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## A stronger voice

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## **A stronger voice: Action research in mental health services using carers and people with experience as co-researchers.**

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### **Structured Abstract:**

**Purpose:** This article discusses learning about service-user and carer involvement from an action research study into self-directed support implementation in one English mental health trust. The article promotes appointing and supporting carers and people with experience as co-researchers to obtain authentic local perspectives when undertaking service implementation or redesign.

**Design/Method/Approach:** The researchers used an action research spiral method incorporating carers and people with mental health experience as co-researchers. The co-researchers worked alongside the lead researcher gathering data from focus groups, training sessions and other meetings over four years and attending collaborative steering group meetings alongside professional workers throughout the study.

**Findings:** We suggest that participation gave co-researchers a powerful and effective voice in this service redesign. This approach revealed more authentic research data and required professionals to be more accountable for their perceptions and to make explicit their understandings throughout the study, which enabled more effective working. Steering group participation was central to securing this [participation](#).

**Originality:** We illustrate how carer and service-user co-researchers can be supported to benefit both mental health organisations undergoing change and to co-researchers themselves. It also identifies action research's utility in uncovering learning as well as structuring change.

**Keywords:** User involvement, Organisational learning, Organisational change, Empowerment.

**Article Classification:** Viewpoint

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### **Introduction**

This article arises from an action research (AR) study set in a large health and social care English mental health trust. The study was designed to integrate service-user and carers views on

implementing self-directed support (SDS), which describes how individuals and families can have informed choice and greater control about how support is provided to them (Scottish Government, 2010). The belief underpinning SDS is that it empowers people to design their own support plans and decide their nature (Carr, 2010). Here SDS included direct payments (DP) or managed personal budgets (PB) for those assessed as needing social care resources in their support plan. Implementing SDS using an AR study aimed to provide better outcomes for people through personalised support, flexibility, transparency and control over their support plans and was intended to bring authenticity and a more critical stance from local project voices. Barriers to service-user and carer involvement, as experienced by co-researchers in involvement roles, have already been revealed. These include: professionals not using plain English and not respecting service-user views (who might be perceived as challenging service culture) and organisational discourse that may devalue emotive service-user contributions. Provoking emotional responses in service-user or carer participant discussions is a risk (Rose, 2003; Carr, 2004; Steel, 2005; Connor and Wilson, 2006; Hitchen *et al.*, 2011). We explore and discuss how user and carer involvement in this study afforded the co-researchers a more meaningful, powerful and effective voice in the change process. We argue that this approach could be considered in similar change projects when that involve carers and people receiving mental health services.

## **Background**

There has been growing emphasis on patient-centred services from the UK Department of Health (DH). This is reflected in governmental guidance that aims to create a health service that genuinely responds to patients and carers by listening and learning from their experiences (DH, 2001). This encompasses moving from a centrally-led to a patient-led service through better systems for feedback and involvement (DH, 2005b) with a focus on involving service-users and carers in research design, conduct, analysis and reporting (DH, 2005a, 2006). There is a growing literature on involving service-users in research (Telford and Faulkner, 2004; Faulkner, 2004; SURGE, 2005). User involvement is defined by Abelson *et al.*, (2010) as occurring where the following three attributes are evident: information provision to participants about the topic/issue being discussed, an opportunity for interactive discussion among participants and organisations, and explicit processes for collecting individual or collective input. It is clear that positive benefits for service-users and for research studies are maximised when there is participation from an early stage and where that participation is in-depth (Brett *et al.*, 2014). Additionally, research activity itself can be subject to radically different imperatives where service-users are involved as researchers no longer solely arbitrate knowledge production, which becomes knowledge co-production (Gillard *et al.*, 2012).

