Getting ready for user involvement in a systematic review

Elizabeth Smith BSc MSc PhD,* Sheila Donovan BSc MSc RGN DN,† Peter Beresford OBE BA Hons, PhD, AcSS, FRSA, Dip WP,‡ Jill Manthorpe MA FRSA,§ Sally Brearley BSc MA AKC,¶ John Sitzia BA MPhil** and Fiona Ross BSc PhD RGN DN††

*Research Associate, National Nursing Research Unit, King's College London, †Research Fellow, Faculty of Health and Social Care Sciences, Kingston University and St George's, University of London, ‡Professor and Director, Centre for Citizen Participation, Brunel University, and Chair of Shaping Our Lives, §Professor and Director, Social Care Workforce Research Unit, King's College London, ¶Visiting Senior Research Fellow, National Nursing Research Unit, King's College London, **Director of Planning & Programmes NIHR CRN Coordinating Centre and ††Dean, Faculty of Health and Social Care Sciences, Kingston University and St George's, University of London, UK

Correspondence
Elizabeth Smith
National Nursing Research Unit
King's College London
James Clerk Maxwell Building
57 Waterloo Road
London SE1 8WA
UK
E-mail: elizabeth.m.smith@kcl.ac.uk

Abstract

Objective This paper aims to support the critical development of user involvement in systematic reviews by explaining some of the theoretical, ethical and practical issues entailed in 'getting ready' for user involvement.

Background Relatively few health or social care systematic reviews have actively involved service users. Evidence from other research contexts shows that user involvement can have benefits in terms of improved quality and outcomes, hence there is a need to test out different approaches in order to realize the benefits of user involvement and gain a greater understanding of any negative outcomes.

Design Setting up a service-user reference group for a review of user involvement in nursing, midwifery and health visiting research involved conceptualizing user involvement, developing a representation framework, identifying and targeting service users and creating a sense of mutuality and reciprocity.

Setting and participants Recruitment was undertaken across England by two researchers. Members from 24 national consumer organizations were selected to participate in the review.

Main variables studied Learning was gained about finding ways of navigating consumer networks and organizations, how best to communicate our goals and intentions and how to manage selection and 'rejection' in circumstances where we had stimulated enthusiasm.

Results and conclusions Involving service users helped us to access information, locate the findings in issues that are important to service users and to disseminate findings. User involvement is about relationships in social contexts: decisions made at the early conceptual level of research design affect service users and researchers in complex and personal ways.

Introduction

In the UK, government policy and research evidence suggest that the active involvement of service users (patients, carers and the public) in health and social research is a 'good thing'.[1–3] The term 'user involvement' broadly encompasses different approaches to direct participation or representation;[4] either as a one-off occurrence or as an ongoing relationship.[5] Issues associated with developing and sustaining new types of relationships with service users can vary considerably in different research contexts and paradigms,[6] hence there is a need to test different approaches in order to realize the benefits of user involvement and gain a greater understanding of any negative outcomes.

Although systematic reviews are increasingly being commissioned to inform policy development and provide recommendations for practice and research, when compared with other research contexts user involvement appears scarce and highly variable.[7] Approaches to systematic reviewing include effectiveness models, where quantitative findings are amalgamated across research studies, and exploratory approaches where information is gathered and synthesized to examine the scope of a topic or build an interpretation of the issues.[8,9] Some approaches have been described as meta-analysis, systematic research synthesis, narrative review and realistic synthesis;[10] and classified as effectiveness-based, problem-based or theory-based.[11] Hence, review can make use of quantitative or qualitative research methods, including grounded theory, hermeneutics and phenomenology; policy discourse analysis; or historical approaches to documentary analysis.[9] The purpose of this paper is not to examine such differences; it is to explore some of the theoretical, practical and ethical issues of involving service users in these contexts. This paper does not explore issues about user involvement in the commissioning of systematic reviews, in ethical review processes or in peer review. Nor does it discuss variations in research policy or practice internationally. Issues about the status of lay knowledge in relation to definitions of what counts as evidence have been raised by previous authors.[12,13]

The paper is informed by our experiences of recruiting service users to a reference group for a review of user involvement in nursing, midwifery and health visiting research. The findings of the review showed that ideas and approaches to user involvement are broadly influenced by social and political forces, that they are shaped by the research contexts they are emergent within and that user involvement can influence research but this is difficult to plan for or to measure because of attribution and diffusion of effects. The final report provides details of these findings.[14] The first part of the paper analyses previous work in this area and explains issues of definition, conceptualization and representation. We then describe the approach we took for involving users in the review and explain how this meant navigating consumer networks and organizations, learning how best to communicate our goals and intentions and how to manage selection and 'rejection' in circumstances where we had stimulated enthusiasm. We illustrate the issues using reflective notes written by members of the project team and service users at the time of the review. The discussion draws this learning together to suggest what the implications might be for future systematic reviews.

Previous work to involve service users in reviews

The value of lay perspectives has been long recognized in systematic review and more so since the rise of health service research.[15,16] A review of social science research shows that involving service users and carers in systematic reviews can help to define scope[7] and the questions being posed.[17] Service users can also support the retrieval and analysis of sources of data, contribute to the formulation of recommendations or inform guidelines[18] and enable dissemination beyond academic communities. User involvement can also enable a greater level of understanding through appreciating how people experience and talk about a topic.[19,20] Staniszewska *et al.*[17] provide an account of involving service users in writing a research bid for a

review project and explain how this improved the relevance of the proposal. Our experiences of involving service users show further benefits in terms of accessing unpublished information and locating findings and recommendations in issues that are important to service users.[14] Service users helped us to formulate key messages for a range of target audiences (including policy makers and the research community) and to disseminate findings through developing a 'lay' executive summary and web-based project newsletters. In this paper, we also explain that the process of recruiting service users helped us to reflect on the purpose of the review and to find ways to connect an academic project with language and issues that were recognizable to those that the research was about.

