the research at a number of stages - setting the question, protocol design (and in particular the development of outcome measures), gaining funding, overseeing the research, and interpreting and disseminating the results.

The authors conclude that responsibility for developing effective collaboration should not rest solely with professionals - consumers and consumer groups should be involved in promoting collaborative working - and that no voice, including that of the consumer, should have greater weight than any other stakeholder. They argue that collaborative research requires a shift in attitude by researchers, consumers, policymakers and commissioners, so that all are committed to partnership working.

Category: reflecting on public involvement in research

Tierney, E., McEvoy, R., O'Reilly-de Brún, M., de Brún, T., Okonkwo, E., Rooney, M., Dowrick, C., Rogers, A. & MacFarlane, A. (2014) **A critical analysis of the implementation of service user involvement in primary care research and health service development using normalisations process theory**, Health Expectations, doi: 10.1111/hex.12237. [Epub ahead of print]

Abstract
Aim: To review current practice to examine the factors that influence whether an activity like service user involvement becomes routine.

Method: A review of the literature identified a sample of 26 articles describing service user involvement in primary care research and health service development.

Findings/recommendations: The factors that influence whether an activity becomes routine include:

- how it is defined and whether there is a shared understanding of this definition

- why people get involved
- how the activity is carried out
- how the activity is appraised.

The literature review identified problems within all these areas. Firstly, few studies provided a definition of involvement. Policy imperatives were given as the main reason for involvement, without understanding individual motivations. The methods used were often standard research methods (e.g. surveys to obtain patient opinion) and therefore not genuine involvement, and finally the reports mostly focused on positive outcomes.

The reporting of service user involvement initiatives needs to be improved to enhance our understanding of what will help this approach to become a standard way of working.

Category: nature and extent of public involvement in research, reflecting on public involvement in research

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Tritter, J. & Korivusalo, M. (2013) **Undermining patient and public engagement and limiting its impact: The consequences of the Health and Social Care Act 2012 on collective patient and public involvement**, Health Expectations, 16(2), 115-8.

Abstract
This article reflects on the impact of The Health and Social Care Act 2012 on public involvement in the NHS. The authors conclude that the Act weakens public involvement by reducing the power of the Local Involvement Networks (LINks). In addition, the Clinical Commissioning Groups with responsibilities for commissioning services that are asked to carry out involvement have no accountability to local people as to how they will do it. The overall effect is to undermine the principle of public involvement and to return the power to an ‘unaccountable medical elite’ to make decisions about priorities.

Category: reflecting on public involvement in research

Trivedi, P. & Wykes, T. (2002) **From passive subjects to equal partners Qualitative review of user involvement in research,** British Journal of Psychiatry, 181, 468-472.

Abstract
Aim: To illustrate the challenges of involving service users in research projects.

Methods: The authors subjected the process of 'user involvement' in a study investigating the effects of group medication education sessions on in-patients in a psychiatric hospital to ten questions.

These were:

1. What is the value of user involvement?
2. How will users be involved in the research process?
3. What projects might be suitable for user involvement?
4. What proposal will be prepared for presentation to users?
5. How will the initial approach be made?
6. How will users' responses be considered?
7. Will research partnerships with users be formalised?
8. How will the proposal be jointly assessed?
9. How will the project be written up?
10. How will dissemination occur?

Findings/recommendations: The findings consist of the authors' reflection of their own experiences in this and other projects, combined with evidence from literature, grouped under the ten questions listed. The authors conclude that the process of involving service users was challenging but profitable, and advocate the use of their '10 questions' framework in the future.

An appendix consists of a draft partnership research contract between the lead researcher and service user researchers drafted by service users involved in the project.

Category: impact of public involvement, reflecting on public involvement in research

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Truman, C. & Raine, P. (2001) **Involving users in evaluation: the social relations of user participation in health research,** Critical Public Health, 11(3), 215-229.

Abstract
This paper describes the development of a participatory research project that aimed to evaluate services in a community mental health service. The goal was to provide evidence to inform service development.

At the beginning of the project there was little user involvement, but this increased over time. At the later stages users set their own agenda and developed their own line of work beyond the scope of the project. The authors reflect on how the users changed the direction of the research and conclude that the quality and the validity of the research improved as user participation increased.

They believe that their study would have benefited from user involvement right from the beginning and also conclude that users are the best critics of any research protocol.

Category: impact of public involvement, reflecting on public involvement in research

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Tuffrey-Wijne, I. & Butler, G. (2010) **Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis,** Health Expectations, 13(2),174-84.

Abstract
This article contains the reflections of two researchers - one with and one without learning disabilities. They worked together to analyse the data of an ethnographic study of people with learning difficulties with cancer. The contributions of the user researcher to the data analysis were found to complement those of the other members of the research team. There were also unexpected benefits in terms of developing a more equal and supportive relationship between the two researchers.

Category: impact of public involvement, reflecting on public involvement in research

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Turner, T. & Beresford, P. (2005) **User-controlled research. Its meanings and potential,** Eastleigh: INVOLVE

Abstract
Aim: To find out about the definition, nature and operation of user-controlled research.

Methods: The authors carried out a literature review as well as interviews and group discussions with service users and service user researchers.

Findings/recommendations:
The report discusses:

- defining user-controlled research
- good practice for user-controlled research
- whether the researcher should be a service user
- the benefits of user-controlled research
- the barriers facing user-controlled research
- the future of user-controlled research

It also makes recommendations about taking forward user-controlled research and suggests that an effective strategy would need to address:

- sharing knowledge about user-controlled research
- recognising the resource implications
- training to support user-controlled research
- including black and minority communities
- safeguarding the future of user-controlled research

Category: reflecting on public involvement in research

Tyler, P., Turner, C. & Mills, H. (2006) **Involving young people in research.** London: Barnardo's Policy and Research Unit.

Abstract

This research project aimed to explore young people's experiences of bullying.The idea for the project came from Barnardo's Yorkshire Peer Research Group. The young people were involved at every stage of the process.

As a result of being involved in this project, the peer researchers thought their self-confidence and social skills had increased. They also valued having had opportunities to develop new skills e.g. through media training.

The key achievement was thought to be the project's impact on Barnardo's internal policy and guidance. By influencing the organisation's anti-bullying policy, this small research project will have a effect on a very large number of service users.

The researchers involved thought that the young people brought different perspectives to the work, they asked different questions and focused much more on the practical application of the research. The young people also had suggestions on how to address the ethical issues in the project.

The researchers also believe that the fact that this was a young persons' project generated more interest in the research and created more opportunities for dissemination. This in turn has meant the project has been able to influence Barnardo's practice.

Category: impact of public involvement

Vale C., Thompson L., Murphy C., Forcat S. and Hanley B. (2012) **Involvement of consumers in studies run by the Medical Research Council (MRC) Clinical Trials Unit: Results of a survey,** Trials, 13, 9.

Abstract

Aim: To establish levels of consumer involvement in studies carried out by the UK MRC Clinical Trials Unit.

Method: Semi-structured survey of staff responsible for studies included in a Unit Progress Report (2009).

Findings/recommendations: 31% of the studies had consumer involvement mostly as members of trial management groups. Levels of involvement had increased over time.

Impacts on the research and researchers were identified as:

- Improvements in study design and recruitment
- Improvements in study promotion and dissemination
- Improvements in study documentation
- Improvements in decision making
- Increased confidence amongst researchers in their studies

The main challenges were lack of resources and time.

Category: nature and extent of public involvement in research, impact of public involvement

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Vale, C., Tierney, J., Spera, N., Whelan, A., Nightingale, A. & Hanley, B. (2012) **Evaluation of patient involvement in a systematic review and meta-analysis of individual patient data in cervical cancer treatment**, Systematic Reviews, 1, 23.

Abstract

This article reports on the findings from an evaluation of patient involvement in a systematic review and meta-analysis of patient data in cervical cancer. The authors report that the greatest impact of the patient research partners was to identify a gap in the evidence around late side effects of treatment which led the researchers to get involved in an another research project. The research partners valued their involvement but one questioned how much they had been able to influence the meta-analysis. The authors conclude that future involvement in systematic reviews should be prioritised to projects where the greatest impacts could be achieved.

Category: impact of involvement

Van Bekkum, J. and Hilton, S. (2014) **UK research funding bodies' views towards public participation in health-related research decisions: An exploratory study**, BMC Health Services Research, 14, 318.

Abstract

This study aimed to explore the views of non-commercial heath-research funding bodies on public participation in funding decisions. The researchers interviewed at least two members of staff from ten different organisations. This included staff with responsibilities for public participation and staff involved in funding decision-making. Only two of these organisations involved the public in funding decision-making processes. Public involvement tended to be more active and embedded in organisations that fund applied health and social research than those funding biomedical and physical sciences. In these cases, the aim of the involvement was to access the expertise and knowledge of specific groups, for example people with experience of a health condition. Other organisations tended to have a narrower view of relevant expertise – limited to the technical knowledge of scientists. Some were concerned that the subjective views and values of the public might damage the integrity of science. The authors conclude that for research to have maximum impact on health care policy and practice there needs to be more sensitivity to different kinds of expertise and knowledge and the underlying values across science and society.

Category: nature and extent of public involvement in research

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Viswanathan, V., Eng, E., Gartlehner, G., Lohr, K., Griffith, D., Rhodes, S., Samuel-Hodge, C., Maty, S., Lux, L., Webb, L., Sutton, S., Swinson, T., Jackman, A. & Whitener, L. (2004) **Community-based participatory research (CBPR): Assessing the evidence,** Evidence Report/Technology Assessment No. 99. Rockville, MD: Agency for Healthcare Research and Quality.

Abstract
Aim: To carry out a systematic review of the literature relating to CBPR and its role in improving community health.

Methods: A group of experts including community research partners, researchers and funders helped shape the review, influencing the search terms and research questions.

Findings/recommendations: A review of the publications which reported on an evaluation of CBPR showed that community involvement influences the research process by:

- making research tools more culturally relevant
- helping test research tools - which improved their reliability
- sometimes changing the direction of the research or identifying priorities
- improving recruitment and retention of research participants
- carrying out surveys in the languages of the target groups
- increasing external validity

It also benefits the individuals involved as well as the communities by increasing their skills and capacity. In addition, community members tend to appreciate more of the long-term gains of research, in comparison with the short-term nuisance of data collection.

Disadvantages of CBPR were not frequently reported but included:
- introducing bias in recruitment
- decreased randomisation
- selection of a group of motivated groups not representative of the broader population

Many reports described the lengthy process of building partnerships between institutions and communities, but formal evaluation of this process was rare.

The authors also comment that researchers often publish their findings and their processes in separate articles. Otherwise they are forced to distil 'years of partnership development and collaboration into a few descriptive words in a small number of journals willing to publish this more descriptive evidence'. This means that information about the implementation of CBPR is often missing.

Category: impact of public involvement

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von Staa, A., Jedeloo, S., Latoru, J. & Trappenburg, M. (2010) **Exciting but exhausting: experiences with participatory research with chronically ill adolescents.** Health Expectations, 13(1), 95-107.

Abstract
Aim: This project explored the feasibility, benefits and limitations of involving chronically-ill adolescents as co-researchers. The aim was to evaluate hospital services for young people.

Methods: The adolescents were involved in developing a set of interview questions and interviewed each other and fellow patients at a disco held for this purpose. They did not take part in the data analysis although they were invited.

Findings/recommendations: The researchers conclude that it was difficult to find adolescents to get involved in the research, that the peer-interviewers did not probe deeply enough in their questioning and therefore the findings were limited. They also note that maintaining the young people's interest in involvement was difficult and the process was very resource intensive.

However the authors also note that the peer interviewers only received one afternoon of training and so were not very well-prepared. Most interviews only lasted 10 mins and took place in a noisy, crowded environment that prevented tape-recording. Typists transcribed the notes on the spot and may have missed important details and nuances.

