SYSTEMATIC REVIEW

A Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities

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Abstract

Objective Patient and public involvement (PPI) in research has expanded nationally and internationally over the last decade, and recently there has been significant attention given to understanding its impact on research. Less attention has been given to the impact of PPI on the people involved, yet it has been shown that the success of PPI in research can be reliant on the processes of engagement between these individuals and communities.

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This paper therefore critically explores the impact of PPI on service users, researchers and communities involved in health and social care research.

Data Sources Searches were undertaken from 1995 to April 2012 in the electronic databases MEDLINE, EMBASE, PsycINFO, Cochrane library, CINAHL, HMIC and HELMIS. Searches were undertaken for grey literature using the databases InvoNet and NHS Evidence.

Study Selection Studies were included if they included the impact of PPI on individual service users, researchers or communities under research. Studies were excluded if they were in a foreign language (unless they were deemed critical to the systematic review) or were in children and adolescent services.

Study Appraisal Data were extracted using a narrative synthesis, and quality was assessed using the Critical Appraisal Skills Programme.

Main Results Service users reported feeling empowered and valued, gaining confidence and life skills. Researchers developed a greater understanding and insight into their research area, gaining respect and a good rapport with the community. The community involved in research became more aware and knowledgeable about their condition. However, lack of preparation and training led some service users to feel unable to contribute to the research, while other service users and communities reported feeling overburdened with the work involved. Researchers reported difficulties in incorporating PPI in meaningful ways due to lack of money and time.

Conclusion This is the first international systematic review to focus on the impact of PPI on the people involved in the process. The beneficial and challenging impacts reported highlight the importance of optimising the context and processes of involvement, so creating the potential for PPI to impact positively on the research itself.

Key Points for Decision Makers

While debates around the impact of patient and public involvement (PPI) often focus on research and the research process, this paper demonstrates the importance of the impact of PPI on the people and communities involved.

The success of PPI on research often relies on the nature of the interactions between individuals involved in the process. The importance of these context and process factors cannot be underestimated in developing positive impacts.

Careful planning, training and ensuring adequate funding for involvement may improve the success of PPI.

1 Introduction

Patient and public involvement (PPI) has become a key element in health and social care research in the UK and internationally, helping to promote patient-centred research [1, 2]. More recently, PPI has received strong policy support with its active promotion through organisations such as INVOLVE and Research Design Services [1, 3, 4] and through the emphasis funding programmes such as the National Institute for Health Research (NIHR) have placed on PPI [5, 6]. Furthermore, global interest in PPI has spread through key networks such as the Health Technology Assessment International Citizen and Patient Sub-Group, which aims to incorporate PPI into the work of its 59 member countries [7].

While PPI has become increasingly embedded in research, interest has grown in understanding the difference it makes to research. An earlier paper reporting the Conceptualisation, measurement, impact and outcomes of patient and public involvement (PIRICOM) study focused specifically on the impacts of PPI on research and identified a wide range of beneficial and challenging impacts [8]. A sister review, which focused on the impact of PPI on health and social care services, also identified a wide variety of positive and negative impacts [9].

While understanding the impact of PPI on research is of great importance, developing a wider view which considers the impact of PPI on the people involved in the process can be critical to our understanding of why some studies that involve patients and the public thrive, while others fail or wither, even though their approach or methods may essentially appear similar. In addition, the complex social processes that underpin PPI can affect the research process, and enhancing our understanding of the context and process of PPI may help identify factors that promote or inhibit successful PPI.

Interest in broader societal benefits of research has been enhanced more recently, particularly in the UK context, where the Research Excellence Framework Higher Education Funding Council for England (HEFCE) 2012 has emphasised the importance of research impacting on individuals and society [10]. This has provided an important impetus for researchers and academics to consider how they embed public involvement more widely in their work.

This paper reports an aspect of the findings of the PIRICOM systematic review, and is the first published review to report these wider impacts on the people involved in the process, including services users, patients, researchers and wider community patient groups under research.

2 Methods

Systematic searches were undertaken from 1995 to April 2009, and then updated in 2012, using the following databases: MEDLINE, EMBASE, PsycINFO, Cochrane library (medical literature); CINHAL (nursing literature); and Healthcare Management Information Consortium (HMIC) and HELMIS. Hand searching of reference lists of papers and hand searching of specialist journals was conducted. Grey literature was searched using the databases InvoNet and NHS Evidence. Grey literature was also obtained by contact with key experts in the field.

