A Snapshot Review

The costs and benefits of end user engagement in disability research

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Executive Summary

The purpose of this snapshot review is to provide an overview of existing evidence regarding the benefits and costs of end users being more involved in the research process. In particular, evidence from the disability field was identified and critically evaluated in order to determine the extent to which the current available evidence base supports this hypothesis in this field. The research question for this review is: *Does end user involvement in disability research improve research outcomes and knowledge translation?* Our evidence review provides some emerging evidence that involving users of TAC services in the research process has the potential to improve the quality and relevance of future research delivered through the Neurotrauma Research Strategy at ISCRR.

We searched peer reviewed literature using academic electronic databases, hand searching reference lists of papers and grey literature. Academic electronic databases searched included The Cochrane Library, Medline, EMBASE, CINAHL, PsycINFO and Google scholar. Search terms were determined which included “disability”, “user”, “ involvement”, “consumer”, “research”, “spinal cord injury”, “rehabilitation”, “client centeredness”, “collaborative research” and “patient participation”. The search was restricted to articles published in English between January 2000 and April 2013.

Twenty-five papers were identified and considered for inclusion in this review. Of these papers, four were systematic reviews including a Cochrane systematic review, nine reported on case studies, eight were non-systematic literature reviews and three used qualitative and/or survey methodology. We included papers if they involved the participation of patients, clients or consumers of health services in the research or policy development process. Overall, the quality of studies included in the review rated poorly with respect to research design rigour. The two key themes identified from the literature were: the involvement of users as experts in the research process; and the benefits and costs of involving users at each stage of the research process including priority setting, data collection and the dissemination of findings.

Of the 25 papers included, five were specific to user involvement in the neurotrauma context. However, consensus across the evidence is that user involvement can be of benefit to researchers, and research outcomes. In particular, involving users in research ensures relevance and appropriateness that is often overlooked by non-disabled researchers. Acknowledgement was made throughout the literature that user involvement can be resource intensive. Support is required by the user to meaningfully participate alongside the researchers, especially if that includes training which also may come with a financial cost.

Background

Involving end users in research, health service development and policy has been widely recognised as effective in the literature across a variety of disciplines and fields. Most notable is the field of community-based participatory research (CBPR), which involves community members as equal partners, working alongside expert researchers (Wallerstein and Duran 2003). Participatory research has been reported to empower non-academic researchers and to build capacity within the research process that enables better research outcomes. It has been suggested that insider knowledge provided by end users can enrich the research process and improve the relevance and applicability of research outcomes (Cargo and Mercer 2008; Cook 2008; Salimi, Shahandeh, Malekafzali, Loori, Kheiltash, Jamshidi, Frouzan and Majdzadeh 2012).

Internationally, the NHS in the UK has successfully embedded end user involvement into their policy development and health care decision making for over a decade by creating a patient-led health system through the Health and Social Care Act (Department of Health 2001). This development has been an important enabler for increasing user involvement in research. For example, NHS research and funding bids now require evidence of end user involvement (Beresford 2002; Carr 2004; Livita, Canvin, Shepherd, Jacoby and Gabbay 2009). Similar trends have occurred in the Netherlands, Sweden and Denmark (Abma 2005; Tritter and McCallum 2006).

Despite promising evidence from other fields, end users have not been significantly involved in disability and rehabilitation research historically. If they have been involved, this typically only occurs at the research priority setting stage and to a lesser extent, during the research design phase (Craig 2008; Hammell 2010; Hammell, Miller, Fowler, Forman and Jacobsen 2012). To this end, it has been reported that little is understood about how the process of involvement might occur in order to ensure that it is authentic and beneficial to both the end users and researchers (Abma 2005). A number of commentators have proposed in recent years that if end users of rehabilitation and related health services were more involved in research and knowledge translation this might well lead to improved research outcomes and a comprehensive evidence base on which to make more informed decisions about improvements to health services and their delivery (Hammell 2001; Crawford, Rutter, Manley, Weaver, Bhui, Fulop and Tyler 2002; Hammell 2010; Priestly, Waddington and Bessozi 2010).