The project did not therefore contribute any new insights to inform the design or evaluation of services. However, it did create a lot of interest from the media and health-providers both in the hospital and nationwide. This helped to increase hospital professionals' awareness of the healthcare needs and preferences of adolescents with chronic conditions.

Category: impact of public involvement

Walker, D. & Pandya-Wood, R. (2013) **Can research development bursaries for patient and public involvement have a positive impact on grant applications? A UK-based, small scale service evaluation**, Health Expectations doi: 10.1111/hex.12127 [Epub ahead of print].

Abstract

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
- 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.

Category: impact of public involvement

Walmsley, J. (2004) **Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research**, Nursing Inquiry, 11(1), 54-64.

Abstract

The author reflects on her experience of working with people with learning difficulties on health-related research, to draw out the lessons that could inform practice. She discusses the tensions between ensuring the research produces high-quality information and ensuring a high-quality involvement process. She also comments on accessibility issues, and the need to include those with the most severe impairments, rather than relying on the most able people with learning difficulties. She concludes that it is important to ensure involvement brings added value, given the high cost of doing it well.

Category: reflecting on public involvement in research

Walmsley, J. & Mannan, H. (2010) **Parents as co-researchers: A participatory action research initiative involving parents of people with intellectual disabilities in Ireland.** British Journal of Learning Disabilities, 37, 271-276.

Abstract

In this project, parents of people with intellectual disabilities were recruited and trained to facilitate focus groups of similar parents in Ireland. The aim was to learn about the parents' experiences to inform service providers about how they could support families better.

Having the parents as co-researchers made a difference to the way the focus group discussions developed by:

- being prepared to talk frankly about their own experiences, they created a sense of safety for others to follow
- taking a lead in initiating discussions they helped draw out important insights into people's experience of services

The co-researchers also contributed to planning the focus groups which helped maximise attendance. They also co-presented the findings to an invited audience of the Chief Executive Officers (CEOs) of local service providers. This gave them a sense of their collective power.

As a result of their experience two of the co-researchers talked about how they would like to sustain the momentum of the project by creating sustainable local groups of parents. They hoped this would enable parents to lead change in their own localities. One of the CEOs said they would be in favour of creating leadership training and opportunities for parents, to help bring about changes in attitude amongst service providers. However, at the time of writing, this had not yet been achieved.

The authors conclude that it might be helpful to plan for sustainability from the outset, as a way of enhancing the impact of this kind of research.

Category: impact of public involvement

Walter, I., Davies, H. & Nutley, S. (2003) **Increasing research impact through partnerships: evidence from outside health care,** Journal of Health Services Research and Policy 8(supplement 2), S2:58-S261.

Abstract
Aim: This paper summarises the findings of a review of research impact initiatives. This was international in scope and covered education, health care, criminal justice and social care literature. This paper focuses on findings from outside health care, to try to draw out learning for health.

Methods: A literature review of English language papers from 1990. It looked at the conceptual frameworks that underpin different research impact initiatives and evidence of their effectiveness.

Findings/recommendations: The authors found strong evidence that formalised collaborations between researchers and research users can encourage use of research. Partnerships are most effective when research users are involved at all stages of the research process, rather than just being involved in dissemination.
Partnerships can also make research usable in a wider context. The allocation of specific funds for dissemination and development and the inclusion of evidence of partnerships as one of the criteria for funding also led to an increase in the range and number of dissemination and implementation activities. The researchers conclude that partnerships can enhance the credibility of research amongst research users, thus promoting its use.

They summarise the benefits of partnership as described by researchers - these include the development of enhanced networks, increased understanding of the field and increased motivation. A number of barriers to partnership are also summarised.

Category: impact of public involvement, nature and extent of public involvement in research

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Ward, P., Thompson, J., Barber, R., Armitage, C., Boote, J., Cooper, C. & Jones, G. (2009) **Critical perspectives on 'consumer involvement' in health research.** Journal of Sociology, 46(1), 63-82.

Abstract
This paper discusses the findings from a study of UK researchers' experiences and views of consumer involvement in health research. Two main themes are discussed:

1. The 'know-do' gap which relates to the tensions between researchers' perceptions of the potential benefits of involvement and their actual practice.
2. One of the reasons for this 'know-do' gap - researchers' concerns about the validity of lay knowledge in relation to professional knowledge and the likelihood of disagreement.

Category: reflecting on public involvement in research

Warren, L., Cook, J., Clarke, N., Hadfield, P., Haywood-Reed, P., Millen, L., Parkinson, M., Robinson, J., Winfield, W. **(2003) Working with older women in research: some methods-based issues,** Quality in Ageing - Policy, Practice and Research, 4(4), 24-31.

Abstract
Aim: This paper describes a project in which older women from a range of communities collaborated with researchers to listen to the experiences of women aged 50+ from a

range of ethnic groups, with a particular focus on growing older, the services they used (or would like to use) and having a say.

Methods: The researchers ran a series of discussion groups with 100 older women from a range of communities in Sheffield. 10 older women were then recruited from three discussion groups and trained to interview individual members of the groups in more detail about their lives.

Findings/recommendations: The older women who acted as interviewers helped to identify key themes and to publicise the study. The authors state that the older women who acted as co-researchers "valued the intrinsic and not just the practical outcomes of the project. Learning from and supporting one another, realising that they were not alone; feeling valued, validated and important, and building confidence and motivation." A video has been made of the women's experiences of involvement, and poems and reflections from the women have been collected.

Category: impact of public involvement

Weinstein, J. (2006) **Involving mental health service users in quality assurance,** Health Expectations, 9, 98-109.

Abstract
Aim: To compare the process and outcomes of two different approaches to engaging mental health service users in the quality assurance (QA) process. QA involves service users in evaluation and service development.

Methods: The author reviewed the documents from two QA reviews of the mental health day centre including the survey tools, service user responses and final reports. One was a traditional inspection carried out in 1998 and the other was a collaborative project with a user-led QA agenda carried out in 2000.

Findings/recommendations: The first QA process had less ownership from service users and staff and simply demonstrated that the services met required standards.

The second focused on different priorities, developed a new approach to seeking users' views and achieved a higher response rate. Because staff and users had worked together on the second review, they were more willing to work in partnership to implement the action plan to improve the service.

Category: impact of public involvement

Wicks, P. (2014) **Could digital patient communities be the launch pad for patient-centric trial design**? Trials, 15, 172.

Abstract
The author suggests that digital technology could be used as a way of involving large numbers of patients throughout a clinical trial. He reports on recent examples where online communities of patients have shared data informally, and suggests such a mechanism is used to deliver the benefits of involvement for clinical trial design.

Category: reflecting on public involvement in research

Williams, V., Simons, K. & Swindon People First Research Team (2005) **More researching together: the role of nondisabled researchers working with People First members,** British Journal of Learning Disabilities, 33, 6-14.

Abstract
This paper reflects on the role of a research supporter. As a non-disabled researcher, one of the authors worked as a supporter to a team of three researchers with learning difficulties, on a project about direct payments. She comments that this role is not always easy and a supporter needs to learn how to step back and find ways for researchers with learning difficulties to do things for themselves.

She reviews how the project progressed, how her role developed over time and what she learnt from the experience. A key issue was that of empowerment and the realisation that power cannot be handed from one person to another.

She concludes that this type of research is new and different: it does not draw on any existing model as it crucially depends on the identity of researchers as people with learning difficulties.

She recommends that all parties in any project of this kind remain vigilant about issues of power and control. The research supporter's role is extremely sensitive in this respect.

Category: reflecting on public involvement in research

Williamson, T., Brogden, J., Jones, E. & Ryan, J. (2010) **Impact of public involvement in research on quality of life and society: a case study of research career trajectories.** International Journal of Consumer Studies, 34(5), 551-557.

Abstract
Aim: This case study describes the research careers of two lay researchers who were

involved in a Big Lottery funded study of loneliness and isolation among older people.

Methods: The two lay researchers made a difference to the design and conduct of the initial study by improving the research documentation, influencing data collection and analysis, and contributing to the writing up and dissemination.

Findings/recommendations: The research team concluded that the involvement of the lay researchers enhanced the quality, validity and relevance of the study. The lay researchers also describe the impact of involvement on their own quality of life, particularly in terms of developing new skills and gaining greater self-confidence.

Their involvement also had an impact on the wider community. The participants reported they had benefited from taking part, and in particular they valued someone listening to their stories and taking time to listen. Based on the advice of the lay researchers, an event used to recruit participants made sure people were offered useful information about local services and health issues, so that community members benefited as well as the researchers.

The two lay researchers have gone on to get involved in much larger research projects. They have also used their new skills and confidence to act as advocates for the greater involvement of older people in initiatives aiming to improve services.

Category: impact of public involvement

Williamson, T., Kenney, L., Barker, A., Cooper, G., Good, T., Healey, J., Heller, B., Howard, D., Matthews, M., Prenton, S., Ryan, J. & Smith, C. (2014) **Enhancing public involvement in assistive technology design research**, Disability and Rehabilitation Assistive Technology [Epub ahead of print]

Abstract
Aim: To assess the impact of following good practice for public involvement within an assistive technology (AT) research project, and to assess the impact of the involvement.

Methods: Critical reflection and a within project evaluation. Individual and group interviews were carried out with lay members of the study advisory group and the research team members.

Findings/ recommendations: The advisory group was set up and supported by facilitator with extensive experience of good practice in public involvement. The group reported that the facilitation made all the processes much smoother and the overall approach used was exemplary.

Although the researchers were initially sceptical about the value of involvement, their attitudes became more positive after witnessing its impact first-hand. They reported positive benefits of the involvement in terms of improvements to the new device (which aimed to assist people to walk after a stroke). The involvement increased the researchers' understanding of the day-to-day use of the device, which meant they were better equipped to make it useful to patients. The advisory group also fed into the development of a clinical trial of the new device, which the researchers believe improved the recruitment and retention of trial participants.

The patients involved reported that involvement had improved their confidence, skills and self-esteem and that they valued being able to contribute to the care of others. The authors conclude that other AT researchers should consider involving patients/ the public if they want to develop a product that is 'fit for purpose' and enhance the design of their clinical studies.

Category: impact of public involvement

Wood, M. (2003) **Disability, participation and welfare to work in Staffordshire,** Journal of Integrated Care, 11(2), 43-48.

Abstract

Aim: To survey the views of disabled people on barriers to employment and strategies to overcome them.

Methods: A partnership was established between the Steering Group overseeing Staffordshire's Welfare to Work Joint Investment Plan (JIP) and Staffordshire University. They worked together to promote the participation of disabled people as researchers in carrying out research to support the development of the JIP.

A total of 17 disabled people were trained on the Consumers as Researchers course at the University over two years. They set priorities, decided on methods, carried out surveys and compiled and presented the results.

Findings/recommendations: The course was a learning process for all involved in the partnership. The tutors learnt how to better adapt their teaching to meet the different students' needs. They also realised they may need to adapt the course to make it more accessible for people with learning difficulties, and better meet the needs of people with mental health problems.

The students reported that they:

- learnt about each other's disabilities
- increased their self-confidence
- had some success in securing longer-term employment and accessing higher education

The user researchers presented their findings at a conference. One of the most powerful aspects was that the researchers spoke from personal experience.

Through modelling good practice, the research project itself helped to raise awareness of the social model of disability and the wider JIP agenda. It gave disabled people a greater voice to influence employment practice and service development. The results were fed into the JIP which helped to raise awareness amongst employers, employees and service providers of the need for long-term change.

Category: impact of public involvement

Wright, D., Corner, J., Hopkinson, J. & Foster, C. (2006) **Listening to the views of people affected by cancer about cancer research: an example of participatory research in setting the cancer research agenda,** Health Expectations, 9(1), 3-12.

Abstract
Aim: To explore the views people affected by cancer have about research and to identify their research priorities.

Methods: People affected by cancer were asked about their views on research through focus groups held across the UK. A participatory approach was used to involve patients and carers in the design and conduct of the study. Some also received training and support to co-facilitate the focus groups and analyse the data.