2.1 Study Selection

Studies of all designs, published and unpublished, that were in English language and reported data on the involvement of adult service users who had been involved in a health or social care research study were included in the first round of study selection. Ten per cent of the abstracts or summaries of material were reviewed independently by two researchers (JB, SS). As agreement by the two reviewers on included papers was high (94 %) and because of the large number of papers involved in this process, the rest of the abstracts were reviewed by one reviewer and agreement was checked by a second reviewer.

2.2 Quality Assessment

The methodological quality of published studies was assessed using the Critical Appraisal Skills Programme (CASP), Oxford, UK [11], which provides critical appraisal guidelines for randomised controlled trials, systematic reviews, cohort studies, case controlled studies, qualitative studies, economic evaluations, and diagnostic studies. Grey

literature was assessed using the Dixon-Woods checklist (2005), as used by Hubbard et al. to review grey literature [12, 13].

2.3 Data Extraction and Synthesis

A narrative synthesis was chosen because of the mixed study designs included in the review [14]. This involved familiarisation with the papers, then the identification of emergent themes. The synthesis aimed to draw out key themes that related to our research aims. This has been summarised in a descriptive form to draw conclusions about the evidence. The data are presented in a descriptive or non-quantitative synthesis with data tabulated in a way to allow readers to look at the evidence, the methods used, the populations studied, the interventions used, and the outcomes of the studies [8].

For tabulated data and quality assessment, refer to the full PIRICOM report (http://www.ukcrc.org/category/publications/reports/).

2.4 User Involvement in the Study

Three users were recruited to the advisory group of this study, and contributed to the design, methodology and analysis in the systematic narrative review. An expert seminar was held at the end of the project, including 24 service users and individuals who work in the field of PPI, to provide an opportunity for them to contribute to the synthesis of findings from the systematic review and add their interpretations and perspectives.

3 Results

The first searches for the wider review identified 13,890 potential papers that included evidence of any conceptualisation, impact, measurement or outcome of PPI in health and social care research, as per the inclusion and exclusion criteria. Updated searches identified a further 17 papers, of which seven were included. Studies were included (1) if they reported the impact of the research on individual users or research team members (e.g. personal development/new skills/financial issues or work load/emotional journey), on groups (e.g. communities, user groups, teams), on organisations (e.g. communities, charities, NHS, council), and on policy (local and national); (2) if research evidence was from 1995 to 2012; (3) if they were written in the English language; and (4) if the service users involved were adults. Studies were excluded if they were not written in English; if they included child and adolescent services; if the evidence was in the format of letters, opinions, and editorials;

or if the study had a fatal flaw, in terms of quality assessment, which compromised its results.

The results section is divided into impact on service users, impact on researchers, and impact on the community under research.

3.1 Impact on Service Users

In total, 65 papers reported impacts of PPI on health and social care service users. Of these studies, 42 were qualitative studies, 12 were case studies, three were a case series, three were cross-sectional studies, and five were reviews of the evidence. Forty-five papers were from the UK, 12 were from the USA, two were from Canada, two were from Australia, two were from Sweden and two were from the Netherlands.

Personal benefits to users were reported, including feeling listened to and empowered [15–25], and feeling valued [20, 24, 26–33]. Users talked of being able to give something back and of doing something meaningful for the research community [20, 29–31, 34]. Studies reported service users felt they had better confidence and greater self-worth after their involvement, and also reported a sense of mutual support from fellow users [20, 21, 35–39], who often felt part of a team [20, 28, 31, 32, 37, 40–42].

Furthermore, the evidence shows that where training in research had been conducted with users, studies reported users had an improved knowledge of research [20, 35, 42–47] and improved knowledge of the study [20, 26, 36, 48]. Service users reported that involvement in the research demystified research and gave users a more open attitude to research, leading to a better understanding of and improved trust in researchers [24, 49–51].

Improved direct access to information on the current treatment or management of their illness and exchange of information with researchers were reported as beneficial to users [20, 39, 52]. This also improved their ability to problem solve regarding issues they had in relation to their condition [13, 50, 53].

Gaining skills such as interviewing, confidence in speaking, and listening in groups, where group work was conducted [16, 38, 39, 43, 54–60], was also reported, and these new skills helped improve the users' chances of future employment [19, 23, 43, 45, 61, 62].