Increasing focus on patient-centred services means that there is now a legal duty in the UK to involve service-users in research design and conduct. This is believed to benefit research by producing better quality studies, which in turn achieve more effective service redesign and service quality improvement (Staniszewska, 2009). This patient and public involvement (PPI) extends to the whole healthcare research spectrum from medicinal product randomised controlled trials to qualitative research, and funders insist on processes [for](#) involvement. However, while PPI models are useful for evaluating research impact into relatively simple outcomes including quality of life studies, they have been less useful in demonstrating outcomes in service redesign studies and, moreover, there is less attention on the effect that being involved can have on service-users and carers (Staniszewska, 2009). Staniszewska *et al.*, (2011) argue that

PPI definitions are inconsistent, which has hampered conceptual development and that this can be ameliorated by a quantitative focus. Gaventa and Barrett (2012) delineate a ~~four~~-democratic and developmental outcome typology: strengthening citizenship construction, strengthening participation, strengthening accountability and developing inclusive and cohesive societies. This typology provides an ~~overview~~ ~~—meta-cognition~~ of the field, but models that emphasize community provision for service-users in mental healthcare have been subject to limited empirical research about their effectiveness (Carr, 2004, Minogue *et al.*, 2005; Buckland, 2007).

It would appear that tensions exist between service-user and professional perspectives, particularly concerning a person's capacity for involvement and absent provider awareness of possibilities for changing care delivery (Storm and Edwards, 2013). Professionals should routinely involve users and carers and be trained to do so, argue Minogue *et al.*, (2005), in processes to make services relevant and consumer involvement meaningful. Principles include: clarity about the reasons for involvement; honesty about the potential for change; and training for front line staff about participant involvement. Extra time and support, sensitivity and clear communication are required. Ensuring organisational commitment and agreeing how outcomes are fed back to service-users is also important (Crawford *et al.*, 2003; Rose *et al.*, 2003).

Studies show that user involvement brings mixed blessings with increasing opportunities for involvement. Truman and Raine (2002) argue that service-user perspectives need to be addressed within service evaluations if their interests are to be central to services, but how this is achieved tests mental health service staff. A Health Technology Assessment (Oliver *et al.*, 2004) into consumer involvement in research and development agenda-setting for the NHS concluded that productive methods for involving consumers require appropriate resources, skills and time to develop. Oliver *et al.*, (2004) advise that to influence research agendas consumers require information, support and resources to consult with their peers and prioritise topics, as well as repeated engagement. It is also clear that participants in well-designed engagement processes report high satisfaction with ~~the~~ objectives, logistics and change management, and this relates to their ability to engage in discussion and participate in partnerships (Abelson, 2010).

Conducting studies with co-researchers raises ethical dilemmas not usually encountered where people are research subjects. This requires assessing vulnerability, sensitivity to capacity for decision-making, transparency and researcher self-awareness to navigate the group dynamics that may arise (Tee and Lathlean, 2004). It is clear that service-user-involvement in research needs its strengths, weaknesses and impact ~~to safeguard its future~~ evaluating systematically ~~to safeguard its future~~ (Beresford, 2012), not least to understand service-user and carer experiential knowledge. More work to evaluate knowledge management is required and involvement models that provide sound ethical, effective and more equal voice to co-researchers need to be evidenced.

### **Participants and their participation**

To understand service-user and carers' unique contribution in this study, we need to know who was involved, how they were recruited and how they contributed. This was an AR study and used a spiral method (Figure 1) to structure progress and negotiate change, based on planning, taking action and then reflecting on the results to plan further action (Coghlan and Brannick, 2010). Co-researchers (service-users and carers) worked alongside the lead researcher (SH) gathering data from focus groups, training sessions and other meetings and attending collaborative steering group meetings alongside professional workers. The study received ethical approval from the National Health Service (NHS) Research Ethics Service, the University at

which the lead author was studying and research governance approval from the NHS trust in which it took place. The full project design, methods and findings are reported elsewhere (Hitchen *et al.*, 2014). Qualitative data from the focus groups and other meetings were transcribed and thematically analysed, and informed consent was secured from participants and continually re-negotiated throughout the project.

