

Service users as collaborators in mental health research: less stick, more carrot

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Involving service users in research improves its quality and relevance. Many research organizations funding and supporting research now ask researchers about involvement as part of their application process. Some researchers are facing challenges in taking forward involvement as the research infrastructure is not always facilitative. Researchers need greater reward and recognition for carrying out good quality involvement to encourage more effective processes.

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Introduction

Involving service users as collaborators in research is a recent innovation, starting around the mid-1990s. It is assuming growing significance for the way research is conducted. There is a strong moral case to support this development (see Kitcher, 2001; Szumukler, 2009 for an account), but here we focus on its impact on research practice and especially the implications for researchers.

Although it is still early days, service-user and carer involvement is now generally accepted as having benefits for clinical research. Deriving evidence for effectiveness in improving research is complex and context dependent, with service-user involvement taking place at different stages and with different expectations; for example, there are different purposes of involvement – improving the practical aspects of the study thus enhancing recruitment (Donovan *et al.* 2002), choosing appropriate outcome measures (Crawford *et al.* 2011), improving data acquisition or interpretation (Gillard *et al.* 2010; Rose *et al.* 2011), and so on. These require different methods of evaluation. While evaluation has not generally reached this level of sophistication, evidence is accumulating. Vale *et al.* (2012), surveying user involvement in studies run by the Medical Research Council Trials Unit, found that researchers generally stated that involvement was beneficial and reported a range of positive impacts on

the research and researchers, including improved credibility, design and quality, trial recruitment and dissemination. Few stated they did it primarily because funding bodies required it. Further evidence, mainly from case studies, indicates that service-user involvement enhances the credibility of research and ensures that findings are genuinely useful to the end-users, i.e. service users and carers (Smith *et al.* 2008; Staley, 2009; Boote *et al.* 2009; Brett *et al.* 2010). In recognition of this fact, the UK's Department of Health Research and Development Directorate (2006) stated its commitment to involving service users in research in its national research policy 'Best research for best health'. All National Institute for Health Research (NIHR) programmes now encourage researchers to involve service users in their work and plans for involvement are part of the standard application for funding.

The NIHR Mental Health Research Network (MHRN) is one of the eight clinical research networks that have been established to promote clinical research in the UK. It does not directly fund projects, but provides practical support to facilitate mental health research. Since its inception in 2004, the MHRN has asked researchers to describe their plans for service-user involvement prior to a project being adopted by the network. Over this time there has been a marked increase in the number of projects where service users have been involved in the performance of studies. In 2011, of 374 non-commercial studies, virtually all had service-user involvement (4% user initiated or controlled; 15% 'jointly researcher-user initiated collaboration'; 44% 'researcher initiated collaboration'; 37% 'consultation').

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Table 1. MHRN evaluation of service-user involvement in 45 studies (Staley, 2012): method of involvement

Method of involvement	% (number) of projects ^a
Steering committee/group member	41% (17)
Consultation during early stage of project design	17% (7)
More than one method used at different stages	10% (4)
Service user as grantholder	10% (4)
Service-user researcher	10% (4)
Service-user reference group/ advisory group	10% (4)
Member of management group/ research team	7% (3)
Service-user interviewers	5% (2)
A service-user adviser – consulted throughout	2% (1)
No involvement	2% (1)

MHRN, Mental Health Research Network.

^a The total adds up to more than 100% because some projects used more than one method.

To determine whether this involvement is making a difference to research, the MHRN conducted a small-scale evaluation of adopted projects. Forty-five projects were selected at random from the portfolio, a third of which were just starting, a third about mid-way and a third near completion. A series of brief, semi-structured phone interviews were conducted with the lead researcher from each project. They were asked about the impact that involvement was having on their research, what challenges they were facing and how they thought these might be overcome (Staley, 2012).