Studies also reported more challenging, sometimes negative, impacts on service users. Several studies reported that users involved in PPI consultation felt they were not being listened to or felt their views were marginalised [51, 63, 64]. They reported feeling frustration at what they saw as the rigid and rather limited beliefs of some 'experts' [63]. Furthermore, users reported frustrations with regard to assumptions that they lacked knowledge and therefore their views were not to be taken seriously [31, 57, 59, 63,

65]. In one study, users reported the perceived insensitivity of health professionals and researchers [29], while another reported that researchers 'speak another language' [51]. Low self-esteem and unease at expressing their opinions were reported [24, 66].

The lack of preparation and training of the service users left them feeling inexperienced and unable to contribute in group situations, which in turn led to low attendance rates throughout one study [22, 23, 56, 67, 68]. Lack of preparation also led to misunderstandings about why they were involved, and disappointment that they were not given support in how to manage their condition [69]. Studies reported users' confusion and conflict due to lack of clarity about their roles in the research [26, 42, 44, 51, 63, 70, 71]. Furthermore, users reported unease at the changing roles between users and health professionals (e.g. changing from a doctor–patient relationship to meeting as colleagues), and concern that close working relationship with clinicians may lead other patients to assume they receive preferential clinical care [31].

Users found the formal procedures of research limiting, for example, the strict use of interview schedules instead of gaining data through more informal discussions with interviewees [24, 50, 56, 70]. Users also reported frustration at having to adapt pre-developed materials for studies, limiting their contribution to more user friendly materials [28, 56]. Service users also reported the emotional burden of listening to participants recount their experiences, the emotional burden of recalling their own experiences [19, 29, 56, 72, 73], and the burden of responsibility of being a 'bridge' between the research team and the community [36, 50, 70]. A lack of understanding of research methodology and unfamiliar processes, acronyms and technical language led to concerns about the research being conducted [22, 41, 51, 69, 74]. For example, a lack of understanding of randomised controlled trials led to concern about the use of randomisation in the trial, specifically, the non-selection of a participant for treatment [74].

The failure of researchers to provide feedback to users about the impact of their involvement meant that users were not able to learn how useful their input had been, which led to a lack of motivation to be involved in future research projects [66]. Furthermore, studies reported that users felt left out of regular communication within research teams, as routine use of e-mail, corridor meetings by researchers, and attendance at academic conferences could exclude users [21, 31, 32]. Another study reported that users perceived that more weight was put on issues expressed by those who were able to present their views more cogently than others ('Posh articulate got more attention') [34].

Studies reported that users' involvement in research was time consuming, which may discourage them from being involved in future research [17, 22, 26, 31, 34, 39, 50, 52, 57, 59, 60]. They reported difficulty fitting the work in around other life commitments [75], and reported feeling overburdened with tasks and having limited time to read unfamiliar documents before meetings [22, 28, 31, 33, 69].

3.2 Impact of PPI on Researchers

In total, 35 papers reported impacts of PPI on health and social care researchers. Twenty-six papers were qualitative, four were case studies, one was a case series, one was cross-sectional, and three reviewed the evidence. Twenty-five papers were from the UK, six were from the USA, two were from Australia, one was from Canada, and one was from the Netherlands.

Through involving users in the research, researchers gained fresh insights into issues [16, 27, 31, 33, 50, 65, 76]. Beliefs and attitudes could be challenged as researchers gained a greater understanding of the community health needs; barriers to research could be identified; and researchers developed skills to resolve differences [17, 31, 50, 57]. One study reported that when seeking research topics, face-to-face discussion with a user group was more productive than scanning consumer research reports or consumer health information [51].

In collaborations with users, researchers found that by spending time with community members, they built a good rapport with users, and one study reported that researchers found their preconceived assumptions on the community under research were challenged [19, 49]. Researchers were given an insight into how users think and feel, and gained experience in providing background project information to users, which may have led to greater respect towards the community they were studying [33]. In turn, researchers worked with committed lay researchers who wanted to make a difference, and often committed to helping further research [34, 52, 77]. Researchers remained focussed on the issues important to the community they were researching, and by listening to the questions and concerns of client organisations, researchers improved trust and confidence with community collaborators [69]. PPI provided greater diversity within the research team, and in the case of collaborative work or user-led research, often lightened the workload for the researchers, whose role became more one of professional advice and support [68, 77].

One of the most challenging impacts reported by researchers was the impact that PPI had on time, resources and funding [24, 27, 39, 52, 69, 77, 78]. Gaining additional funds for PPI can be challenging, and additional time is required to build working relationships with service users and to plan and conduct PPI.

Researchers could be sceptical about PPI, leading to a lack of commitment and a tokenistic attitude towards

involving users in their research [20, 28, 30, 31]. Researchers reported having concerns about what contribution users could make to a research project and concern over the competence of users to assist with research [66, 69, 71]. They were also concerned that users may come with their own lobbying agenda [65].