Findings/recommendations: Working with a reference group of patients and carers had a positive impact on the design of the study, the plans for feedback for participants in the study, the recruitment strategy, the patient information sheet and the questions asked at the focus group meetings. Involving patients and carers as co-researchers also greatly improved the effectiveness of the focus group discussions. The participatory approach thus strengthened the relevance and appropriateness of the research findings and methods.

Category: impact of public involvement

Wright, D., Foster, C., Amir, Z., Elliott, J. & Wilson, R.(2010) **Critical appraisal guidelines for assessing the quality and impact of user involvement in research.** Health Expectations, 13(4), 359–368.

Abstract
The authors have developed guidelines for appraising the quality and impact of user involvement in published papers and grant applications. These guidelines are based on a review of the literature and experiences from studies involving cancer patients and

carers in the design and conduct of research.

Category: reflecting on public involvement in research

Wright, D., Hopkinson, J., Corner, J. & Foster, C. (2006) **How to involve cancer patients at the end of life as co-researchers**, Palliative Medicine, 20, 821-827.

Abstract
Aim: To explore cancer patients' views and attitudes towards cancer research, and to identify their research priorities.

Methods: The study was informed by participatory research approaches. Patients and carers worked with the experienced researchers as equal partners. 15 patient and carer co-researchers were involved in the study, including two patients at the day hospital of a hospice. 17 focus groups were held.

Findings/recommendations: The authors briefly report the main benefits of working with patients and carers as co-researchers - the development of a more accessible patient information sheet and set of topics for the focus group discussions. The patient and carer researchers also used their local knowledge to respond to and prompt participants during the focus groups. However, the main focus of this paper is on the practical, ethical and methodological challenges faced as a result of working with cancer patients. Under each of these three headings, the authors report on the challenges they faced, and their attempts to overcome them. A series of 8 recommendations to other researchers using similar methods with palliative care service users are then given.

Category: impact of public involvement

Wyatt, K., Carter, M., Mahtani, V., Barnard, A., Hawton, A. & Britten, N. (2008) **The impact of consumer involvement in research: An evaluation of consumer involvement in the London Primary Care Studies Programme,** Family Practice, 25(3), 154-161.

Abstract
Aim: To evaluate consumer involvement in the 11 studies within the London Primary Care Studies Programme and understand the impact on research processes and outcomes.

Methods: A multi-method approach was used, including surveys, interviews, focus groups, observation and scrutiny of written documents. The evaluation team included a service user researcher.

Findings/recommendations: Consumers had an impact on the various projects in:

- the initial design of the study
- recruitment of research subjects
- developing data collection tools and collecting the data
- the analysis and findings
-

The greatest impacts of involvement were in the projects that sought to ensure service users and carers were partners throughout the research.

Category: impact of public involvement

Wykes, T. (2014) **Great expectations for participatory research: What have we achieved in the last ten years?** World Psychiatry, 13(1), 24-27.

Abstract
The author reflects on the recent history of involvement of mental health service users in research. She highlights the potential for involvement to identify research priorities, boost recruitment to clinical trials, to develop relevant outcome measures and define good quality treatments. She suggests that involvement should be expanded to the early stages of drug development, and not be limited to clinical research.

Category: reflecting on public involvement in research

Wykes, T. (2003) **Blue skies in the Journal of Mental Health? Consumers in research,** Journal of Mental Health, 12(1), 1-6.

Abstract
This article provides the author's personal view of the positive outcomes of service user involvement in research.

The main benefits that she describes include:

- improving the scientific quality of the research by changing research questions
- ensuring that outcomes measures more closely relate to what's important to service users
- developing outcome measures that more directly reflect meaningful changes to everyday life and better capture the complexities of the effects of a treatment
- adapting research proposals and methodology to better reflect the interests of service users e.g. running qualitative studies of users' views of treatments

alongside quantitative clinical trials that focus on overly simplistic clinical outcome measures.

Category: impact of public involvement

Index

Categories:
New references added since Bibliography 4 are highlighted in grey ▨
N = Nature and extent of public involvement in research eg mapping
I = Impact of public involvement in research
R = Reflections on public involvement in research
A = Service user, carer or member of the public author(s)

Publications	N	I	R	A	page
Andejeski, Y., Breslau, E., Hart, E., Lythcott, N., Alexander, L., Rich, I., Bisceglio, I., Smith, H. & Visco, F. (2002) **Benefits and drawbacks of including consumer reviewers in the scientific merit review of breast cancer research,** Journal of Women's Health and Gender-Based Medicine, 11(2), 119-136.		x		x	**6 - 7**
Angell, K., Kreshka, M., McCoy, R., Donnelly, P., Turner-Cobb, J., Graddy, K., Kraemer, H. & Koopman, C. (2003) **Psychosocial intervention for rural women with breast cancer,** Journal of General Internal Medicine, 18, 499-507.		x		x	**7 - 8**
Arain, M., Pyne, S., Thornton, N., Palmer, S. & Sharma, R. (2013) **Consumer involvement in cancer research: example from a Cancer Network**, Health Expectations, doi: 10.1111/hex.12143. [Epub ahead of print]		x		x	**8**
Association of Medical Research Charities (2006) **Briefing Paper: Using lay reviewers in the peer review process,** London: AMRC.	x				**8 - 9**
Avard, D., Jean, M., Gregoire, G. & Page, M. (2010) **Public involvement in health genomics: the reality behind the policies,** International Journal of Consumer Studies, 34(5), 508-524.	x				**9**
Bailey, S., Boddy, K., Briscoe, S. & Morris, C. (2014) **Involving disabled children and young people as partners in research: a systematic review**, Child: care, health and development, doi: 10.1111/cch.12197 [Epub ahead of print].		x		x	**9 - 10**
Barber, R., Beresford, P., Boote, J., Cooper, C. & Faulkner, A. (2011) **Evaluating the impact of service user involvement on research: a prospective study,** International Journal of Consumer Studies, 35, 609-615.		x	x	x	**10**
Barber, R., Boote, J., Parry, G., Cooper, C., Yeeles, P. & Cook, S. (2012) **Can the impact of public involvement on research be evaluated? A mixed methods study,** Health Expectations 15(3), 229-41.			x		**11**
Barnard, A., Carter, M., Britten, N., Purtell, R., Wyatt, K. & Ellis, A. (2005) **The PC11 Report. An evaluation of consumer involvement in the London Primary Care Studies Programme,** Exeter, UK: Peninsula Medical School.		x		x	**11 - 12**

Publications	**N**	**I**	**R**	**A**	**page**
Bastian, H. (2005) **Editorial: Consumer and researcher collaboration in trials: filling the gaps,** Clinical Trials, 2(1), 3-4.			x		**12**
Becker, S., Sempik, J. & Bryman, A. (2010) **Advocates, agnostics and adversaries: Researchers' perceptions of service user involvement in social policy research,** Social Policy & Society, 9(3), 355-366.	x				**13**
Beer, D., Keeble, P., MacInnes, D., Rees, D. & Reid, L. (2005) **Development of a questionnaire to measure service user satisfaction within in-patient forensic services - The Forensic Satisfaction Scale,** Liverpool: National Programme on Forensic Mental Health R&D.		x		x	**13 - 14**
Bench, S., Day, T. & Griffiths, P. (2013) **Effectiveness of critical care discharge information in supporting early recovery from critical illness,** Critical Care Nurse, 33(3), 41-52.	x				**14**
Bengtsson-Tops, A. & Svensson, B. (2010) **Mental health users' experiences of being interviewed by another user in a research project. A qualitative study.** Journal of Mental Health 19(3),234-242.		x			**14 - 15**
Beresford, P. (2005) **Developing the theoretical basis for service user/survivor-led research and equal involvement in research,** Epidemiologia e Psichiatria Sociale, 14(1), 4-9.			x	x	**15**
Beresford, P. (2007) **The role of service user research in generating knowledge-based health and social care: From conflict to contribution,** Evidence & Policy, 3(3), 329-341.		x	x	x	**16**
Beresford, P. (2002) **User involvement in research and evaluation: Liberation or regulation?** Social Policy & Society, 1(2), 95-105.			x	x	**16**
Bindels, J., Baur, V., Cox, K., Heijing, S. and Abma, T. (2014) **Older people as co-researchers: A collaborative journey**, Ageing & Society, 34(6), 951-973.		x		x	**17**
Bird, D., Culley, L. & Lakhanpaul, M. (2013) **Why collaborate with children in health research: an analysis of the risks and benefits of collaboration with children**, Archives of Disease in Childhood: Education & Practice Edition, 98(2), 42-48.			x		**17**

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Blackburn, H., Hanley, B. and Staley,K. (2010) **Turning the pyramid upside down: examples of public involvement in social care research,** Eastleigh: INVOLVE.	x	x	x	x	**18**
Blair, T. & Minkler, M. (2009) **Participatory action research with older adults: Key principles in practice.** The Gerontologist, 49(5), 652-662.		x	x		**18**
Boaz, A., Biri, D. & McKevitt, C. (2014) **Rethinking the relationship between science and society: Has there been a shift in attitudes to patient and public involvement and public engagement in science in the United Kingdom?** Health Expectations, doi: 10.1111/hex.12295 [Epub ahead of print].	x		x		**18 - 19**
Boote, J., Baird, W. & Beecroft, C. (2010) **Public involvement at the design stage of primary health research: A narrative review of case examples,** Health Policy, 95(1), 10-23.		x	x		**19**
Boote, J. Baird, W. & Sutton, A. (2011) **Public involvement in the systematic review process in health and social care: A narrative review of case examples,** Health Policy, 102(2-3), 105-116.		x			**20**
Boote, J., Baird, W. & Sutton, A. (2011) **Public involvement in the design and conduct of clinical trials: A review,** The International Journal of Interdisciplinary Studies, 5(11), 91-106.		x			**20**
Boote, J., Baird, W. & Sutton, A. (2012) **Involving the public in systematic reviews: a narrative review of organisational approaches and eight case examples**, Journal of Comparative Effectiveness Research, 1 (5), 1-12.		x			**20 - 21**
Boote, J., Barber, R. & Cooper, C. (2006) **Principles and indicators of successful consumer involvement in NHS research: Results of a Delphi study and subgroup analysis,** Health Policy, 75, 280-297.			x		**21**
Boote, J., Dalgleish, M., Freman, J., Jones, Z., Miles, M. & Rodgers, H. (2014) **'But is it a question worth asking?' A reflective case study describing how public involvement can lead to researchers' ideas being abandoned,** Health Expectations, 17(3), 440-51.		x		x	**21 - 22**

Publications	**N**	**I**	**R**	**A**	**page**
Boote, J., Telford, R. & Cooper C. (2002) **Consumer involvement in health research: a review and research agenda,** Health Policy, 61(2), 213-236.			x		**22**
Boote, J., Twiddy, M., Baird, W., Birks, Y., Clarke, C. & Beever, D. (2013) **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),** Health Expectations, doi: 10.1111/hex.12130. [Epub ahead of print]		x			**22 - 23**
Boote, J., Wong, R. & Booth, A. (2012) **'Talking the talk or walking the walk' A bibliometric review of the literature on public involvement in health research published between 1995 and 2009**, Health Expectations, doi: 10.1111/hex.12007 [Epub ahead of print]	x				**23**
Boxall, K. and Beresford, P. (2013) **Service user research in social work and disability studies in the United Kingdom**, Disability & Society 28 (5), 587-600.	x			x	**23**
Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C. & Suleman, R. (2014) **Mapping the impact of patient and public involvement in health and social care research: a systematic review**, Health Expectations, 17(5) pp. 637–650.		x		x	**24**
Brett, J., Staniszewska, S., Mockford, C., Seers, K., Herron-Marx, S. & Bayliss, H. (2010) **The PIRICOM Study: A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research,** London: UKCRC.		x		x	**24**
Broad, B. & Saunders, L. (1998) **Involving young people leaving care as peer researchers in a health research project: A learning experience,** Research, Policy and Planning, 16(1), 1-9.		x			**25**
Broerse, J., Zweekhorst, M., van Rensen, A. & de Haan, M. (2009) **Involving burn survivors in agenda setting on burn research: An added value?** Burns, 36(2), 217-231.		x		x	**26**
Brownlie, J., Anderson, S. & Ormston, R. (2006) **Children as researchers,** Edinburgh: Scottish Executive Education Department.	x				**26 - 27**