Research question

The purpose of this review is to inform the Neurotrauma Research Strategy 2011-2015 concerning the available evidence for involving end users more systematically and extensively in research initiatives conducted under the priority areas of the Strategy. It is hypothesised that increased involvement of TAC clients with neurotrauma might facilitate the identification of key research questions and the delivery of applied research to meet the key objectives of the ISCRR Neurotrauma Research Strategy. The Strategy seeks to deliver research that will improve client outcomes and experience and reduce scheme liability.

This snapshot review provides an overview of existing evidence regarding end user involvement in the research process in the disability field. In particular, evidence from the disability field has been identified to determine if the involvement of clients, end users or patients in all stages of the process has the potential improve the results of the research and contribute to better outcomes with increased knowledge translation. The key research question for this review is:

Does end user involvement in disability research improve research outcomes and knowledge translation?

Method

The method for this snapshot review was an evidence review of the literature on the topic of end user involvement in disability research. This is not a systematic review. Peer reviewed literature was searched using electronic databases, hand searching reference lists of papers and grey literature. Electronic databases searched included The Cochrane Library, Medline, EMBASE, CINAHL, PsycINFO and Google scholar. The search was restricted to articles published in English between January 2000 and April 2013. Search terms used were:

Client centered practice
Client centered research
Consumer oriented approach
Collaborative research
Community research partners
Client centeredness
Disability
Experiential knowledge
Knowledge translation
Participatory research
Patient choice
Patient experience
Patient participation
Spinal cord injury (SCI)
Traumatic brain injury (TBI)
User involvement

Inclusion and exclusion criteria

Due to the limited number of studies directly related to end user involvement in neurotrauma research our inclusion criteria was broad. We included papers if they involved the participation of patients, clients or consumers of health services in the research or policy development process. Types of studies included descriptive and qualitative studies and were not limited to just RCTs. The term disability included neurotrauma, intellectual and mental health disabilities. Papers were excluded if they were lower levels of evidence e.g. opinion articles or were not related to a health care setting.

End user involvement in disability research

There is currently no single definition of end user involvement in research. The ‘end user’ can be referred to as the ‘user’, ‘patient’, and stakeholder ’,‘ consumer and in some instances ‘carer’. These terms indicate the diversity of lay people who can participate in the decision making of their health care. End user involvement in research has been categorised into three tiers: consultative, collaborative and user-led (Rose 2003; Hewlett, de Witt, Richards, Quest, Hughes, Heidberg and Kirwan 2006). User-led research involves end users controlling all stages of the research process which include study design, recruitment, ethics, data collection and analysis, report writing and dissemination of findings (Truman and Raine 2001; Faulkner and Thomas 2002; Ross, Donovan, Brearley, Victor, Cottee, Cowther and Clark 2005; Tuffrey-Wijne and Butler 2009). All three levels of user involvement are considered in this review.

To understand the concept of ‘involvement’, Arnstein’s ladder of citizen participation (1969) has been cited throughout the literature to consider the level of participation that patients and clients of health services might have in the research process (Beresford 2002; Tritter and McCallum 2006; Abma, Nierse and Widdershoven 2009). The ladder comprises eight types of participation categorised into three tiers: Non-participation, Degrees of Tokenism and Degrees of Citizen Power. Through this, issues of power and inequality are illustrated which may influence the collaboration between the ‘expert’ and ‘non-expert’ during involvement of any research endeavour. Tritter and McCallum (2006) note that the model does not recognise levels of knowledge and experience held by both the end user and the health professional or researcher. As such, the model must be approached with some caution when used to guide how involvement can be improved to move from non-participation to meaningful involvement, that is, where the non-expert researcher holds equal power in the research process. This is explained later in this review.

Results

Of the thirty-five studies identified by the search, twenty-five articles met the inclusion criteria (Table 1). Four systematic reviews were sourced, including one Cochrane systematic review (16%). Eight (32%) studies were (narrative, or non-systematic) literature reviews and nine (36%) were case studies. Two (8%) were results of surveys, two (8%) used qualitative methodology and one study employed a mixed methods design (4%).