### **Figure 1 here**

Participants included five co-researchers, although one dropped out due to personal reasons after four months, leaving two carers and two people with mental health service-user experience. These co-researchers were recruited through advertising a job description for the role in existing support networks. Additional time to respond than is usual for job applications was given to enable them to fully consider the opportunity. Application letters were submitted by those interested, including relevant experience. Interviews including questions on motivation were constructed from the literature on service-user involvement (Buckland and Gorrin, 2001; Faulkner and Thomas, 2002; Telford and Faulkner, 2004; Williamson, 2004; Minogue *et al.*, 2005; Connor and Wilson, 2006). Expenses were paid and an hourly rate almost double the minimum wage was agreed. The co-researchers attended each steering group meeting and co-facilitated focus groups, having undergone qualitative methods training provided by Folk.Us, a user involvement in research group. Owing to their potential vulnerability, additional safeguards for service-users and carers were also built into the AR study by the lead researcher as one-to-one meetings, group meetings/debriefings and opportunities for contact at any time during the project's duration. Local authority and trust staff were also recruited for their relevance to the SDS agenda and together with the co-researchers they formed a project steering group who met regularly throughout the study. Professional staff included recovery care coordinators with a direct responsibility for care planning and delivery with service-users. Other professional staff in attendance included those with management and finance roles. In England, responsibility for community mental healthcare is split between NHS trusts who deliver care and local authorities (local government) who contract and fund service delivery. The recovery care coordinators were NHS employees with professional backgrounds in nursing, occupational therapy or social work. Meetings between the co-researchers and the lead researcher were held following every steering group meeting and at other regular periods throughout the research. These meetings were designed to provide formal and regular support to the co-researchers to safeguard their well-being (Truman and Raine, 2002).

#### *Steering group collaboration*

The collaborative steering group discussed, planned and implemented action, critically reflecting on data from those actions, and then re-planned interventions in the cyclical AR process. All major decisions were discussed and finalised through this forum. Participants were updated and informed about developments. The steering group role in AR appears to have been little researched; however, groups are generally regarded as a good idea. Coughlan and Coughlan (2002) state that it is common for action researchers to have a project steering group, which enables them to manage the project by providing a team to plan, implement and evaluate by building on insider knowledge. In this research, the steering group guided the project; however there are significant differences between this AR project and one where a research topic is collaboratively agreed and a group formed to steer the research process. This research project

was initiated to interpret governmental policy to introduce SDS by collaborative means, including local stakeholders, whilst also researching the process. The research focus therefore was externally provided and whilst the group had considerable discretion and flexibility over timing and how to design the implementation programme, it was limited in its decision making power, reporting both to local authority and trust managers.

Bushe and Shani (1991) propose a parallel structure in AR programmes that includes a steering committee setting directions and providing authority to promote a climate conducive to learning, innovation and group problem solving, with members having a formal position in the structure. This enabled their participants to think, talk and act differently from their usual work role, providing a setting where organisational norms can be questioned and doubts are acceptable. The steering group in this project mirrored the Bushe and Shani (1991) steering committee acting as a learning group with reference terms agreed at the outset, a commitment to challenge assumptions and treat all participants as peers. The group provided a safe place for people to challenge and question organisational practice, and co-researcher involvement caused the professional staff to consider activities in greater depth. Reflections, dialogue and differing perspectives were encouraged with an emphasis on returning to consider what difference proposals would make for people receiving social care services. The steering group was chaired using an actively collaborative approach, where participants could express their views, whether or not these were compatible with organisational or national ethos. Ground rules were agreed by all participants that reflected open, respectful and explanatory dialogue. This approach provided, as far as possible, equality for all to participate with equal weight given to their contributions, and was important when engaging service-users with mutual respect and genuine partnerships (Read and Maslin-Prothero, 2011).