Publications	**N**	**I**	**R**	**A**	**page**
Bryant, L. & Beckett, J. (2006) **The practicality and acceptability of an advocacy service in the emergency department for people attending following self-harm,** Leeds: Academic Unit of Psychiatry, University of Leeds.		x		x	**27 - 28**
Burrus, B., Liburd, L. & Burroughs, A. (1998) **Maximising participation by black Americans in population-based diabetes research: The project DIRECT pilot experience,** Journal of Community Health, 23(1), 15-27.		x			**28 - 29**
Butcher, L. (2005) **No home, no job,** CareandHealth MAGAZINE, May 10 - May 16, 30.		x			**29**
Caldon, L., Marshall-Cook, H., Speed, G., Reed, M. & Collins, K. (2010) **Consumers as researchers - innovative experiences in UK National Health Service Research.** International Journal of Consumer Studies, 34(5), 547-550.		x		x	**29 - 30**
Callard, F., Rose, D. & Wykes, T. (2012) **Close to the bench as well as at the bedside: involving service users in all phases of translational research,** Health Expectations, 15(4), 389-400.			x	x	**30**
Caron-Flinterman, F. (2005) **A new voice in science: Patient participation in decision-making on biomedical research,** Zutphen: Wöhrmann Print Services.			x		**30**
Caron-Flinterman, J., Broerse, J. & Bunders, J. (2005) **The experiential knowledge of patients: a new resource for biomedical research?** Social Science & Medicine, 60, 2575-2584.		x			**31**
Carter, P., Beech, R., Coxon, C., Thomas, M. & Jinks, C. (2013) **Mobilising the experiential knowledge of clinicians, patients and carers for applied health-care research**, Contemporary Social Science: Journal of the Academy of Social Sciences, 8(3), 307-320.		x	x		**31**
Cashman, S., Adeky, S., Allen, A., Corburn, J., Israel, B., Montano, J., Rafelito, A., Rhodes, S., Swanston, S., Wallerstein, N. & Eng, E. (2008) **The power and the promise: Working with communities to analyse data, interpret findings and get to outcomes,** American Journal of Public Health, 98(8), 1407-1417.		x		x	**32**

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Cayton, H. & Hanley, B. (2001) **Improving research through consumer involvement,** M. Baker & S. Kirk (Eds.) Research and development for the NHS (pp 195-207). Oxford: Radcliffe Publishing Ltd.		x			**32**
Chalmers, I. (1995) **What do I want from health research and researchers when I am a patient?** British Medical Journal, 310, 1315-1318.		x	x		**33**
Chambers, R., O'Brien, L., Linnell, S. & Sharp, S. (2004) **Why don't health researchers report consumer involvement?** Quality in Primary Care, 12, 151-157.	x				**33 - 34**
Chappell, A. (2000) **Emergence of participatory methodology in learning difficulty research: Understanding the context**, British Journal of Learning Disabilities 28, 38-43.			x		**34**
Clark, C., Scott, E., Boydell, K. & Goering, P. (1999) **Effects of client interviewers on client-reported satisfaction with mental health services**, Psychiatric Services, 50(7), 961-963.		**x**			**34**
Clark, M., Glasby, J. & Lester, H. (2004) **Cases for change: User involvement in mental health services and research,** Research Policy and Planning, 22(2), 31-38.		x			**35**
Collins, K., Boote, J., Ardron, D., Gath, J., Green, T., Ahmedzai, S.; on behalf of the NTCRN CRP. (2014) **Making patient and public involvement in cancer and palliative research a reality: academic support is vital for success**, BMJ Supportive & Palliative Care doi:10.1136/bmjspcare-2014-000750 [Epub ahead of print]	**x**		x	x	**35 - 36**
Cook, T. (2012) **Where participatory approaches meet pragmatism in funded (health) research: The challenge of finding meaningful spaces,** Forum: Qualitative Social Research, 13(1), Art. 18.			x		**36**
Coren, E. (2007) **Collection of examples of service user and carer participation in systematic reviews,** London: SCIE.		x			**36 - 37**

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Corneli, A., Piwoz, E., Bentley, M., Moses, A., Nkhoma, J., Adair, L., Mtimuni, B., Ahmed, Y., Duerr, A., Kazembe, P., van der Horst, C. & the UNC Project BAN study (2007) **Involving communities in the design of clinical trial protocols: The BAN study in Lilongwe, Malawi.** Contemporary Clinical Trials, 28(1), 59-67.		x		x	**37**
Cornes, M., Peardon, J., Manthorpe, J. & The 3YO Project Team. (2008) **Wise owls and professors: the role of older researchers in the review of the National Service Framework for Older People.** Health Expectations, 11(4), 409-417.		x	x	x	**37 - 38**
Cotterell, P. (2007) **Exploring the value of service user involvement in data analysis: 'Our interpretation is about what lies below the surface'.** Educational Action Research, 16(1), 5-17.		x	x		**38 - 39**
Cotterell, P., Clarke, P., Cowdrey, D., Kapp, J., Paine, M. & Wynn, R. (2007) **Becoming involved in research: a service user research advisory group.** Chapter 11. In: Creative Engagement in Palliative Care, (Ed: Jarrett, L.), Radcliffe Publishing Ltd.		x		x	**39**
Coupland, H., Maher, L., Enriquez, J., Le, K., Pacheco, V., Pham, A., Carroll, C., Cheguelman, G., Freeman, D., Robinson, D. & Smith, K. (2005) **Clients or colleagues? Reflections on the process of participatory action research with young injecting drug users,** International Journal of Drug Policy, 16, 191-198.		x		x	**40**
Davies, K., Gray, M. & Webb, S. (2014) **Putting the parity into service-user participation: An integrated model of social justice**, International Journal of Social Welfare, 23(2), 119-127.			x		**40 - 41**
Davies, R & Evans, D. (2010) **Public involvement in research: How can organisations collaborate to improve involvement?** Bristol: University of the West of England.	x	x		x	**41**
Davies, S. & Nolan, M. (2003) **Editorial: Nurturing research partnerships with older people and their carers: Learning from experience,** Quality in Ageing - Policy, Practice and Research, 4(4), 2-5.		x			**41 - 42**

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Davila-Seijo, P., Hernandez-Martin, A., Morcillo-Makow, E., de Lucas, R., Dominguez, E., Romero, N., Monros, E., Feito, M., Carretero, L., Aranegui, B. & Garcia-Doval, I. (2013) **Prioritisation of therapy uncertainties in Dystrophic Epidermolysis Bullosa: where should research direct to? An example of priority setting partnership in very rare disorders**, Orphanet Journal of Rare Diseases, 8, 61.		x		x	**42**
Denis, J. & Lomas, J. (2003) **Convergent evolution: the academic and policy roots of collaborative research,** Journal of Health Services Research and Policy, 8 (supplement 2), S2:1-S2:6.			x		**42 - 43**
Dewar, B.J. (2005) **Beyond tokenistic involvement of older people in research - a framework for future development and understanding,** International Journal of Older People Nursing in association with Journal of Clinical Nursing, 14(3a), 48-53.		x	x		**43**
Dickson, G. & Green, K. (2001) **Participatory action research: Lessons learned with Aboriginal grandmothers,** Health Care for Women International, 22(5), 471-482		x			**44**
Dobbs, L. & Moore, C. (2002) **Engaging communities in area-based regeneration: The role of participatory evaluation,** Policy Studies, 23(3/4), 157-171		x			**45**
Dona, G. (2006) **Children as research advisers: Contributions to a 'methodology of participation' in researching children in difficult circumstances,** International Journal of Migration, Health and Social Care, 2(2), 22-34.		x			**45 - 46**
Donovan, J., Mills, N., Smith, M., Brindle, L., Jacoby, A., Peters, T., Frankel, S., Neal, D. & Hamdy, F. (2002) **Improving design and conduct of randomised controlled trials by embedding them in qualitative research: ProtecT (prostate testing for cancer and treatment) study,** British Medical Journal, 325, 766-770.		x			**46**
Dyer, S. (2004) **Rationalising public participation in the health service: The case of research ethics committees,** Health & Place, 10, 339-348.			x		**46 - 47**
Edwards, V., Wyatt, K., Logan, S. & Britten, N. (2011) **Consulting parents about the design of a randomised controlled trial of osteopathy for children with cerebral palsy,** Health Expectations, 14(4), 429-38.		x			**47**

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Elberse, J., Pittens, C., Buning, T. & Broerse, J. (2012) **Patient involvement in a scientific advisory process: Setting the research agenda for medical products**, Health Policy, 107(2-3), 231-42.		x			**47**
Elliott, E., Watson, A. & Harries, U. (2002) **Harnessing expertise: involving peer interviewers in qualitative research with hard-to-reach populations,** Health Expectations, 5, 172-178.		x			**48**
Ennis, L. & Wykes, T. (2013) **Impact of patient involvement in mental health research: longitudinal study**, The British Journal of Psychiatry, 203(5), 381-6.		x			**48 - 49**
Entwistle, V., Renfrew, M., Yearley, S., Forrester, J. & Lamont, T. (1998) **Lay perspectives: advantages for health research,** British Medical Journal, 316, 463-466.			x		**49**
Evans, C. & Fisher, M. (1999) **Collaborative evaluation with service users: Moving towards user-controlled research,** Ian Shaw & Joyce Lishman (Eds.), Evaluation and Social Work Practice (pp101-117), London: Sage.		x	x	x	**49 - 50**
Evans, C. & Fisher, M. (1999) **User controlled research and empowerment,** W. Shera & L. Wells (Eds.), Empowerment practice in social work: Developing richer conceptual foundations (pp 348-369). Toronto: Canadian Scholars Press.		x	x	x	**50**
Evans, D. (2014) **Patient and public involvement in research in the English NHS: A documentary analysis of the complex interplay of evidence and policy**, Evidence and Policy, 10(3), 361-77.			x		**51**
Evans, J., Rose, D., Flach, C., Csipke, E., Glossop, H., McCrone, P., Craig, T. & Wilkes, T. (2012) **VOICE: Developing a new measure of service users' perceptions of inpatient care, using a participatory methodology,** Journal of Mental Health, 21(1), 57-71.		x		x	**51**
Evans, I., Thornton, H. & Chalmers, I. (2006) **Testing treatments: Better research for better healthcare,** London: British Library. (ISBN 071234909X)		x		x	**52**