Difficulties arose for researchers when there was a lack of pre-defined roles for lay researchers and academic researchers. This lead to misunderstandings about what researchers expected of users [31, 71]. Some researchers had difficulty accepting the views of users when they did not match that of the academic researchers, particularly when research deemed worthy and viable by 'experts' was not received so well by users [34, 53, 68, 69]. Furthermore, studies reported that researchers had difficulty in relinquishing control over or sharing power over research [19, 22, 53], with researchers feeling users were encroaching on their 'territory' [73]. In one study, where the patient partners led in the interviews, the interaction created a confusing situation for the professional researcher, who felt excluded during the interview process [16].

Researchers found having to change working practices to include service users difficult, which could lead to conflict [19, 24, 31, 66]. Tension between what constitutes a good research study (academic criteria vs. user perspectives) also caused difficulties for researchers [17, 59], and researchers found the constant criticism difficult to take [31]. One study reported that the researchers were not convinced the additional effort and resources were worthwhile [66].

3.3 Impact of PPI on the Community

In total, 23 papers reported impacts of PPI on the community involved in research (i.e. the wider patient group under research). Seventeen studies were qualitative studies, one was a cross-sectional study, four were case studies, and one was a review of the evidence. Thirteen studies were from the UK, six were from USA, two were from Canada, one was from the Netherlands and one was from Australia.

Studies report that a mutual respect between researchers and the community may develop as a result of PPI [22, 24, 25, 42, 49, 50], increasing the acceptability and trust of the research in the community [24, 25], and resolving conflict between researchers and the community [25, 42], and therefore aiding the success of the research. The improved trust may in turn build a more research co-operative spirit within the community [25, 40, 42], and give research credibility in the community [25, 39].

User involvement was reported to increase the awareness of the disease or condition in the community through presentations and dissemination of information from public and charitable associations [25, 35, 36, 51, 52, 79, 80],

which developed greater knowledge of and better distribution of information on diagnosis and treatment in the community [40, 52, 80], potentially leading to a better-informed patient population [52]. PPI also led to increased membership for community groups [52] and to greater intercultural understanding by all parties involved in the research about issues of the disease or the condition within the community, such as the taboo of diabetes in Asian communities and the challenges of health promotion within Hispanic communities [39, 50].

User collaborations with researchers provided a new interface by which research is fed back to the community [66, 80], as users became advocates of the research in the community [48, 81]. PPI also led to a sense of community ownership of research as parties worked together to develop a better action plan for dissemination of research findings [42].

PPI activity may also have other community benefits, such as relating the research more directly to the illness experiences of the community [22, 77, 80]. Broadening the research agenda beyond that set by clinicians and researchers [77] can make the science more accountable to the community [22, 50] and create links to specific seldom heard communities [24, 25, 50]. A greater mutual trust may help overcome resistance to new ideas in the research community [42], develop better targeted services based on the identified needs [33, 42], create new ways of communicating with health professionals [38], and increase the likelihood that community members comply with treatment and care plans [33].

Five published papers reported the challenging impact of PPI on the researched community. The evidence reports that PPI may uncover or create conflict and power struggles within the community [24], and may increase the time and cost burdens of the community organisations involved [46, 64]. Furthermore, there may be difficulty representing those in the community who are severely disabled or severely ill, because of their health status.

4 Discussion

While PPI in research has become embedded in many ways, much of the focus has been on impacts on research. The PIRICOM systematic review also considered the impact on individuals involved in PPI—service users, researchers and the wider community patient groups—an area which often receives less attention.

This paper reports international evidence of the beneficial and challenging impacts of PPI on service users, researchers and communities engaged in the research. The evidence reported highlights that PPI impacts these different groups in different ways, and may be linked to

differing motivations and values, less often explored in studies of impact.

For service users, the impacts reported are more of a personal journey, with reports of users feeling empowered, valued, listened to and generally more positive about their experiences. Users also increased their knowledge of their condition and developed life skills. Many of these impacts reflect the wider societal benefits that demonstrate the potential for research to act as a positive force in society, engaging a broader range of individuals, involving them in meaningful ways to contribute to the generation of research that has potentially broader utility and relevance for the wider public. This positive experience motivated service users during and after the study to continue being involved in research. However, if negative impacts are reported, such as experiencing researchers' negative attitudes and perceptions, not feeling valued by the researchers, not receiving feedback from researchers, or feeling overloaded or emotionally overburdened, they can lead to reduced motivation of service users to be involved in research, and therefore have negative impacts on the research [66, 82].