The projects that were evaluated were mainly randomized controlled trials (44%) or observational studies (37%). Most involved service users as members of a trial steering committee or project steering group (41%). Otherwise service users were involved in many different ways (Tables 1, 2), including being consulted at the early stages of research design, as co-applicants on grant proposals, joining research teams as service-user researchers, being on advisory groups and/or conducting interviews with other service users. Some projects involved service users using more than one approach.

The impact of the involvement and the challenges faced by researchers were directly linked to the context, in particular the nature of the research project and the way in which service users were involved. We therefore discuss the findings in relation to the three main approaches to involvement that

Table 2. MHRN evaluation of service-user involvement in 45 studies (Staley, 2012): nature of impact of involvement

Nature of the impact of involvement	% (number) of projects reporting this impact ^a
Impact on the design of the study	61% (25)
Impact on conceptual elements	22% (9)
Impact on practicalities	27% (11)
Impact on recruitment material and processes	12% (5)
Extensive influence throughout a study	20% (8)
Limited or no impact	20% (8)
Provided a service-user perspective on the findings	7% (3)
Made interviews better for the interviewees	5% (2)
Better retention of participants	5% (2)
Confirmed the topic was important to service users	5% (2)
Motivated the research team	2% (1)

MHRN, Mental Health Research Network.

^a The total adds up to more than 100% because some researchers reported more than one kind of impact.

MHRN-supported researchers had employed: as contributors to the research design, as members of steering groups and as co-researchers.

Contributors to research design

Researchers used various approaches to involve service users at this early stage – running focus groups or a pilot study, establishing a service-user reference group, or drawing on the views of participants from previous studies. The impact of this involvement varied, influencing both conceptual and practical elements of the project design.

A small number of researchers reported that their research question had been identified by service users. They had consulted service-user panels established for this purpose. Other researchers reported their choice of research question had been influenced via more informal communication channels, for example, talking to service users at support group meetings or consultation events.

Some researchers sought service users' views on relevant outcome measures to use in their study. Some worked with service users to develop or refine the intervention being tested. Others sought feedback on patient information sheets and recruitment processes and reported this made the project more acceptable to potential participants. Similarly, some researchers

sought service users' advice on how to make participation in their project easier. Service users suggested changes to practical arrangements for participants such as the frequency of follow-up appointments.

The extent of service-user influence seemed to depend on researchers' understanding of the purpose of involvement. This set limits on the impact. For example, in relation to questionnaire design, most researchers asked service users whether the questions were easy to understand and whether the questionnaire was an acceptable length. Fewer asked service users whether the right questions had been included and whether all the important issues had been covered. The purpose seemed to be more about making a research project 'lay-friendly', than about incorporating a service-user perspective. In most cases, power lies with researchers to determine the extent of any involvement.

Involving service users at this early stage has the greatest potential for impact as there is more flexibility to respond to service-users' views. However, this is also the time when researchers find it most difficult to involve service users. This is partly due to meeting demanding deadlines for funding applications and/or ethical review. A key issue is that involvement has to take place before funding has been obtained. This is a particular problem for researchers working with seldom heard groups, who often incur greater costs in working with these communities.

Members of steering groups

There was considerable variation in the role service-user members of steering groups were asked to play and therefore their impact on the study. In some projects, service users had a significant influence on the study design and conduct, for example in shaping recruitment processes. In others, they made little difference, particularly with highly technical projects, or because the steering group as a whole had little impact. In a small number of cases, service users had not been sufficiently prepared to equip them for the role.

Some researchers expressed concerns about how well this involvement was working. They found it difficult to enable service users to make meaningful contributions to group discussions. They recognized that the research culture, where research teams had already established working relationships which service users were not part of, sometimes acted as a barrier to effective involvement. Some reported problems with managing practicalities, which had on occasions led to service users not attending or resigning.