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Fairbother, P., McCloughan, L., Adam, G., Brand, R., Brown, C., Watson, M., Cotter, N., Mackellaig, J. & McKinstry, B. (2013) **Involving patients in clinical research: the Telescot Patient Panel**, Health Expectations doi: 10.1111/hex.12132. [Epub ahead of print]		x		x	**52**
Faulkner, A. (2004) **Capturing the experiences of those involved in the TRUE project: A story of colliding worlds,** Eastleigh: INVOLVE.		x		x	**53**
Faulkner, A. (2007) **Beyond our expectations: A report of the experiences of involving service users in forensic mental health research,** National Forensic Mental Health NHS Research and Development Programme.		x		x	**53 - 54**
Faulkner, A. (2010) **Changing our worlds: Examples of user-controlled research in action**, Eastleigh: INVOLVE.	x	x	x	x	**54**
Fisher, M. (2002) **The role of service users in problem formulation and technical aspects of social research,** Social Work Education, 21(3), 305-312.		x	x		**54 - 55**
Forbes, L., Nicholls, C., Linsell, L., Graham, J., Tompkins, C. & Ramirez, A. (2010) **Involving users in the design of a randomised controlled trial of an intervention to promote early presentation in breast cancer: qualitative ,** BMC Medical Research Methodology, 10, 110-117.		x			**55**
Froggatt, K., Preston, N., Turner, M. & Kerr, C. (2014) **Patient and public involvement in research and the Cancer Experiences Collaborative: Benefits and challenges**, BMJ Supportive & Palliative Care doi:10.1136/bmjspcare-2013-000548.		x			**55 - 56**
Fudge, N., Wolfe, C. & McKevitt, C. (2007) **Involving older people in health research,** Age and Ageing, 36, 492-500.	x		x		**56**
Gagnon, M., Desmartis, M., Lepage-Savary, D., Gagnon, J., St-Pierre, M., Rhainds, M., Lemieux, R., Gauvin, F., Pollender, H. & Légaré, F. (2011) **Introducing patients' and the public's perspectives to health technology assessment: A systematic review of international experiences**, International Journal of Technology Assessment in Health Care, 27(1), 31-42.	x	x			**57**

Publications	**N**	**I**	**R**	**A**	**page**
Gamble, C., Dudley, L., Allam, A., Bell, P., Goodare, H., Hanley, B., Preston, J., Walker, A., Williamson, P. & Young, B. (2014) **Patient and public involvement in the early stages of clinical trial development: A systematic cohort investigation**, BMJ Open, 4, e005234.	x			x	**57 - 58**
Gauvin, F., Abelson, J., Giacomini, M., Eyles, J. & Lavis J. (2011) **Moving cautiously: Public involvement and the health technology assessment community**, International Journal of Technology Assessment in Health Care, 27(1), 43-9.	x				**58**
Gauvin, F., Abelson, J., Giacomini, M., Eyles, J. & Lavis, J. (2010) **"It all depends": Conceptualising public involvement in the context of health technology assessment agencies,** Social Science & Medicine, 70(10), 1518-1526.	x		x		**58 - 59**
Gillard, S., Borschmann, R., Turner, K., Goodrich-Purnell, N., Lovell, K. & Chambers, I. (2010) **'What difference does it make?' Finding evidence of the impact of mental health service user researchers on research into the experiences of detained psychiatric patients,** Health Expectations, 13(2), 185-194.		x		x	**59 - 60**
Gillard, S., Simons, L., Turner, K., Lucock, M. & Edwards, C. (2012) **Patient and public involvement in coproduction of knowledge: Reflection on the analysis of qualitative data in a mental health study,** Qualitative Health Research, 22(8),1126-37.		x	x	x	**60**
Gillard, S. & Stacey, E. (2005) **All talk: Experiencing user-led research,** A Life in the Day, 9(2), 27-30.		x		x	**61**
Godfrey, M. (2004) **More than 'involvement'. How commissioning user interviewers in the research process begins to change the balance of power,** Practice, 16(3), 223-231.			x		**61 - 62**
Gooberman-Hill, R., Jinks, C., Boucsas, S., Hislop, K., Dziedzic, K., Rhodes, C., Burston, A. & Adams, J. (2013) **Designing a placebo device: Involving service users in clinical trial design**, Health Expectations, 16(4), e100-10.		x			**62**
Goodare, H. & Lockwood, S. (1999) **Involving patients in clinical research,** British Medical Journal, 319, 724-725.			x	x	**62**

Publications	**N**	**I**	**R**	**A**	**page**
Goodman, C., Mathie, E., Cowe, M., Mendoza, A., Westwood, D., Munday, D., Wilson, P., Crang, C., Froggatt, K., Illiffe, S., Manthorpe, J., Gage, H. & Barclay, S. (2011) **Talking about living and dying with the oldest old: Public involvement in a study on end of life care in care homes,** BMC Palliative Care, 10, 20.		x		x	**63**
Gradinger, F., Britten, N., Wyatt, K., Froggatt, K., Gibson, A., Jacoby, A., Lobban, F., Mayes, D., Snape, D., Rawcliffe, T. & Popay, J. (2013) **Values associated with public involvement in health and social care research: a narrative review**, Health Expectations, doi: 10.1111/hex.12158. [Epub ahead of print].			x		**63 - 64**
Gray, B., Larsen, J. & Faulkner, A. (2013) **Third sector facilitation of lived experience in research: A case study of service user and carer involvement in the PRIMROSE project**, Journal of Mental Health Training, Education and Practice, 8(3), 141-151.		x		x	**64**
Griffiths, K., Jorm, A. & Christensen, H. (2004) **Academic consumer researchers: a bridge between consumers and researchers,** Australian and New Zealand Journal of Psychiatry, 384, 191-196.			x		**65**
Guarino, P., Elbourne, D., Carpenter, J. & Peduzzi, P. (2006) **Consumer involvement in consent document development: a multicenter cluster randomised trial to assess study participants' understanding,** Clinical Trials, 3(1), 19-30.		x			**65 - 66**
Hall, V. (2009) **Reflections on engaging in participatory research,** Evidence Based Midwifery, 7(2), 40-45			x		**66**
Hamilton, S., Pinfold, V., Rose, D., Henderson, C., Lewis-Holmes, E., Flach, C. & Thornicroft, G. (2011) **The effect of disclosure of mental illness by interviewers on reports of discrimination experienced by service users: A randomised study**, International Review of Psychiatry, 23(1), 47-54.		x			**66 - 67**
Hanley, B., Morris, C. & Staley, K. (2009) **An evaluation of the process and impact of patient and public involvement in the advisory groups of the UK Clinical Research Collaboration.** London: UK Clinical Research Collaboration.		x		x	**67**
Hanley, B., Truesdale, A., King, A., Elbourne, D. & Chalmers, I. (2001) **Involving consumers in designing, conducting and interpreting randomised controlled trials: questionnaire survey,** British Medical Journal, 322, 519-523.	x	x			**68**

Publications	N	I	R	A	page
Happell, B. & Roper, C. (2007) **Consumer participation in mental health research: articulating a model to guide practice.** Australasian Psychiatry, 15(3), 237-241.			x	x	**68**
Harding, E., Brown, D., Hayward, M, & Pettinari, C. (2010) **Service user perceptions of involvement in developing NICE mental health guidelines: A grounded theory study.** Journal of Mental Health, 19(3), 249-257.		x			**69**
Heritage N., Barnes, E., Perry, B., Nelson, B., Shaw M. & Matata, B. (2010) **Evaluation of the Liverpool Cardiac Phase-4 Rehabilitation Programme: A service user-led community-based investigation**, International Journal of Medicine and Medical Sciences, 2(6), 178–183.			x		**69**
Hewlett, S., de Wit, M., Richards, P., Quest, E., Hughes, R., Heiberg, T., Kirwan, J. (2006) **Patients and professionals as research partners: Challenges, practicalities and benefits,** Arthritis & Rheumatism, 55(4), 676-680.		x	x	x	**69 - 70**
Hofmann, D., Ibrahim, F., Rose, D., Scott, D., Cope, A., Wykes, T. & Lempp, H. (2013), **Expectations of new treatment in rheumatoid arthritis: developing a patient-generated questionnaire**, Health Expectations doi: 10.1111/hex.12073. [Epub ahead of print]		x			**70**
Holmes, W., Stewart, P., Garrow, A., Anderson, I. & Thorpe, L. (2002) **Researching Aboriginal health: Experience from a study of urban young people's health and well-being,** Social Science & Medicine, 54(8), 1267-1279.		x			**70 - 71**
Howe, A., Delaney, S., Romero, J., Tinsley, A. & Vicary, P. (2010) **Public involvement in health research: a case study of one NHS project over 5 years,** Primary Health Care Research & Development, 11(1), 17-28.		x		x	**72**
Hull, D., Barton, D., Guo, K., Russell, C., Aucott, B. & Wiles, D. (2012), **Patient and public involvement to support liver disease research**, British Journal of Nursing, 21(16), 972-976.		x			**72 - 73**
Hutton, E. & Coxon, K. (2008) **Involving parents as service users in an interprofessional research project.** Journal of Interprofessional Care, 22(6), 661-663.		x		x	**73**

Publications	**N**	**I**	**R**	**A**	**page**
Iliffe, S., McGrath, T. & Mitchell, D. (2013) **The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies,** Health Expectations, 16(4), 351-61.		x			**74**
INVOLVE (2013) **Exploring public involvement in research funding applications**, Eastleigh: INVOLVE.		x			**74**
INVOLVE (2013), **Exploring the impact of public involvement on the quality of research: examples**, Eastleigh: INVOLVE.		x		x	**75**
INVOLVE (2012), **Public involvement in research: impact on ethical aspects of research**, Eastleigh: INVOLVE.		x			**75**
Ives, J., Damery, S. & Redwood, S. (2012) PPI, paradoxes and Plato: **Who's sailing the ship?** Journal of Medical Ethics doi:10.1136/medethics-2011-100150 [Epub ahead of print]			x	x	**75**
Jagosh, J., Macaulay, A., Pluye, P., Salsberg, J., Bush, P., Henderson, J., Sirett, E., Wong, G., Cargo, M., Herbert, C., Seifer, S., Green, L. & Greenhalgh, T. (2012) **A realist review for health research and practice**, Milbank Quarterly, 90(2), 311-46.		x	x		**76**
Johns, T., Miller, P., Kopp, K., Carter, Z., Cooper, G., Johnston, J., Nicholas, Z. & Wright, N. (2004) **Equal lives? Disabled people evaluate an independent living strategy for Essex Social Services,** Research Policy and Planning, 22(2), 51-57.		x		x	**77**
Jones, E., Williams-Yesson, B., Hackett, C., Staniszewska, S., Evans, D. & Francis, N. (2014) **Quality of reporting on patient and public involvement within surgical research: A systematic review**, Annals of Surgery, [Epub ahead of print].	x	x		x	**78**
Kara, H. (2013) **Mental health service user involvement in research: where have we come from, where are we going?** Journal of Public Mental Health, 12(3), 122-135.		x	x	x	**78 - 79**
Katz, M., Archer, L., Peppercorn, J., Kereakoglow, S., Collyar, D., Burstein, H., Schilsky, R. & Partridge, A. (2012) **Patient advocates' role in clinical trials,** Cancer, 118(19), 4801-5.		x		x	**79**
Kellett, M. (2006) **Children as researchers: Exploring the impact on education and empowerment,** childRight, 226 (May), 11-13.		x			**79 - 80**

Publications	N	I	R	A	page
Kellett, M., Forrest, R., Dent, N. & Ward, S. (2004) **'Just teach us the skills please, we'll do the rest': Empowering ten-year-olds as active researchers,** Children & Society, 18(5), 329-343.			x	x	**80**
Kennedy, S. in association with involved carers (2011) **Older carers involvement in research: Why, what and when?** Nottingham: University of Nottingham and London: Macmillan Cancer Support.			x	x	**80 - 81**
Kernick, D. & Mitchell, A. (2010) **Working with lay people in health service research: A model of co-evolution based on complexity theory.** Journal of Interprofessional Care, 24(1), 31-40.	x		x		**81**
Kirwan, J., Newman, S., Tugwell, P. & Wells, G. (2009) **Patient perspective on outcomes in rheumatology - A position paper for OMERACT 9,** Journal of Rheumatology, 36(9), 2067-2070.		x			**81 - 82**
Koops, L., Lindley, R. (2002) **Thrombolysis for acute ischaemic stroke: consumer involvement in design of new randomised controlled trial,** British Medical Journal, 325, 415-418.		x			**82**
Kreis, J., Puhan, M., Schunemann, H. & Dickersin, K. (2012) **Consumer involvement in systematic reviews of comparative effectiveness research,** Health Expectations, 16(4), 323-37.	x				**83**
Krieger, J., Allen, C., Cheadle, A., Ciske, S., Schier, J., Senturia, K. & Sullivan, M. (2002) **Using community-based participatory research to address social determinants of health: Lessons learned from Seattle Partners for Healthy Communities,** Health Education & Behaviour, 29(3), 361-382.		x			**83 - 84**
Lammers, J. & Happell, B. (2004) **Research involving mental health consumers and carers: a reference group approach.** International Journal of Mental Health Nursing, 13(4), 262-266.		x			**84 - 85**
Langston, A.L., McCallum, M., Campbell, M.K., Robertson, C. & Ralston, S.H. (2005) **An integrated approach to consumer representation and involvement in a multicentre randomized controlled trial,** Clinical Trials, 2(1), 80-87		x		x	**85**
Leamy, N. & Clough, R. (2006) **How older people became researchers: Training, guidance and practice in action,** York: Joseph Rowntree Foundation. (ISBN 1 85935 435 1)		x			**85 - 86**