For researchers, the positive impacts reported were about gaining new insights into their work and gaining a greater understanding of the area under study. Researchers found possibilities for working in new ways and developed trust and advocates of their research within the community under research. This can lead to the development of more patient focussed protocols, improvement in recruitment and the quality and relevance of data collected, more patient-related themes being identified in the analysis, and wider dissemination of the results [83, 84].

One of the most challenging impacts on researchers is the lack of funding and time to conduct the PPI activity following the right processes and in the right context in order for the PPI activity to have a valid impact. There is a general feeling that PPI is still not taken seriously enough by funders, who see it as a low priority and therefore don't provide enough funding for it, although some funders such as NIHR in the UK now provide important support for PPI. Furthermore, PPI involvement needs additional time, and this needs to be accounted for in research proposals.

A lack of commitment and a tokenistic attitude towards PPI by researchers can have challenging impacts on the service users, who feel undervalued, unimportant in the process, and unable to contribute, which may lead to a reduced impact or no impact of user involvement on the research.

For the community, beneficial impacts reported included greater awareness of the condition and a better understanding of research. However, the increased expectations on the community can be time consuming and costly for community members, often with little money to compensate for this.

A common theme identified in this review is the potential for challenging impacts which can result from colliding worlds, where the values and assumptions researchers have meet with the needs and aspirations of users and the community as a whole, and do not necessarily mesh well. This may negatively impact parties involved in PPI, and subsequently impact the success of PPI. Researchers report the challenging impact of having to compromise their working practices, and express concern that the impact of PPI may affect the integrity of the research, while service users report the issues of not being taken seriously, not being given a clear role, and not being given the knowledge or training needed to be able to contribute, leading to the loss of any hopes and aspirations for future involvement. This can create frustration and conflict between parties. Pre-planning, the training of both service users and researchers, and the development of trust and a good working relationship, so issues can be resolved as and when they arise, may alleviate such tensions.

While other reviews have reported the effects of PPI in research, this is the first systematic review to explore the impacts (INVOLVE report). However, although this paper has reported some important impacts on the people involved in research, the primary studies often report impact poorly, particularly in relation to the depth and content validity of the reporting, that is, the extent to which all the impacts identified in a study are actually reported in the final papers [85]. Studies are variable in the context and process information that they report around PPI and perhaps do not recognise the importance of reporting this in adequate detail alongside the impact results in order to aid our interpretation of why some forms of PPI work while other similar efforts have struggled. In this review it became clear that some aspects of context and process are more likely to create positive impacts, while others may lead to more challenging or negative impacts. For example, adequate funding and time, planning and procedures put in place early on, clear definition of roles, a positive attitude of researchers towards PPI, and trust and respect between parties increase the opportunity for a positive impact. A lack of funding and time, poor planning, unclear procedures and roles, a negative attitude of researchers, and a lack of trust and respect between parties increase the potential for a negative impact.

Future studies evaluating the beneficial and challenging impacts of PPI on researchers should be aware of the complexities of evaluating such impacts. A better conceptualisation of impact, prospective longitudinal studies to capture how impact changes over time, and development of valid and reliable tools with which to measure this impact are needed to contribute to significantly enhancing our understanding of PPI, what works, for whom, why, and in what circumstances.

5 Conclusion

The impact of PPI on the individuals and communities engaged in research is critical for the success of PPI in research. It is therefore essential to create a supportive environment with the right context and processes to enable the greatest chance of having a beneficial impact.