Problems were encountered: there were numerous occasions where co-researchers were unable to comprehend all the nuances and acronyms used in conversations and so the post-steering group meetings were vital to ensure [that](#) understanding and learning [whereas](#) taking place. Although ground rules had been agreed, professionals found it difficult to speak plain English. Inconsistent trust representation at the meetings also compounded the problem with new representatives needing to acclimatise to the emphasis on inquiry, explicit assumptions and a slower pace within the meeting. Zuber-Skerrit (2005) suggests that in AR, collaboration, team spirit and symmetrical communication accepting uniqueness, differences and capacity to contribute to problem solving leads to synergy and systemic development. O'Brien (1998) confirms AR's collaborative resource principle, suggesting that this presupposes each person's ideas are equally significant as potential resources for analysis and that insights are gleaned from contradictions between many viewpoints. Hitchen (2007) views collaboration as providing the key to working across stakeholder groups in service development. The co-researchers provided direct questioning from perspectives that were not immersed in day-to-day social care matters, generating a reflexive approach. Questions starting with why, where, what and how were encouraged allowing underlying assumptions and philosophies to surface. Coughlan and Coughlan (2002) suggest that a steering group may not have the time to engage with much introspective monitoring and may resist efforts to do so; however the steering group was encouraged to be more inquisitive by the constant co-researcher attendance and their questioning approach.

*Steering groups and the co-production of meaning*

Responsibility for data collection and analysis was the lead researcher's (SH). She also ensured that the project was moving forward and agreeing change strategies. However, the research role was shared with the co-researchers who consistently attended the steering group and were involved in focus group data collection and training sessions with the lead researcher. Initial data analysis was shared with the co-researchers for verification and then the wider steering group who focussed on practical outcomes whilst simultaneously building knowledge and producing meaning from the enquiry process. Through small group and one-to-one meetings with the co-researchers, the lead researcher developed a close collaborative working relationship with them. This was demonstrated by their relaxed behaviour and communication and their direct feedback by email, conversation and letter. This enabled the co-researchers to be more confident within the steering group, knowing that they had a supporter, as chairperson, who valued their perspectives ~~and contributions~~ and could help them, if necessary, to make valid points. Additionally the co-researchers worked alongside the lead researcher collecting data and feeding this back to the group; a process that increased respect for their expert by experience contribution, and enabled them to participate more fully with added legitimacy. They believed they were acknowledged differently, more respectfully, in this steering group than in other involvement groups in which they had previously participated.

#### *Action research as a suitable approach for novice co-researchers*

Coughlan and Coughlan (2002) consider that directly observable behaviour is an important AR data source, suggesting the critical issue is how to improve things for participants whilst inquiring into what is being observed. The steering group in this study provided two observation levels for the lead researcher: (i) group dynamics relating to co-researchers in a project steering group, traditionally the professionals' preserve; and (ii) in relation to the SDS subject matter. Steering group participant observations provided data to build an emerging service-user and carer perspective of current services. They were listened to respectfully, their views discussed and accepted, as they added a perspective grounded in recent experience. Thus the steering group introduced the co-researchers as organisational actors and provided them with legitimacy and confidence from the lead researcher to influence change. In this way the steering group provided a pivotal structure for conducting an AR study. With four co-researchers alongside (on average) six professional workers within the steering group, this allowed the co-researchers to feel their involvement was valued.

Our study suggests that AR can provide a suitable method to enable people to undertake first time research as co-researchers under the lead researcher's guidance and support. From the outset, the way in which the co-researchers were recruited gave authenticity to their roles as seen by others and confirmed to them that they were being recruited to a valuable and meaningful role in a professional manner. A collaborative co-researcher approach provided more research capacity within the project and also provided a dual learning process; i.e., the co-researchers directly influenced the subject matter. Magnusson (2003) concluded that users contribute ideas that hold greater value, are original and can be used as a learning tool to better understand user needs. This also applies to health and social care research (Waterman *et al.*, 2001; Sainsbury's Centre for Mental Health, 2010).