Publications	**N**	**I**	**R**	**A**	**page**
Lindenmeyer, A., Hearnshaw, H., Sturt, J., Ormerod, R. & Aitchison, G. (2007) **Assessment of the benefits of user involvement in health research from the Warwick Diabetes Care Research User Group: A qualitative case study,** Health Expectations, 10, 268-277.		x		x	**86 - 87**
Lindow, V. & Morris, J. (1995) **Service user involvement: Synthesis of findings and experience in the field of community care,** York: York Publishing Services (ISBN 1 899987 00 2)		x	x	x	**87**
Lloyd, K., Rose, D. & Fenton, M. (2006) **Identifying uncertainties about the effects of treatments for schizophrenia,** Journal of Mental Health, 15(3), 263-268			x	x	**88**
Lowes, L. & Hulatt, I. (Eds.) (2005) **Involving service users in health and social care research,** London: Routledge.	x	x	x		**88**
Lowes, L., Robling, M., Bennert, K., Crawley, C., Hambly, H., Hawthorne, K., Gregory, J. and the DEPICTED Study Team (2010) **Involving lay and professional stakeholders in the development of a research intervention for the DEPICTED study**, Health Expectations 14(3), 250-260.			x		**89**
Lucas, P., Allnock, A. & Jessiman, T. (2013), **How are European birth-cohort studies engaging and consulting with young cohort members?** BMC Medical Research Methodology, 13, 56.	x				**89**
Marias, F. (2007) **Toward the improvement of tuberculosis control and participatory research,** London: Department of Primary Care and Social Medicine, Imperial College London.		x			**90**
Marsden, J. & Bradburn, J. (2004) **Patient and clinician collaboration in the design of a national randomized breast cancer trial,** Health Expectations, 7, 6-17.		x			**91**
Marston, C. & Renedo, A. (2013) **Understanding and measuring the effects of patient and public involvement: an ethnographic study**, The Lancet, 382, S69.		x			**91 - 92**
Mathie, E., Wilson, P., Poland, F., McNeilly, E., Howe, A., Staniszewska, S., Cowe, M., Munday, D. & Goodman, C. (2014) **Consumer involvement in health research: A UK scoping and survey**, International Journal of Consumer Studies, 38, 35-44.	x			x	**92**

Publications	**N**	**I**	**R**	**A**	**page**
Mayer, M. (2012) **Seeking what matters: Patients as research partners**, Patient, 5(2), 71-74.			x	x	**92**
McClimens, A., Grant, G. & Ramcharan, P. (2007) **Looking in a fairground mirror: reflections on partnerships in learning disability research.** In: M. Nolan, E. Hanson, G. Grant & J. Keady (Eds.) User participation in health and social care research: voices, values and evaluation (pp104-119). Maidenhead: Open University Press.			x		**93**
McCormick, S., Brody J., Brown, P. & Polk, R. (2004) **Public involvement in breast cancer research: An analysis and model for future research,** International Journal of Health Services, 34(4), 625-646.	x	x	x		**93 - 94**
Mckeown, M., Malihi-Shoja, L., Hogarth, R., Jones, F., Holt, K., Sullivan, P., Lunt, J., Vella, J., Hough, G., Rawcliffe, L., Mather, M. & CIT. (2012) **The value of involvement from the perspective of service users and carers engaged in practitioner education: Not just a cash nexus**, Nurse Education Today, 32(2), 178-84.		x	x	x	**94**
McKevitt, C., Fudge, N. & Wolfe, C. (2009) **What is involvement in research and what does it achieve? Reflections on a pilot study of the personal costs of stroke,** Health Expectations, 13(1), 86-94.		x	x		**94 - 95**
McLaughlin, H. (2010) **Keeping service user involvement in research honest.** British Journal of Social Work, 40(5), 1591-1608.			x		**95**
McLaughlin, H., (2006) **Involving young service users as co-researchers: Possibilities, benefits and costs,** British Journal of Social Work, 36, 1395-1410.		x			**96**
McLaughlin, H. (2005) **Young service users as co-researchers. Methodological problems and possibilities,** Qualitative Social Work, 4(2), 211-228		x			**96**
Meyer, M., Torres, S., Cereno, N., MacLean, L. & Monzon, R. (2003) **Immigrant women implementing participatory research in health promotion,** Western Journal of Nursing Research, 25(7), 815-834.		x		x	**97**

Publications	N	I	R	A	page
Miller, E., Cook, A., Alexander, H., Cooper, S., Hubbard, G. Morrison, J. & Petch, A. (2006) **Challenges and strategies in collaborative working with service user researchers: Reflections from the academic researcher,** Research Policy and Planning, 24(3),197-208.		x			**97 - 98**
Miller, E., Morrison, J. & Cook, A. (2006) **Brief encounter: Collaborative research between academic researchers and older researchers,** Generations Review, 16(3/4), 39-41.		x			**98 - 99**
Minkler, M., Fadem, P., Perry, M., Blum, K., Moore, L. and Rogers, J. (2002) **Ethical dilemmas in participatory action research: A case study from the disability community,** Health Education & Behaviour, 29(1), 14-29.		x		x	**99**
Minkler, M., Vasquez, V., Warner, J., Steyssey, H. & Facente, S. (2006) **Sowing the seeds for sustainable change: A community based participatory research partnership for health promotion in Indiana USA and its aftermath,** Health Promotion International, 21(4), 293-300.		x		x	**100**
Minogue, V., Boness, J., Brown, A. & Girdlestone, J. (2005) **The impact of service user involvement in research,** International Journal of Health Care Quality Assurance, 18(2-3), 103-112.		x			**100 - 101**
Mockford, C., Staniszewska, S., Griffiths, F., & Herron-Marx, S. (2012) **The impact of patient and public involvement on UK NHS health care: a systematic review**, International Journal for Quality in Health Care, 24(1), 28-38.		x			**101**
Morris, M., Nadkarni, M., Ward, F. & Nelson, R. (2004) **Exception from informed consent for pediatric resuscitation research: Community consultation for a trial of brain cooling after in-hospital cardiac arrest,** Pediatrics, 114(3), 776-781.		x			**101 - 102**
Morrow, E., Cotterell, P., Robert, G., Grocott, P. & Ross F. (2013) **Mechanisms can help to use patients' experiences of chronic disease in research and practice: An interpretative synthesis**, Journal of Clinical Epidemiology, 66(8), 856-864.			x		**102**
Morrow, E., Ross, F., Grocott, P. & Bennett, J. (2010) **A model and measure for quality service user involvement in health research.** International Journal of Consumer Studies, 34(5), 532-539.			x		**102 - 103**

Publications	**N**	**I**	**R**	**A**	**page**
Mosavel, M., Simon, C., van Stade, D. & Buchbinder, M. (2005) **Community-based participatory research (CBPR) in South Africa: Engaging multiple constituents to shape the research question,** Social Science & Medicine, 61(12), 2577-2587.		x			**103**
Muir, D. (2011) **Patient and public involvement in pressure ulcer research**, Journal of Tissue Viability, 20, 132-133.		x			**103 - 104**
Nacif, A. (2005) **Young researchers: Can I ask you some questions?** Children & Young People Now, 29 March 2005.		x			**104**
Newell, C. & South, J. (2009) **Participating in community research: exploring the experiences of lay researchers in Bradford,** Community, Work & Family, 12(1), 75-89.		x			**104**
Niba, M. & Green, J. (2005) **The impact of participatory and non-participatory evaluations on meeting project objectives,** African Journal of AIDS Research, 4(2), 103-113.		x			**105**
Nierse, C., Schipper,K., van Zadelhoff, E., van de Griendt, J. & Abma, A. (2012) **Collaboration and co-ownership in research: dynamics and dialogues between patient research partners and professional researchers in a research team,** Health Expectations, 15(3), 242-54.		x			**105 - 106**
Nilsen, E., Myrhaug, H., Johansen, N., Oliver, S. & Oxman, A. (2006) **Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Review),** Cochrane Database of Systematic Reviews, Issue 3, Art. No. CD004563.		x			**106**
Noonan Walsh, P. (2003) **A courtly welcome: observations on the research initiative,** British Journal of Learning Disabilities, 31, 190-193.			x		**106 - 107**
O'Connel, D. & Mosconi, P. (2006) **An Active Role for Patients in Clinical Research?** Drug Development Research Vol.67 pp.188-192.	x		x		**107**
O'Donnell, M. & Entwistle, V. (2004) **Consumer involvement in decisions about what health-related research is funded**, Health Policy, 70(3), 281-290.	x				**108**

Publications	N	I	R	A	page
O'Donnell, M. & Entwistle, V. (2004) **Consumer involvement in research projects: the activities of research funders,** Health Policy, 69(2), 229-238.	x				**108**
Oliver, S. (1996) **The progress of lay involvement in the NHS Research and Development Programme,** Journal of Evaluation in Clinical Practice 2(4), 273-280.	x				**109**
Oliver, S., Armes, D. & Gyte, G. (2009) **Public involvement in setting a national research agenda,** Patient, 2(3), 179-190.		x			**109**
Oliver, S., Clarke-Jones, L., Rees, R., Milne, R., Buchanan, P., Gabbay, J., Gyte, G., Oakley, A. & Stein, K. (2004) **Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach,** Health Technology Assessment, 8(15).	x				**110**
Oliver, S. & Gray, J. (2006) **A bibliography of research reports about patients', clinicians' and researchers' priorities for research,** London: James Lind Alliance.	x				**110 - 111**
Oliver, S., Liabo, K., Stewart, R. & Rees, R. (2014) **Public involvement in research: Making sense of the diversity**, Journal of Health Services Research & Policy, doi: 10.1177/1355819614551848. [Epub ahead of print]			x		**111**
Owens, C., Farrand, P., Darvill, R., Emmens, T., Hewis, E. & Aitken, P. (2011) **Involving service users in intervention design: A participatory approach to developing a text-messaging intervention to reduce repetition of self-harm**, Health Expectations, 14(3), 285-95.		x		x	**111 - 112**
Palmer, R. & Paterson, G. (2013) **To what extent can people with communication difficulties contribute to health research?** Nurse Researcher, 20 (3), 12-16.		x			**112**
Parker, E., Israel, B., Williams, M., Brakefield-Caldwell, W., Lewis, T., Robins, T., Ramirez, E., Rowe, Z. & Keeler, G. (2003) **Community action against asthma: Examining the partnership process of a community-based participatory research project,** Journal of General Internal Medicine, 18(7), 558-567		x		x	**112 - 113**