References

1. Department of Health. The Local Government and Public Involvement in Health Act; 2007.
2. Coulter A, McGee H. The European patient of the future. Maidenhead: Open University Press; 2003.
3. NIHR RDS. http://www.rds-yh.nihr.ac.uk/patient-and-public-involvement. Accessed 2012.
4. http://www.invo.org.uk/about-involve/involve-organisation-publications/. Accessed 2010.
5. NETCC. http://www.netscc.ac.uk/getting_involved/. Accessed 2012.
6. NIHR. http://www.rds-nw.nihr.ac.uk/public-involvement/. Accessed 2012.
7. HTA: http://www.hta.ac.uk/PPIguidance/. Accessed 2012.
8. Brett J, Staniszewska S, Mockford C, et al. Mapping the impact of patient and public involvement in health and social car research: a systematic review. Health Expect. 2012;. doi:10.1111/j.1369-7625.2012.00795.x.
9. Mockford C, Staniszewska S, Griffiths F, Herron-Marx S. The impact of patient and public involvement on UK NHS health care: a systematic review. Int J Qual Health Care. 2012;24(1):28–38.
10. HEFCE. http://www.ref.ac.uk/users/. Accessed 2012.
11. Critical Appraisal Skills Programme. http://www.phru.nhs.uk/Pages/CASP.htm. Accessed 1 April 2009.
12. Dixon-Woods M, Kirk D, Agarwal S, et al. Vulnerable groups and access to health care. A critical interpretative review. London: National Co-ordinating Centre for NHS Service; 2005.
13. Hubbard G, Kidd L, Donaghy E, McDonald C, Kearney N. A review of literature about involving people affected by cancer in research, policy and planning and practice. Patient Educ Couns. 2007;65(1):21–33.
14. Popay J, Roberts H, Sowden A, et al. Guidance on the conduct of narrative synthesis in systematic reviews. ESRC methods Programme; 2006.
15. Brett J, Staniszewska S, Mockford C, Seers K, Herron-Marx S, Bayliss H. 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); 2010.
16. Walmsley J, Mannan H. Parents as co-researchers: a participatory action research initiative involving parents of people with intellectual disabilities in Ireland. Br J Learn Disabil. 2009;37:271–6.
17. Nierse C, Schipper K, van Zadelhoff E, van de Griendt J, Abma A. Collaboration and co-ownership in research: dynamics and dialogues between patient research partners and professional researchers in a research team. Health Expect. 2011. doi:10.1111/j.1369-7625.2011.00661.x.
18. Hewlett S, de Wit M, Richards P, et al. Patients and professionals as research partners: challenges, practicalities and benefits. Arthritis Rheum. 2006;55(4):676–80.
19. Coupland H, Maher L, Enriquez J, Le K, Pacheco V, Pham A, Carroll C, Cheguelman G, Freeman D, Robinson D, Smith K. Clients or colleagues? Reflections on the process of participatory action research with young injecting drug users. Int J Drug Policy. 2005;16:191–8.
20. Minogue V, Boness J, Brown A, Girdlestone J. The impact of service user involvement in research. Int J Health Care Qual Assur. 2005;18(2):103–12.
21. Barnard A, Carter M, Britten N, Purtell R, Wyatt K, Ellis A. The PC11 Report. An evaluation of consumer involvement in the London Primary Care Studies Programme 2005; Peninsula Medical School, Exeter.
22. McCormick S, Brody J, Brown P, Polk R. Public involvement in breast cancer research: an analysis and model for future research. Int J Health Serv. 2004;34(4):625–46.
23. Clark M, Glasby J, Lester H. Cases for change: user involvement in mental health services and research. Res Policy Plan. 2004;22(2):31–8.
24. Dickson G, Green KL. Participatory action research: lessons learned with Aboriginal grandmothers. Health Care Women Int. 2001;22(5):471–82.
25. Burrus BB, Liburd LC, Burroughs A. Maximizing participation by black Americans in population-based diabetes research: the Project DIRECT pilot experience. J Community Health. 1998;23(1):15–27.
26. UK CRC. An evaluation of the process and impact of patient and public involvement in the advisory groups of the UK Clinical Research Collaboration; 2009.
27. Wyatt K, Carter M, Mahtani V, Barnard A, Hawton A, Britten N. The impact of consumer involvement in research: an evaluation of consumer involvement in the London Primary Care Studies Programme. Family Pract. 2008;25(3):154–61.
28. Cornes M, Peardon J, Manthorpe J. Wise owls and professors: the role of older researchers in the review of the National Service Framework for Older People. Health Expect. 2008;11(4):409–17.
29. Cotterell P. Exploring the value of service user involvement in data analysis: 'our interpretation is about what lies below the surface'. Educ Action Res. 2008;16(1):5–17.

30. McLaughlin H. Involving young service users as co-researchers: possibilities, benefits and costs. Br J Soc Work. 2006;36:1395–410.

31. Hassey Dow K, Ferrell BR, Leigh S, Melancon CH. The cancer survivor as co-investigator. The benefits of collaborative research with advocacy groups. Cancer Pract. 1997;5:255–7.

32. Collins K, Stevens T, Ahmedzai SH. Can consumer research panels become an integral part of the cancer research community? Clin Effect Nursing. 2005;9(3–4):112–8.

33. Davenport-Ennis N, Cover M, Ades TB, Stovall E. An analysis of advocacy: a collaborative essay. Semi Oncol Nurs. 2002;18:290–6.