Incorporating service-users and carers provided learning for them about organisational processes including decision-making, culture and how to become a more effective voice influencing that organisation; and for the lead researcher about the involvement process as experienced by service-users and carers. It may be that AR, using experienced co-researchers,

can be more easily applied in NHS mental health trusts because organisational cultures are less hierarchical than other health services. It may also be the case that more equitable relationships between professionals assessing social care services and those receiving them could be achieved by adopting recovery principles including personalisation. Action research's reflexive nature is conducive to learning as it provides an approach where all participants can express their underlying concerns about the research and its goals. This project's co-researchers were interested in the potential research outcomes, as demonstrated through their recruitment interviews and their sustained involvement. This adds richer data to the research and may reveal more authentic data than if researchers alone led the research.

A Norwegian study (Moltu *et al.*, 2012) into how co-researchers with a mental health background viewed the co-researching process described it as both enriching and demanding. It required self-definition of their role and value when contributing to the research. Moltu *et al.*, (2012) suggest that there may be added value in mental health research incorporating service-user and professional researchers, but that continual reflections are needed. First, the researcher supporting the constructive differentiation between their and co-researcher roles and second, co-researchers developing their own mandate. This project's steering group was collaborative in nature and this enabled dialogue for opposing viewpoints without blame, and listening to the co-researcher's experiences was as a learning tool to better understand their perspectives. Koch and Kralik (2006) suggest that practical knowing in AR is empowering as it focuses on the potential for development rather than any participant deficit. This is demonstrated here as the co-researchers were willing to share their experiences ~~not~~ for learning purposes.

#### *Co-researching as an empowering process*

Empowering people was the project's central aspect and was important for service-users. Three co-researchers in this project described being empowered through their role and the value that they placed on it. An extract from a letter from one co-researcher, by comparison a quieter participant, spoke of the time spent as a co-researcher being important and valued, helping her to grow from being frightened and feeling obscure to someone more confident and in control. Another co-researcher went on to gain employment with a third sector organisation and another to represent mental health across wider service developments in social care. This correlates with Koch and Kralik's (2006) work in participatory AR, which suggests that commitment increases as people identify therapeutic benefits from their involvement and that telling their personal stories can be empowering, described as giving 'voice to the voiceless' (Koch and Kralik, 2006, p.19) ~~allowing people to feel empowered~~, increasing their self-awareness and providing an impetus for change. Hutchinson and Lovell (2013) describe their participatory AR study's transformative effect over three years, involving six co-researchers with mental health problems, who gained greater control over their lives. Hutchinson and Lovell (2013) suggest that self-belief is central to underpinning collaboration so learning from one another can be more pronounced, and that involvement can illustrate to professionals what it is like to feel socially excluded. Whilst it is impossible to say whether in this study the co-researcher's self-growth was directly attributable to their role, the democratic style and the responsibility that they held in the project group influenced their lives.

#### *Co-researching and shared learning*

Conducting an inquiry alongside co-researchers provided co-learning with shared responsibility for the learning experience. They shared their world view, which caused the lead researcher to



review her beliefs and look at issues with a fresh understanding. The lead and co-researchers had fundamentally different experiences; e.g., being an assessor and risk manager in contrast to being personally risk-assessed or as a carer in the risk management strategy. This produced a cognitive and discursive conflict but a shared understanding was established from the two perspectives and incorporated into joint learning. A participatory inquiry with co-researchers with mental health problems undertaken by Tee *et al.*, (2007) found similar benefits to those in this study and included insight into service-user perspectives, enhanced confidence in decision-making and appreciating power issues. Working with co-researchers here also tutored participants to speak precisely; glib remarks or acronyms were interrogated to enable shared meaning.