Publications	**N**	**I**	**R**	**A**	**page**
Paterson, C. (2003) **Consumer involvement in research into complementary therapies,** Bristol: Medical Research Council Research Collaboration.	x	x			**113 - 114**
Paterson, C. (2004) **'Take small steps to go a long way': consumer involvement in research into complementary and alternative therapies,** Complementary Therapies in Nursing & Midwifery, 10, 150-161.		x			**114**
Paterson, C., Allen, J., Browning, M., Barlow, G. & Ewings, P. (2005) **A pilot study of therapeutic massage for people with Parkinson's disease: the added value of user involvement,** Complementary Therapies in Clinical Practice, 1(3), 161-171.		x		x	**115**
Patterson, S., Trite, J. & Weaver, T. (2014) **Activity and views of service users involved in mental health research: UK survey**, British Journal of Psychiatry, 205(1), 68-75.		x	x	x	**115 - 116**
Pearson, M., Monks, T., Gibson, A., Allen, M., Komashie, A., Fordyce, A., Harris-Golesworthy, F., Pitt, M., Brailsford, S. & Stein, K. (2013) **Involving patients and the public in healthcare operational research: The challenges and opportunities**, Operations Research for Health Care, 2(4), 86–89.	x	x	x	x	**116**
Pennisi, E. (2000) **Patients help track down disease gene,** Science, 288(5471), 1565-1567.		x			**116**
Petit-Zeman, S., Philpots, L. & Denegri, S. (2010) **"Natural Ground" for medical research charities: Patient and public involvement in research funding,** Journal of Ambulatory Care Management, 33(3), 249-256.	x				**117**
Petit-Zemen, S. & Locock, L. (2013) **Bring on the evidence**, Nature, 501, 160-161.			x		**117**
Petrie, S., Fiorelli, L. & O'Donnell, K. (2006) **If we help you what will change? Participatory research and young people,** Journal of Social Welfare and Family Law, 28(1), 31-45.		x		x	**117 - 118**
Phillips, W. & Grams, G. (2003) **Involving patients in primary care research meeting worked well,** British Medical Journal 326 (7402), 1329.		x			**118**

Publications	**N**	**I**	**R**	**A**	**page**
Philpot, M., Collins, C., Trivedi, P., Treloar, A., Gallacher, S. & Rose, D. (2004) **Eliciting users' views of ECT in two mental health trusts with a user-designed questionnaire,** Journal of Mental Health, 13(4), 403-413.		x		x	**118 - 119**
Pizzo, E., Doyle, C., Matthews, R. and Barlow, J. (2014) **Patient and public involvement: how much do we spend and what are the benefits?** Health Expectations doi: 10.1111/hex.12204. [Epub ahead of print]		x			**119**
Plumb, M., Price, W. & Kavanaugh-Lynch, M. (2004) **Funding community-based participatory research: lessons learned,** Journal of Interprofessional Care, 18(4), 428-439.		x			**120**
Poland, F., Mapes, S., Pinnock, H., Katona, C., Sorensen, S., Fox, C. & Maidment, I. (2014) **Perspectives of carers on medication management in dementia: lessons from collaboratively developing a research proposal**, BMC Research Notes, 7, 463.		x			**120**
Purtell, R. & Wyatt, K. (2011) **Measuring something real and useful in consumer involvement in health and social care research,** International Journal of Consumer Studies, 35(6), 605-608.			x		**121**
Ramon, S. (2000) **Participative mental health research: Users and professional researchers working together,** Mental Health Care, 31(7), 224-228.		x			**121**
Reed, J., Weiner, R. & Cook, G. (2004) **Partnership research with older people - moving towards making the rhetoric a reality.** International Journal of Older People Nursing, 13(3a), 3-10.			x	x	**122**
Reeve, P., Cornell, S., D'Costa, B., Janzen, R. & Ochocka, J. (2002) **From our perspective: Consumer researchers speak about their experience in a community mental health research project,** Psychiatric Rehabilitation Journal, 25(4), 403-408.		x	x	x	**122**
Renedo, A. & Marston, C. (2011) **Healthcare professionals' representations of 'Patient and Public Involvement' and creation of 'Public Participant' Identities: Implications for the development of inclusive and bottom-up community participation initiatives**, Journal of Community and Applied Social Psychology, 21, 268-180.			x		**123**

Publications	**N**	**I**	**R**	**A**	**page**
Restall, G. (2013) **Conceptualising the outcomes of involving people who use mental health services in policy development**, Health Expectations, doi: 10.1111/hex.12091. [Epub ahead of print]			x		**123**
Rhodes, P., Nocon, A., Booth, M., Chowdrey, M., Fabian, A., Lambert, N., Mohammed, F. & Walgrove, T. (2002) **A service users' research advisory group from the perspectives of both service users and researchers,** Health and Social Care in the Community, 10(5), 402-409.	x	x		x	**124**
Rickard, W. & Purtell, R. (2011) **Finding a way to pay in the UK: methods and mechanisms for paying service users involved in research**, Disability & Society, 26(1), 33-48.			x	x	**124 - 125**
Rose, D. (2014) **Patient and public involvement in health research: Ethical imperative and/or radical challenge?** Journal of Health Psychology, 19(1), 149-158.			x	x	**125**
Rose, D., (2004) **Telling different stories: user involvement in mental health research,** Research and Policy Planning, 22(2), 23-30.		x	x	x	**125**
Rose, D. (2003) **Collaborative research between users and professionals: peaks and pitfalls,** Psychiatric Bulletin, 27, 404-406.	x		x	x	**126**
Rose, D., Leese, M., Oliver, D., Sidhu, R., Bennewith, O., Priebe, S. & Wykes, T. (2011) **A comparison of participant information elicited by service user and non-service user researchers,** Psychiatric Services 62(2), 210-3.		x		x	**126 - 127**
Rosenbaum, P. (2005) **From research to clinical practice: Considerations in moving research into people's hands. Personal reflections that may be useful to others,** Developmental Neurorehabilitation, 8(3), 165-171.			x		**127**
Ross, F., Donovan, S., Brearley, S., Victor, C., Cottee, M., Crowther, P. & Clark, E. (2005) **Involving older people in research: methodological issues,** Health and Social Care in the Community, 13(3), 268-275.		x			**127 - 128**

Publications	**N**	**I**	**R**	**A**	**page**
Ross, F., Smith, P., Byng, R., Christian, S., Allan, H., Price, L. & Brearley, S. (2014) **Learning from people with long-term conditions: new insights for governance in primary care**, Health and Social Care in the Community 22(4), 405-416.		x			**128**
Rowe, A. (2006) **The effect of involvement in participatory research on parent researchers in a Sure Start Programme,** Health and Social Care in the Community, 14(6), 465-473.		x			**129**
Royle, J. & Oliver, S. (2001) **Consumers are helping to prioritise research,** British Medical Journal, 323, 48-49.		x			**130**
Savage, C., Xu, Y., Lee, R., Rose, B., Kappesser, M. & Anthony, J. (2006) **A case study in the use of community-based participatory research in public health nursing,** Public Health Nursing, 23(5), 472-478.		x			**130**
Schneider, B., Scissons, H., Arney, L., Benson, G., Derry, J., Misurelli, N., Nickerson, D. & Sunderland, M. (2004) **Communication between people with schizophrenia and their medical professionals: A participatory research project,** Qualitative Health Research, 14(4) 562-577.		x	x		**131**
Schulz, A., Israel, B., Parker, E., Lockett, M., Hill, Y. & Willis, R. (2001) **The East Side Village Health Worker Partnership: Integrating research with action to reduce disabilities,** Public Health Reports 116, 548-557.		x	x		**131 - 132**
Scotton, W., Kolias, A., Shen Ban, V., Crick, S., Sinha, R., Gardner, A., Massey, K., Minett, T., Santarius, T. & Hutchinson, P. (2013) **Community consultation in emergency neurosurgical research: lessons from a proposed trial for patients with chronic subdural haematomas**, British Journal of Neurosurgery, 27(5), 590-594.		x		x	**132**
Shah, S. & Robinson, I. (2007) **Benefits of and barriers to involving users in medical device technology development and evaluation.** International Journal of Technology Assessment in Health Care, 23(1), 131-137.		x			**133**
Shippee, N., Garces, J., Lopez, G. et al. (2013) **Patient and service user engagement in research: a systematic review and synthesised framework**, Health Expectations doi: 10.1111/hex.12090. [Epub ahead of print].		x			**133**

Publications	**N**	**I**	**R**	**A**	**page**
Simpson, A., Jones, J., Barlow, S., Cox, L. and SUGAR (2014) **Service user and carer collaboration in mental health nursing research**, Journal of Psychosocial Nursing and Mental Health Services, 52(1), 22-30.		x		x	**134**
Sims, S., Brearly, S., Hewitt, G., Greenwood, N., Jones, F., Ross, F. & Harris, R. (2013) **How to develop a patient and carer advisory group in stroke care research**, Nurse Researcher, 20(3), 6-11.		x			**134**
Slade, M., Bird, V., Chandler, R., Fox, J., Larsen, M (2010) **The contribution of advisory committees and public involvement to large studies: case study,** BMC Health Services Research, 10, 323.		x			**135**
Smith, E., Manthorpe, J., Brearley, S., Ross, F., Donovan, S., Sitzia, J. & Beresford, P. (2005) **User involvement in the design and undertaking of nursing, midwifery and health visiting research,** London: National Co-ordinating Centre for NHS Service Delivery and Organisation (NCCSDO).	x				**135 - 136**
Smith, E., Ross, F., Donovan, S., Manthorpe, J., Brearley, S., Sitzia, J. & Beresford, P. (2008) **Service user involvement in nursing, midwifery and health visiting research: A review of evidence and practice**, International Journal of Nursing Studies, 45(2), 298-315.		x	x		**136**
Snape, D., Kirkham, J., Britten, N., Gradinger, F., Looban, F., Popay, J., Wyatt, K. & Jacoby, A. (2014) **Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research: A modified Delphi study**, BMJ Open, 4:e004943.			x		**136 - 137**
Snape, D., Kirkham, J., Preston, J., Popay, J., Britten, N., Froggatt, K., Gibson, A., Lobban, F., Wyatt, K. & Jacoby, A. (2014) **Exploring areas of consensus and conflict around values underpinning public involvement in health and social care research: A modified Delphi study**, BMJ Open, 4, e004217.			x		**137**
Stack, R., Mallen, C., Deighton, C., Kiely, P., Shaw, K., Booth, A., Kumar, K., Thomas, S., Rowan, I., Horne, R., Nightingale, P., Herron-Marx, S., Jinks, C., DELAY Study Syndicate, Raza, K. (2014) **The development and initial validation of a questionnaire to measure help-seeking behaviour in patients with new onset rheumatoid arthritis**, Health Expectations doi: 10.1111/hex.12203.		x		x	**138**

Publications	**N**	**I**	**R**	**A**	**page**
[Epub ahead of print]					
Staley, K. (2013) **Lay REC members – patient or public?** Journal of Medical Ethics, 39(12), 780-2.			x		**138**
Staley, K. (2013) **A series of case studies illustrating the impact of service user and carer involvement on research**, Mental Health Research Network: London.			x		**138 - 139**
Staley, K. (2013) **There is no paradox with PPI in research**, Journal of Medical Ethics, 39, 186-187.		x			**139**
Staley, K. (2012) **An evaluation of service user involvement in studies adopted by the Mental Health Research Network,** London: Mental Health Research Network.		x			**139 - 140**
Staley, K. (2009) **Exploring impact: Public involvement in NHS, public health and social care,** Eastleigh, INVOLVE.		x	x		**140**
Staley, K., Buckland, S., Hayes, H. & Tarpey, M. (2014) **'The missing links': Understanding how context and mechanism influence the impact of public involvement in research**, Health Expectations, 17(6), 755–764.			x		**140**
Staley, K. & Minogue, V. (2006) **User involvement leads to more ethically sound research.** Clinical Ethics, 1, 95-100.			x		**141**
Staniszewska, S., Adebajo. A., Barber, B., Beresford, P., Brady, L., Brett, J., Elliott, J., Evans, D., Haywood, K., Jones, D., Mockford, C., Nettle, M., Rose, D. & Williamson, T. (2011) **Developing the evidence base of patient and public involvement in health and social care research: the case for measuring impact**, International Journal of Consumer Studies, 35(6), 628-632.			x		**141**
Staniszewska, S., Brett, J., Mockford, C. & Barber, R. (2011) **The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research,** International Journal of Technology Assessment in Health Care, 27(4), 391-399.			x		**141**
Staniszewska, S. & Denegri, S. (2013) **Patient and public involvement in research: Future challenges**, Evidence Based Nursing, 16 (3), 69.			x		**142**