34. Gooberman-Hill R, Horwood J, Calnan M. Citizens' juries in planning research priorities: process, engagement and outcome. Health Expect. 2008;11(3):272–81.

35. Williamson T, Brogden J, Jones E, Ryan J. Impact of public involvement in research on quality of life and society: a case study of research career trajectories. Int J Consum Stud. 2010;34(5):551–7.

36. Newell C, South J. Participating in community research: exploring the experiences of lay researchers in Bradford. Community Work Family. 2009;12(1):75–89.

37. Bryant L, Beckett J. 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; 2006.

38. Schneider B, Scissons H, Arney L, Benson G, Derry J, Misurelli N, Nickerson D, Sunderland M. Communication between people with schizophrenia and their medical professionals: a participatory research project. Qual Health Res. 2004;1494:562–77.

39. Rhodes P, Nocon A, Booth M, Chowdrey MY, Fabian A, Lambert N, Mohammed F, Walgrove T. A service users' research advisory group from the perspectives of both service users and researchers. Health Soc Care Community. 2002;10(5):402–9.

40. Shea B, Santesso N, Qualman A, Heiberg T, Leong A, Judd M, Robinson V, Wells G, Tugwell P, Cochrane Musculoskeletal Consumer Group. Consumer-driven health care: building partnerships in research. Health Expect. 2005;8(4):352–9.

41. Royle J, Oliver S. Consumer involvement in the health technology assessment program. Int J Technol Assess Health Care. 2004;20(4):493–7.

42. Dobbs L, Moore C. Engaging communities in area-based regeneration: the role of participatory evaluation. Policy Stud. 2002;23(3):157–71.

43. Faulkner A. Involving clients in counselling and psychotherapy research. Healthc Counsel Psychother J. 2008;8(3):16–8.

44. Caldon L, Marshall-Cook H, Speed G, Reed M, Collins K. Consumers as researchers—innovative experiences in UK National Health Service Research. Int J Consum Stud. 2010;34(5):547–50.

45. Beer D, Keeble P, MacInnes D, Rees D, Reid L. Development of a questionnaire to measure service user satisfaction within inpatient forensic services—the Forensic Satisfaction Scale. Liverpool: National Programme on Forensic Mental Health Research and Development (R&D); 2005.

46. Plumb M, Price W, Kavanaugh-Lynch M. Funding community-based participatory research: Lessons learned. J Interprof Care. 2004;18(4):428–39.

47. O'Donnell M, Entwistle V. Consumer involvement in decisions about what health-related research is funded. Health Policy. 2004;70(3):281–90.

48. Ross F, Donovan S, Brearley S, et al. Involving older people in research: methodological issues. Health Soc Care Community. 2005;13(3):268–75.

49. Tuffrey-Wijne I, Butler G. Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis. Health Expect. 2010;13(2):174–84.

50. Meyer M, Torres S, Cermeno N, MacLean L, Monzon R. Immigrant women implementing participatory research in health promotion. West J Nursing Res. 2003;25(7):815–34.

51. Oliver S, Milne R, Bradburn J, et al. Involving consumers in a needs-led research programme: a pilot project. Health Expect. 2001;4(1):18.

52. Langston AL, McCallum M, Campbell MK, Robertson C, Ralston SH. An integrated approach to consumer representation and involvement in a multicentre randomized controlled trial. Clin Trials. 2005;2(1):80–7.

53. Sutton J, Weiss M. Involving patients as advisers in pharmacy practice research: what are the benefits? Int J Pharm Pract. 2008;16(4):231–8.

54. Stevens T, Wilde D, Hunt J, Ahmedzai SH. Overcoming the challenges to consumer involvement in cancer research. Health Expect. 2003;6(1):81–8.

55. Bengtsson-Tops A, Svensson B. Mental health users' experiences of being interviewed by another user in a research project. A qualitative study. J Mental Health. 2010;19(3):234–42.

56. Rowe A. The effect of involvement in participatory research on parent researchers in a Sure Start programme. Health Soc Care Community. 2006;14(6):465–73.

57. Sainsbury Centre for Mental Health. A review of service user involvement in prison mental health research; 2008.

58. Godfrey M. More than 'involvement': how commissioning user interviewers in the research process begins to change the balance of power. Practice. 2004;16(3):223–31.

59. Reed J, Weiner R, Cook G. Partnership research with older people—moving towards making the rhetoric a reality. J Clin Nursing. 2004;13(3a):3–10.