Fifteen articles (60%) were related to end users with a disability and five (20%) of these studies were directly related to end user involvement in neurotrauma research. Overall, the quality of studies did not rate high with respect to research design rigour. There were no RCTs, or evaluations investigating the effectiveness of end user involvement specifically.

Table 1: Summary of studies included in the review categorised by types of evidence

Study authors	Location	Nature of evidence	Health focus	Main Findings
Crawford et al (2002)	UK	Systematic review	Public health	Involving patients has had positive effects on the provision of services including accessibility of services and patient information. An evidence base for the use of services, quality of care, satisfaction or the health of patients does not exist.
Nilsen et al (2013)	Norway	Systematic review	Public health	Moderate quality evidence that involving consumers in the development of patient information material increases its relevance. Low quality evidence that consumers who aid in the development of consent documents has impact on consumer understanding. Very low evidence that telephone discussions and face to face group meetings engage consumers better than mail surveys to set priorities.
Oliver et al (2004)	UK	Systematic review	Public health	Productive methods for involving consumers require appropriate skills, resources and time to develop and follow appropriate working practices. The more consumers are involved in determining how this is to be done, the more research programmers will learn from consumers and about how to work with them.
Simpson & House (2002)	UK	Systematic review	Mental health disability	Involving end users as employees of mental health services led to clients having greater satisfaction with personal circumstances and less hospitalisation. Providers of services who had been trained by end users had more positive attitudes towards end users. Clients reported being less satisfied with services when interviewed by end users.
Priestly et al (2010)	Netherlands	Survey	Disability	There is a high degree of readiness for collaboration in academic research but concerns about the readiness of institutions to engaged disabled people as equal partners in the research process. A wide range of research needs and challenges exist for researchers to create user-led research.
Minogue et al (2005)	UK	Survey	Public health	Consumers benefit from involvement through an increase in knowledge and experience, self-esteem and confidence. Researchers involved benefit from a broader perspective of the health issue and better focus on the topic.
Warms et al (2005)	USA	Survey Qualitative	Spinal cord injury	End users are considered experts about their health issue. Examining comments and narratives written in the margins of quantitative survey questionnaires can add value to and extend the understanding of survey findings and implications.
Litva et al. (2009)	UK	Qualitative	Public health	It is necessary to employ different strategies to accommodate different end users and the level of involvement of users.
Abma (2005)	Netherlands	Case study	Spinal cord research	Dialogue between user and research must create positive social environments for users to participate effectively within. Users must be properly represented within the research process. Barriers to involvement include vested interests, poor communication and lack of identification of the research with the user.
Abma et al (2009)	Netherlands	Case study	Intellectual disability	Involvement must occur at all stages of the research process. More successful outcomes can be achieved through fostering experiential learning, mutual learning, openness and respect. Financial reimbursement and acceptable workloads also benefit the partnership.
Bourke et al (2012)	Canada	Case study	Spinal cord injury & rehabilitation	Considerations for end user committee development included good membership representation and expertise and knowledge of members. Process should include members who are research literate which can build the capacity of the research endeavour.
Evans (2004)	UK	Case study	Disability	End users can be commissioners and research producers at every stage of the research process. If research is user-led, users will define the topic, the hypothesis and the methodology. They will be involved in recording and collating the data and decide on the conclusions to be drawn and which lessons will be used for policy and practice.
Clavisi et al (2012)	Australia	Case study	Traumatic brain injury	Stakeholder involvement in research priority setting benefits the research process. Patients and