### **Implications for research and practice**

As communication, power relations and emotional impact were all important issues for our co-researchers, and these factors have not received sufficient focus in the PPI literature (Staniszewska, 2009), our study has implications about how individuals are engaged in involvement projects to lessen potential adverse emotional effects. In this study, debriefing meetings and preparatory sessions were utilised and more care, time and explanations were required to reduce communication problems and improve an individual's contributions when engaging in the project. Professionals must engage with service-users and carers with sensitivity and exemplary communication processes need to be practiced so that their involvement is empowering rather than a disempowering. If this is achieved then participation in a steering group can provide a fundamental role in bringing legitimacy and authority to co-researcher roles, which can also add authenticity to any data collection and analysis processes. The steering group was deliberately collaborative with an emphasis on equal contribution from professional, managerial and experiential viewpoints. The group provided a safe environment for the co-researchers to voice their opinions, share their experiences and display emotions. However even with full preparation and agreement to underlying democratic principles, separate meetings with the co-researchers were needed where reflection took place, which was useful for identifying strategies and knowledge co-production (Gillard *et al.*, 2012). These meetings were designed to minimise any potential adverse emotional consequences for service-users and carers. The meetings also ensured co-researcher understanding and enabled adverse aspects to be de-escalated including comments or discussion, thus re-enforcing their valuable contributions. In this sense, our view is that Staniszewska *et al's* (2011) calls for more PPI quantitative evaluation to provide objective data for measuring outcomes but will do little to ensure that mental health service-users' vulnerabilities are accommodated and safeguarded in research projects.

We suggest that the implications for other mental health professionals and managers from our AR study include the importance of recruitment, formal appointment and support structures for the co-researchers. These processes also afforded joint learning to the lead researcher and co-researchers throughout the project. Co-researcher involvement in the AR steering group adds an extra challenge but is valuable because it grounds all participants in user perspectives and experiences (Brett *et al.*, 2014). The steering group provided a pivotal structure for conducting AR using co-researchers. This approach could usefully and effectively involve co-researchers in similar AR studies. While there are many nascent PPI models that produce different outcomes (Gaventa and Barrett, 2012), implementing these was not a consideration and instead we were concerned to use AR's democratic potential to integrate service-users, carers and professional staff in change management processes in this trust. We contend that AR can be considered a PPI model in itself and one that has a long history in its own right — actively engaging participants

in research and service redesign, which has received scrutiny by the UK NHS Health Technology Agency as an appropriate method for integrating participants in research (Waterman *et al.*, 2001, Williamson *et al.*, 2011). We acknowledge that there are many ways to involve service-users and carers in research but recommend an AR approach to encourage others who are embarking on collaborative studies where it is important to hear the service-users and carers' otherwise-hidden voices (Koch and Kralik, 2006). If the question is 'who is best placed to advise on service needs, the service-user or the professional?' then the 21st century answer will be the service-user and this study shows that AR can successfully accommodate their views.

## **Conclusion**

It is clear from the literature that involving participants in mental health research is a growing field and also that this requires further evaluation. There are many benefits to be gained from integrating service-users and carers in all mental health service change management aspects and this is likely to work best when they are equal participants and are involved from the beginning (Brett *et al.*, 2014). These benefits can include empowering service-users, adding authenticity to the data, active contributions to the change direction and sharing learning between professionals and service-users (Tee *et al.*, 2007, Gillard *et al.*, 2012; Hutchinson and Lovell, 2013; Brett *et al.*, 2014). It can give a voice to people whose views may otherwise be marginalised (Koch and Kralik, 2006) and is thus very powerful where the intention is to offer them better services. Indeed, as there is a legal requirement in the UK NHS to involve service-users (Staniszewska, 2009), it is imperative that research and service redesign project utilise effective mechanisms to do so. Whist PPI frameworks have this potential (Gaventa and Barrett, 2012), literature includes unclear definitions or evaluations and calls for a more quantitative focus to overcome this (Staniszewska *et al.*, 2011). This may emerge in the future but we argue that AR can be more suited to change management because it can integrate and empower participants, can be loosely structured with imprecise aims and remain flexible and responsive to differing priorities as they emerge in the real world (Williamson *et al.*, 2011).

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**Figure 1:** Action research (AR) spiral (adapted from Coghlan and Brannick, 2010, p.8).