60. Minkler M, Fadem P, Perry M, Blum K, Moore L, Rogers J. Ethical dilemmas in participatory action research: a case study from the disability community. Health Educ Behav. 2002;29(1):14–29.

61. Johns T, Miller P, Kopp K, Carter Z, Cooper G, Johnston J, Nicholas Z, Wright N. Equal lives? Disabled people evaluate and independent living strategy for Essex Social Services. Res Policy Plan. 2004;22(2):51–7.

62. Krieger J, Allen C, Cheadle A, et al. Using community-based participatory research to address social determinants of health: lessons learned from Seattle Partners for Healthy Communities. Health Educ Behav. 2002;29(3):361–82.

63. Ong BN, Hooper H. Involving users in low back pain research. Health Expect. 2003;6:332–41.

64. Paterson C. Consumer involvement in research into complementary therapies. Bristol: Medical Research Council Health Services Research Collaboration; 2003.

65. Andejeski Y, Bisceglio IT, Dickersin K, et al. Quantitative impact of including consumers in the scientific review of breast cancer research proposals. J Women's Health Gender Based Med. 2002;11(4):379–88.

66. Howe A, MacDonald H, Barrett B, Little B. Ensuring public and patient participation in research: a case study in infrastructure development in one UK Research and Development consortium. Prim Health Care Res Dev. 2006;7(1):60–7.

67. Ghulam S, Shah S, Robinson I. Benefits of and barriers to involving users in medical device technology development and evaluation. Int J Technol Assess Health Care. 2007;23(1):131–7.

68. Truman C, Raine P. Involving users in evaluation: the social relations of user participation in health research. Crit Public Health. 2001;11:215–29.

69. Abma T. Patient participation in health research: research with and for people with spinal cord injuries. Qual Health Res. 2005;15(10):1310–28.
70. Dewar BJ. Beyond tokenistic involvement of older people in research—a framework for future development and understanding. J Clin Nursing. 2005;14(3a):48–53.
71. Dyer S. Rationalising public participation in the health service: the case of research ethics committees. Health Place. 2004;10:339–48.
72. Maslin-Prothero S. Developing user involvement in research. J Clin Nursing. 2003;12(3):412–21.
73. Elliott E, Watson A, Harries U. Harnessing expertise: involving peer interviewers in qualitative research with hard-to-reach populations. Health Expect. 2002;5:172–8.
74. Morris MC, Nadkarni VM, Ward FR, Nelson RM. Exception from informed consent for pediatric resuscitation research: community consultation for a trial of brain cooling after in-hospital cardiac arrest. Pediatrics. 2004;114(3):776–81.
75. Taylor S. A new approach to empowering older people's forums: identifying barriers to encourage participation. Practice. 2006;18(2):117–28.
76. Belam J, Harris G, Kernick D, et al. A qualitative study of migraine involving patient researchers. Br J Gen Pract. 2005;55:87–93.
77. Morgan L, Chambers R, Banerji J, Gater J, Jordan J. Consumers leading public consultation: the general public's knowledge of stroke. Family Pract. 2005;22:8–14.
78. Trivedi P, Wykes T. From passive subjects to equal partners—qualitative review of user involvement in research. Br J Psychiatry. 2002;181:468–72.
79. Guarino P, Elbourne D, Carpenter J, Peduzzi P. Consumer involvement in consent document development: a multicenter cluster randomized trial to assess study participants' understanding. Clin Trials. 2006;3(1):19–30.
80. Angell K, Kreshka M, McCoy R, Donnelly P, Turner-Cobb J, Graddy K, Kraemer H, Kooperman C. Psycho-social intervention for rural women with breast cancer in isolated rural areas. J Gen Intern Med. 2003;18:499–507.
81. Hanley B, Truesdale A, King A, Elbourne D, Chalmers I. Involving consumers in designing, conducting and interpreting randomised controlled trials: questionnaire survey. Br Med J. 2001;322:519–23.
82. Carr S. Has service user involvement made a difference to Social Care Services. Social Care Institute for Excellence (SCIE); 2004.
83. Blair T, Minkler M. Participatory action research with older adults: key principles in practice. Gerontologist. 2009;49(5):652–62.
84. TwoCan Associates. An evaluation of the process and impact of patient and public involvement in the advisory groups of the UK Clinical Research Collaboration. UK Clinical Research Collaboration; 2009.
85. Staniszewska S, Brett J, Mockford C, Barber R. The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research. Int J Health Technol Assess. 2011;27(4):391–9.