		Literature review		family are critical members of the rehabilitation team. A combination of methods and diverse stakeholder representation are required if research priorities are to be based on the view that all people are affected by the research enterprise.
Henry et al (2002)	USA	Case study	Psychiatric disability	Stigma and stereotypes about the capabilities of people with disabilities exist in the research setting. Staff may be unable or unwilling to provide sufficient support and requires a shift in organisational attitude. Training and support is needed to develop the credentials needed to promote senior researchers.
Hewlett et al (2006)	UK	Case study	Rheumatology	Benefits of user involvement include new insights, peer reviewed grant applications, troubleshooting strategies, co-led investigator meetings, user empowerment and novel outcomes.
Taylor et al (2004)	Australia	Case study	Mental health disability	More support is needed to enable users to be involved in the research process. Involvement may consist of users involved in planning and advisory groups, in the training of professionals or employment as professional care providers.
Tuffrey-Wijne & Butler (2009)	UK	Case study	Learning disabilities	User involvement in data analysis can be beneficial to the research process however tokenism must be avoided and academic rigour maintained. Rational for involvement must be clear. Involvement often requires extra support, time and costs.
Boote et al (2002)	UK	Literature review	Public health	Influence of users in the research depends on level and stage of involvement and issues of power and control. Success factors include trust between researcher and user, reward of user researchers and dissemination of research findings. Quality of the research will be challenged by user representativeness, bias, quality and rigour, influence, consumer expectations, cost and length of research, roles and responsibilities.
Carr (2004)	UK	Literature review	Public Health	Fifteen key messages for policy and practice emerged from the literature including issues of representation, power relations, planning a framework to monitor and evaluate and managing conflict
Frankham (2009)	UK	Literature review		Partnership research literature. More research and evaluation needs to be conducted but there are many benefits of use involvement. Higher quality research would be complex and costly and would benefit from an ethnographic approach.
Hammell (2001)	Canada	Literature review	Occupational therapy & disability	Quantitative methods for client-centred research limits research questions and issues addressed. Qualitative methods are compatible with client-centred research to improve therapy interventions and models of service delivery so that they meet the needs of users.
Hammell (2010)	Canada	Literature review	Spinal cord injury	SCI research participants complain about the lack of relevance of research and poor dissemination of research findings. People with SCI will have a better understanding of appropriate research questions and how to frame them. Establishing research agendas in partnership will reduce the prevalence of unnecessary research.
Hammell et al (2012)	Canada	Literature review	Occupational therapy & disability	Occupational therapy research is not consistently undertaken in a collaborative manner. Power and control issues occur with the research agenda. Study participants want to influence the research agenda so that their needs and priorities are addressed.
Telford & Faulkner (2004)	UK	Literature review	Mental health disability	Barriers to service user involvement highlight challenges to traditional researcher-led ideologies and processes e.g. ideological differences in approach between users and researchers. Shared goals are required for the research process and clarity around motives for collaboration.
Tritter & MacCallum (2006)	UK	Literature review	Public health	End user expertise is distinct from professional experts in the collaboration. There is a distinct different between participation and expert by experience. User involvement often includes a hierarchy of knowledge which creates boundaries for research processes.

Two clear themes emerged from the review of the literature. The first theme concerns end users as co-researchers and 'experts of experience' who can contribute to the process. The second theme concerns the involvement of end users at different stages of the research process and then identifying the associated benefits and barriers. Of course, end users are not a homogenous group and they are likely to engage in the research process with differing perspectives and differing desires to be involved at distinct stages of the research process; and differing abilities to participate in different roles.

1. Including end users as experts

The evidence suggests that involvement by end users with a disability in rehabilitation research brings knowledge and experience to the partnership which may not be held by the researchers themselves and which can "value add" to the diversity of skills and knowledge required for more appropriately designed research (Abma 2005; Hammell 2010). Traditionally, end users involved in research projects have been considered to be subjective and unscientific in their approach (Telford and Faulkner 2004). More recently, the concept of user-led research has been employed to describe users 'determining the research focus, the research process, the interpretation of the research findings, and the conclusions to be drawn for policy and practice' (Evans and Jones 2004). Beresford found that end users hold 'experiential knowledge' which is gaining legitimacy in the disability field (Beresford 2007) but for research to translate to policy and practice effectively, end user knowledge and expertise must be better valued and communicated (Carr 2004).

Abma, Nierse and Widdershoven (2009) used case examples to highlight that patient research partners can be more effective than expert researchers because they are 'closer' to the patients through experience. This was substantiated by a systematic review conducted by Simpson and House (2002) suggesting that end users can elicit more relevant data by building stronger levels of trust with the end user or patient though their shared experience.

Study findings also suggest that a lack of representativeness amongst contributing end users can cause issues of equity (Trivedi and Wykes 2002; Telford and Faulkner 2004) but has been reported as a challenge for researchers to overcome this in reality (Clavisi, Bragge, Tavender, Turner and Gruen 2012). Bourke, Snell, Sinnott and Cassidy's case study (2012) reported on the selection of members to an end-user research consultation committee for people with a disability. The authors recommend identifying users who are 'suitably qualified' to contribute to the process.