Co-researchers

Some researchers employed service users as members of their research team, while others established service-user advisory groups. Service users were then active partners at all stages of a project. The impact of this involvement was therefore all-pervasive, rather than limited to discrete elements. Researchers reported this ensured the research was grounded in the service-user perspective and therefore more practical and relevant. Some researchers attributed high recruitment and retention rates to the influence of their service-user colleagues. Involving service users as facilitators of focus groups or as interviewers was reported to widen the range of people who agreed to participate and to improve the data quality.

One of the main challenges faced by researchers employing service users was being responsive to people's mental health needs. Service users are more likely to need time off work or may not be well enough to take on a full-time role. The challenges lie in planning for this likelihood and ensuring there is capacity within the team to 'take up any slack'. While researchers may be prepared for this eventuality, other stakeholders, such as funders and HR departments, may not be as accommodating.

At the end of a project, helping a service-user researcher to find additional work or further develop their skills and experience is a challenge. There is no formal career structure for service-user researchers. Some may want to continue in research, others may want to use their experience as a means to get back into other forms of employment. As employers, researchers highlighted the importance of supporting service-user researchers in making the next step.

The challenges facing researchers

The overall picture to emerge from this evaluation is that the range and extent of service-user involvement in MHRN-adopted studies has greatly expanded over the past 7 years. More studies supported by the MHRN now involve service users in more diverse and influential ways. However, there is still considerable variation in the impacts of the involvement and researchers' views of its purpose.

The challenges facing researchers depend on where on the spectrum of involvement their activities lie. Those involving service users in in-depth ways maximize the impact, but face organizational barriers to their involvement. They require shifts in policy to support their practice. For example, they need more support from funders to allow early involvement

in research design as well as sufficient flexibility within funding arrangements to meet the needs of service-user employees. Similarly, research organizations may need to adopt more flexible working policies to support the employment and career development of service-user researchers.

However, this evaluation has also revealed that many researchers have much narrower expectations of involvement, consequently limiting its impact. Some saw enhancing the 'lay-friendliness' of research materials and processes as the main purpose, while a smaller number realized the value of incorporating the service-user perspective into research design and delivery. A researcher's understanding sets constraints on what they ask of the service users involved. At the same time, a lack of clarity as to precisely what research funders and organizations like the MHRN expect, leads some researchers to focus on 'tick-box' involvement rather than desired outcomes. This is perhaps why researchers were frequently involving service users as members of steering groups, with very different levels of success. Some believed that this was all that was needed to 'get the study approved'.

Researchers rarely receive training in involvement as part of their early career development, induction processes or on-going professional development. The competencies required to facilitate involvement are not often considered when allocating responsibilities for involvement within a research team (Staley, 2011). If researchers feel obligated to involve service users as a requirement for funding or support for their research, but do not receive additional training and advice to help them do it well, they are likely to feel frustrated and wary of the process, as one researcher commented:

The PI's are being battered into doing it [user involvement]. If you force them to do it, they'll just do something to tick the box – there's no motivation. If you want them to do it well – they've got to really see the benefit of it. The message has become 'You will do this on top of everything else – and you're really bad for not doing it well'. It's become a bit 'them and us' actually.

There is a danger that pointing the finger of blame at researchers for 'not doing it' or 'not doing it right' could create hostility. This problem is exacerbated by the fact that researchers who do involve service users effectively rarely have their efforts recognized and rewarded. As another researcher reported:

You don't get any credit for it in your own organization – no matter how hard someone outside is hitting you with a stick, no matter how well you are doing it – no one in your organization is going to give you a promotion – it's like a hobby of yours on the side. What you've got to do is get the

work done, on time and within budget and get the papers out. So there's no incentive in your working day to do all this extra work. There's no place where you're getting credits for that.

Therefore more carrot is needed with the stick to encourage and motivate researchers. This requires looking at research infrastructure as a whole and tackling the issues systemically. Funders, clinical networks and research organizations need to find ways to reward researchers who successfully involve service users, to help them overcome some of the organizational barriers, and to promote greater investment in more effective involvement processes.

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Declaration of Interest

None.

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