Publications	**N**	**I**	**R**	**A**	**page**
Staniszewska, S., Jones, N., Newburn, M. & Marshall, S. (2007) **User involvement in the development of a research bid: barriers, enablers and impact,** Health Expectations, 10(2),173-183.		x		x	**142**
Staniszewska, S., Thomas, V. & Seers, K. (2013) **Patient and public involvement in the implementation of evidence into practice**, Evidence Based Nursing 16(4), 97.			x		**143**
Stevens, T., Wilde, D., Hunt, J. Ahmedzai, S. (2003) **Overcoming the challenges to consumer involvement in cancer research,** Health Expectations, 6(1), 81-88.	x	x			**143**
Stewart, R., Caird, J., Oliver, K. & Oliver, S. (2010) **Patients' and clinicians' research priorities,** Health Expectations, 14(4), 439-48.	x				**143 - 144**
Stewart, R. & Liabo, K. (2012) **Involvement in research without compromising research quality** Journal of Health Service Research & Policy, 17(4), 248-51.			x		**144**
Stickley, T. (2006) **Should service user involvement be consigned to history? A critical realist perspective,** Journal of Psychiatric and Mental Health Nursing, 13, 570-577.			x		**144**
Stiffman, A., Freedenthal, S., Brown, E., Ostmann, E. & Hibbeler, P. (2005) **Field research with underserved minorities: The ideal and the real,** Journal of Urban Health, 82 (2, Suppl 3), iii56-iii66		x			**144 - 145**
Stockdale, S., Mendel, P., Jones, L., Arroyo, W. & Gilmore, J. (2006) **Assessing organisational readiness and change in community intervention research: Framework for participatory evaluation,** Ethnicity & Disease, 16(1 Suppl 1), S1 136-S1 145.		x			**145 - 146**
Sutton, J. & Weiss, M. (2008) **Involving patients as advisors in pharmacy practice research: What are the benefits?** International Journal of Pharmacy Practice, 16(4), 231-238.		x			**146**
Tanner, D. (2012) **Co-research with older people with dementia: Experience and reflections**, Journal of Mental Health, 21(3), 296-306.		x			**147**
Tarpey M. (2011) **Public involvement in research applications to the National Research Ethics Service**, Eastleigh: INVOLVE.	x				**147**

Publications	**N**	**I**	**R**	**A**	**page**
Tarpey, M. (2006) **Why people get involved in health and social care research: a working paper,** Eastleigh: INVOLVE.			x		**148**
Taylor, S. (2006) **A new approach to empowering older people's forums: Identifying barriers to encourage participation,** Practice, 18(2), 117-128.			x		**148**
Telford, R., Boote, J.D. & Cooper, C.L. (2004) **What does it mean to involve consumers successfully in NHS research? A consensus study,** Health Expectations 2004, 7(3), 209-220.	x				**149**
Telford, R. & Faulkner, A. (2004) **Learning about service user involvement in mental health research,** Journal of Mental Health, 13(6), 549-559.	x			x	**149**
Terry, S., Terry, P., Rauen K., Uitto J. & Bercovitch, L. (2007) **Advocacy groups as research organisations: the PXE International example,** Nature Reviews Genetics, 8(2),157-164.		x		x	**150**
Tetley, J., Haynes, L., Hawthorne, M., Odeyemi, J., Skinner, J., Smith, J. & Wilson, D. (2003) **Older people and research partnerships,** Quality in Ageing - Policy, Practice and Research, 4(4), 18-23.		x		x	**150 - 151**
The Learning Difficulties Research Team with assistance from Bewley, C. & McCulloch, L. (2006) **Let me in - I'm a researcher! Getting involved in research,** London: Department of Health.	x	x	x	x	**151 - 152**
Thompson, J., Barber, R., Ward, P., Boote, J., Cooper, C., Armitage, C. & Jones, G. (2009) **Health researchers' attitudes towards public involvement in health research,** Health Expectations, 12(2), 209-220	x				**152**
Thompson, J., Bissell, P., Cooper, C., Armitage, C. & Barber, R. (2012) **Credibility and the 'professionalised' lay expert: Reflections on the dilemmas and opportunities of public involvement in health research,** Health 25 April 2012, 1461-7196.			x		**152 - 153**
Thompson, J., Bissell, P., Cooper, C., Armitage, C. and Barber, R. (2014) **Exploring the impact of patient and public involvement in a cancer research setting**, Qualitative Health Research, 24(1), 46-54.		x			**153**

Publications	**N**	**I**	**R**	**A**	**page**
Thornton H., Edwards A., Elwyn, G. (2003) **Evolving the multiple roles of 'patients' in health-care research: reflections after involvement in a trial of shared decision-making,** Health Expectations 6, 189-197.			x	x	**154**
Tierney, E., McEvoy, R., O'Reilly-de Brún, M., de Brún, T., Okonkwo, E., Rooney, M., Dowrick, C., Rogers, A. & MacFarlane, A. (2014) **A critical analysis of the implementation of service user involvement in primary care research and health service development using normalisations process theory**, Health Expectations, doi: 10.1111/hex.12237. [Epub ahead of print]	x		x	x	**154 - 155**
Tritter, J. & Korivusalo, M. (2013) **Undermining patient and public engagement and limiting its impact: The consequences of the Health and Social Care Act 2012 on collective patient and public involvement**, Health Expectations, 16(2), 115-8.			x		**155**
Trivedi, P. & Wykes, T. (2002) **From passive subjects to equal partners, Qualitative review of user involvement in research,** British Journal of Psychiatry, 181, 468-472.		x	x	x	**155 - 156**
Truman, C. & Raine, P. (2001) **Involving users in evaluation: the social relations of user participation in health research,** Critical Public Health, 11(3), 215-229.		x	x		**156**
Tuffrey-Wijne, I. & Butler, G. (2010) **Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis,** Health Expectations, 13(2), 174-84.		x	x	x	**157**
Turner, T. & Beresford, P. (2005) **User controlled research. Its meanings and potential,** Eastleigh: INVOLVE.			x	x	**157**
Tyler, P., Turner, C. & Mills, H. (2006) **Involving young people in research,** London: Barnardo's Policy and Research Unit.		x			**158**
Vale C., Thompson L., Murphy C., Forcat S. & Hanley B. (2012) **Involvement of consumers in studies run by the Medical Research Council (MRC) Clinical Trials Unit: Results of a survey,** Trials, 13, 9.	x	x			**158 - 159**
Vale, C., Tierney, J., Spera, N., Whelan, A., Nightingale, A. & Hanley, B. (2012) **Evaluation of patient involvement in a systematic review and meta-analysis of individual patient data in cervical cancer treatment**, Systematic Reviews, 1, 23.		x		x	**159**

Publications	**N**	**I**	**R**	**A**	**page**
Van Bekkum, J. and Hilton, S. (2014) **UK research funding bodies' views towards public participation in health-related research decisions: An exploratory study**, BMC Health Services Research, 14, 318.	x			x	**159 - 160**
Viswanathan, V., Eng, E., Gartlehner, G., Lohr, K., Griffith, D., Rhodes, S., Samuel-Hodge, C., Maty, S., Lux, L., Webb, L., Sutton, S., Swinson, T., Jackman, A. & Whitener, L. (2004) **Community-based participatory research (CBPR): Assessing the evidence,** Evidence Report/Technology Assessment No. 99. Rockville, MD: Agency for Healthcare Research and Quality.		x			**160 - 161**
von Staa, A., Jedeloo, S., Latoru, J. & Trappenburg, M. (2010) **Exciting but exhausting: experiences with participatory research with chronically ill adolescents.** Health Expectations, 13(1), 95-107.		x			**161**
Walker, D. & Pandya-Wood, R. (2013) **Can research development bursaries for patient and public involvement have a positive impact on grant applications? A UK-based, small scale service evaluation**, Health Expectations doi: 10.1111/hex.12127 [Epub ahead of print].		x			**162**
Walmsley, J. (2004) **Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research**, Nursing Inquiry, 11(1), 54-64.			x		**162**
Walmsley, J. & Mannan, H. (2010) **Parents as co-researchers: A participatory action research initiative involving parents of people with intellectual disabilities in Ireland.** British Journal of Learning Disabilities, 37, 271-276.		x			**162 - 163**
Walter, I., Davies, H. & Nutley, S. (2003) **Increasing research impact through partnerships: evidence from outside health care,** Journal of Health Services Research and Policy 8 (supplement 2), S2:58-S261.	x	x			**163 - 164**
Ward, P., Thompson, J., Barber, R., Armitage, C., Boote, J., Cooper, C. & Jones, G. (2010) **Critical perspectives on 'consumer involvement' in health research,** Journal of Sociology, 46(1), 63-82.			x		**164**

Publications	**N**	**I**	**R**	**A**	**page**
Warren, L., Cook, J., Clarke, N., Hadfield, P., Haywood-Reed, P., Millen, L., Parkinson, M., Robinson, J. & Winfield, W. (2003) **Working with older women in research: some methods-based issues,** Quality in Ageing - Policy, Practice and Research, 4(4), 24-31.		x		x	**164 - 165**
Weinstein, J. (2006) **Involving mental health service users in quality assurance,** Health Expectations, 9, 98-109.		x			**165**
Wicks, P. (2014) **Could digital patient communities be the launch pad for patient-centric trial design**? Trials, 15, 172.			x		**166**
Williams, V., Simons, K. & Swindon People First Research Team (2005) **More researching together: the role of non-disabled researchers working with People First members,** British Journal of Learning Disabilities, 33, 6-14.			x	x	**166**
Williamson, T., Brogden, J., Jones, E. & Ryan, J. (2010) **Impact of public involvement in research on quality of life and society: a case study of research career trajectories,** International Journal of Consumer Studies, 34(5), 551-557.		x		x	**166 - 167**
Williamson, T., Kenney, L., Barker, A., Cooper, G., Good, T., Healey, J., Heller, B., Howard, D., Matthews, M., Prenton, S., Ryan, J. & Smith, C. (2014) **Enhancing public involvement in assistive technology design research**, Disability and Rehabilitation Assistive Technology [Epub ahead of print]		x			**167 - 168**
Wood, M. (2003) **Disability, participation and welfare to work in Staffordshire,** Journal of Integrated Care, 11(2), 43-48.		x			**168 - 169**
Wright, D., Corner, J., Hopkinson, J. & Foster, C. (2006) **Listening to the views of people affected by cancer about cancer research: an example of participatory research in setting the cancer research agenda,** Health Expectations, 9(1), 3-12.		x			**169**
Wright, D., Foster, C., Amir, Z., Elliott, J. & Wilson, R. (2010) **Critical appraisal guidelines for assessing the quality and impact of user involvement in research.** Health Expectations, 13(4), 359–368.			x	x	**169 - 170**
Wright, D., Hopkinson, J., Corner, J. & Foster, C. (2006) **How to involve cancer patients at the end of life as co-researchers**, Palliative Medicine, 20, 821-827.		x			**170**

Publications	**N**	**I**	**R**	**A**	**page**
Wyatt, K., Carter, M., Mahtani, V., Barnard, A., Hawton, A. & Britten, N. (2008) **The impact of consumer involvement in research: An evaluation of consumer involvement in the London Primary Care Studies Programme,** Family Practice, 25(3), 154-161.		x		x	**170 - 171**
Wykes, T. (2014) **Great expectations for participatory research: What have we achieved in the last ten years?** World Psychiatry, 13(1), 24-27.			x		**171**
Wykes, T. (2003) **Blue skies in the Journal of Mental Health? Consumers in research,** Journal of Mental Health, 12(1), 1-6.		x			**171 - 172**

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