However the level of involvement of users as experts in the research process can be diminished due to a variety of challenges and expectations of their role. Hewlett, de Witt, Richards, Quest, Hughes, Heiberg and Kirwan (2006) identified some of these challenges as poor communication, tokenism, lack of confidence of users in the research role and an imbalance of power in the relationship between the user and researcher. This has been supported by findings from Bourke, Snell, Sinnott and Cassidy (2012).

Henry, Nicholson, Clayfield, Phillips and Stier (2002) describe the experience of creating research assistant positions for people with a psychiatric disability in a university setting. They report that overall, people with a psychiatric disability were able to integrate into the workplace and undertake the same responsibilities as their non-disabled researchers. However a shift in organisational culture was required by research staff and consistent support mechanisms were required to ensure meaningful integration into the workplace. This study did not report on the benefits associated with the expertise and knowledge contributed by the research assistants.

2. Involvement at different stages of the research process

Priority setting and research questions

Traditionally, researchers have decided on the priorities and research questions for disability research (Hammell 2010; Hammell, Miller et al. 2012). Differing ideologies between the researcher and the end user can create challenges at the initial stage of the process. However emerging evidence suggests that end user involvement in priority setting is becoming the most common stage of involvement (Boote, Telford and Cooper 2002; Telford and Faulkner 2004; Minogue, Boness, Brown and Girdlestone 2005).

A systematic review conducted by Oliver, Clark-Jones, Rees, Milne, Buchanan, Gabbay, Gyte, Oakley and Stein (2004) concluded that there is sufficient evidence to suggest that end user involvement in identifying and prioritising research topics can improve the relevance of the research. This is in spite of the often technical nature and complexity of research projects. Abma, Nierse, Widdershoven (2009) also agree that end user involvement ensures relevance of the research topic.

Clavisi, Bragge, Tavendar, Turner and Gruen (2012) conducted a facilitated mapping workshop and online survey to identify priorities and research questions for patients with a traumatic brain injury. They concluded that involving multiple stakeholders in this process can contribute to improving the relevance of rehabilitation decisions.

Study design, data collection and analysis

A handful of papers were sourced on end user involvement in design, data collection and analysis, including two systematic reviews. Simpson and House (2002) found that users can be involved in the research process in a range of roles without any harmful effect and that end users as interviewers are able to elicit more sensitive information from participants than non-users.

Nilsen, Tinderholdt, Johansen, Oliver and Oxman (2013) conducted a Cochrane systematic review to assess the effects of consumer involvement in developing health policy and research, guidelines and patient information. The review indicates that there is weak evidence to suggest that end user involvement can improve research and policy outcomes. Six randomised controlled trials were included in the review which suggests that end user involvement in the development of patient materials can have a positive impact. They also found that there is low quality evidence to suggest that end users as interviewers can influence satisfaction surveys.

End user involvement in the design of data collection tools can assist in including the right questions in the most appropriate format. Warms, Marshall, Hoffman and Tyler

(2005) analysed the written comments made on survey instruments used in a study on the management of chronic pain in rehabilitation. Respondents were persons with a spinal cord injury or who had experienced an amputation. Content analysis revealed that survey methodology questions do not elicit meaningful data where respondents want a dialogue with the researcher about their health issue. Half of respondents (54.1%) wrote comments and narratives in the margins of the survey in order to provide information about what was important to them which had been missed in the design of the survey.

Challenges of end user involvement in the analysis of data have been highlighted by Tuffrey-Wijne and Butler (2009). Their study involved a co-researcher with a learning disability who conducted content analysis on a series of case studies within an ethnographic study. The authors report that whilst end user involvement can be valuable to both end user and researcher, academic rigour must be maintained. They report that user involvement can be costly as far as time and support are concerned and the issue of ‘value add’ must be considered before making the decision about involvement. Researchers must be clear about what skills can be added that non-disabled researchers cannot provide alone.

Dissemination of findings and knowledge translation

There is a paucity of evidence which explains the issues concerning the dissemination and knowledge translation of research findings. Hammell (Hammell 2001; Hammell 2010) reviewed literature between 1995 and 2009 on involving people with a spinal cord injury when determining research priorities. This study reported that end users complain about the lack of relevance of research despite effort spent participating in research studies, compounded by a lack of translation, an idea shared by Abma (2005). The review was unable to source any studies which described the dissemination of findings or knowledge translation which involved end users in this process.

Discussion

This review has identified and examined existing evidence regarding end user involvement in disability and public health research to determine if their involvement improves research outcomes and knowledge translation in ways that might be relevant and salient for the neurotrauma context. To summarise the findings from the review, the existing evidence suggests that end user involvement in disability research is beneficial, especially if end users are involved in all stages of the research process.

Across the literature it was reported that end users are considered experts about their health issue therefore their involvement improves the relevance of the research. Involvement also empowers the end user, creating an opportunity to build their knowledge and skill base in research. Involvement also helps expert researchers to better understand the health issue from the perspective of the service user.

However there are areas where caution must be taken when considering how to engage end users in the research process:

1. End user involvement must be planned to avoid tokenistic participation as described originally in Arnstein's model of citizen participation (1969) and referred to in many of the papers sourced for this review.

2. Researchers must also avoid considering users as a homogenous group and consider the diversity of skills, experience and knowledge they bring to the collaboration. The evidence clearly outlined that meaningful participation involved the inclusion of the end users as experts in their own right to benefit research outcomes.

3. In many of the studies it was articulated that for end users, participating as a co-researcher may be an unfamiliar role. Time and effort on the side of the researchers is required to ensure that the structures within the organisation and the processes within the research management process ensure that end users are supported. Financial costs may be associated with this level of support and training to ensure that end users are equipped with the relevant skills to be able to contribute to all stages of the research process.

4. This review was restricted by two issues relating to the quality of the evidence presented:

    a. Firstly, there were a very limited number of papers on user involvement in the neurotrauma context specifically. Therefore evidence was sourced more broadly from disability and public health research to understand the benefits and costs of user involvement. There were also very few articles which focussed on the latter stages of the research process, in particular the dissemination and knowledge translation of findings. This is an important process in the research cycle, especially when users often complain about the lack of relevance of research and poor dissemination efforts into policy and practice.

    b. Secondly, the quality of evidence in this area is considered low due to the study design and methodology utilised in extant literature for the study. This point has been acknowledged in the selected systematic reviews and there have been calls for more studies to be conducted with stronger study design. Very few randomised controlled trials exist about end user involvement in the research process to provide evidence of impact. However the evidence also suggests that quantitative methodology may not always be able to appropriately capture the impact of user involvement as a research approach. Much of the research that has been conducted to understand the process and impact of user involvement in research and health service development has engaged qualitative methodologies, mostly in the form of case studies.

    c. By its very nature, a snapshot review may have not involved some evidence and therefore possible bias is introduced by using a rapid rather than full systematic review.

Conclusions and implications

Historically, end users have not been significantly involved in disability and rehabilitation research. Examples of involvement have usually been at the priority setting stage and to a lesser degree at the research design phase. More recently, end users have been involved in user-led research projects which involve end users throughout all stages of the research process.

This snapshot review has shown that existing evidence points towards a range of benefits for both end users and researchers. The user involvement should be better integrated into the latter stages of the research to ensure comprehensive involvement. However, further research is needed in this area to build the evidence base.

Barriers to end user involvement include resource intensive with regard to support especially if that includes training which also may come with a financial cost. Researchers are therefore recommended to plan for the involvement of users to ensure appropriate and meaningful inclusion of users. Again, further research in this area is required.

The main limitation highlighted in this review is the quality of evidence of end user involvement which has made it difficult to determine its impact as a strategy to improve research outcomes and knowledge translation. Caution must therefore be taken when interpreting results. There are methodological limitations to many of the studies included in this review and there is a paucity of high-level evidence to understand the impact of user involvement. Further research and better evidence is needed about end user involvement, in particular at the knowledge translation and dissemination stage of the results.

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