In health research, user involvement has been classified according to the roles or activities service users can take up[14] either to represent personal views (direct) or represent the views of others (indirect).[5] Current conceptualizations suggest involvement has hierarchical levels of control from consultation, through to collaboration and user-control.[21,22] In the context of systematic reviews including lay perspectives and views as a form of data correspond with the level of consultation. In some reviews undertaken by the Cochrane Collaboration, involvement may be classified as collaboration, as service users work with researchers to define topics and ways of undertaking reviews or reviewing what has been done.[23] In the area of clinical guidelines development, the National Institute of Clinical Excellence regularly seeks and includes public views about topics as part of the systematic reviews it undertakes and members of the public can comment on draft guidance (an example of how this can happen through specific studies is provided below). Similarly, researchers applying for the National Institute for Health Research funding are encouraged to involve patients and the public and since 1997 the Health Technology Assessment programme (http://www.hta.ac.uk/public/index.shtml) has actively promoted public involvement in all its key stages.[24]

The Social Care Institute for Excellence aims to build on previous learning by creating a database of examples of service user and carer participation in systematic reviews in social sciences.[25] One such example is a Department of Health commissioned systematic review of what patients thought about electroconvulsive therapy, undertaken by Service User Research Enterprise (SURE). The review aimed to include user perspectives on ECT as compared with clinically rated outcomes to inform the development of national guidelines.[26] Two of the researchers leading the project had received ECT themselves. Users involved in the review emphasized the importance of providing information on consent and information about the nature of the treatment.[18] Another example, funded by the Department of Health and conducted at the Evidence in Policy and Practice Information and Coordination (EPPI) Centre, concerned HIV prevention in men who have sex with men. This review involved service-user organizations as advisory group members who helped to prioritize topics for the review. A key recommendation from this project was the need for a dedicated budget and staff to maximize the potential contribution from advisory group members, as well as the need for research about user involvement in this context.[19] A third example is a review that was part of a programme of work to develop evidence-based policy in the National Newborn Screening Programme. In this particular review, user involvement focused on interpretation and implementation of the findings to form guidance. The project team reported that user involvement influenced the detail and wording of public information leaflets and also enabled the users to become involved in subsequent work to develop guidelines and new research.[27]

Potential barriers

A number of barriers may inhibit or prohibit reviewers from involving service users more actively. For example developments in other research contexts indicate that the terminology can be problematic. The term 'user' has been applied indiscriminately in policy and research publications to mean those *who may use research,*

those *whom research is about*, and those *it might affect*, as well as having additional meanings in the context of health and service use. A review of social science research funded by the European Union found that, of 276 projects, only 88 explicitly defined who the users were.[28] A key question is therefore how researchers define users in relation to particular studies and how they perceive and construct opportunities for involvement. The term 'involvement' is also problematic, as it suggests a situation where members of the public are brought into professional arenas. Although this may be an accurate reflection of how the majority of opportunities for involvement are perceived and constructed, support for user-controlled studies is growing.[5] Indeed, some consumer-led voluntary sector groups commission health research, provide training and are involved in the review of research institutions. Current conceptualizations have been criticized for the tendency to present user involvement as static and premeditated, underplaying its often dynamic and emergent qualities; and for overlooking potential blurring with traditional researcher roles.[5]

Issues of who is involved in research have been debated in the user involvement literature but representation remains an area of tension and confusion.[4] Classifications of service users have been constructed in terms of the involvement of individual patients, patient groups and patient representatives.[4,29,30] The role of consumer groups and voluntary health organizations has also been recognized in representing the collective interests of patients, users and carers.[31] It is important to question on what grounds particular concepts of representation should be applied to systematic review.[32] It may also help to resolve questions about the mandate of service users within review studies.[29] These potential barriers are further explored in the following account of our approach.

Our approach

We think it is important to reframe user involvement as *relationships within social contexts*. In this vein, in the following account, we elucidate how

our relationship with service users began and what we learned about some of the barriers and motivations for involvement in the process.

Envisaging a role for service users

The systematic review discussed here was tendered in April 2003 to review the evidence and theory about user involvement in nursing, midwifery and health visiting research. We proposed to work with national service-user and carer advocacy groups and researchers in health care to determine the scope of the review, identify appropriate sources of information, reflect on the evidence and identify which findings were important and how they should be disseminated. The final report provides details of the literature searches and researcher consultations (national survey and in-depth interviews).[14] Our rationale for developing a service-user reference group was that the group would:

- connect the project with specific service-user issues and perspectives;
- influence the project by contributing to developing priorities and principles;
- be critical, challenging and stimulating; and
- advise on the best ways of disseminating findings through different networks.

At proposal stage, we did not have the time, networks or resources to establish such a group of service users. These factors have previously been identified as barriers to involving service users in developing proposals.[17] Time was further limited because we were responding to a tender rather than developing a proposal for a study. A consumer representative with experience of collaborating on research projects helped develop the plans and was an applicant for the proposal (SB). We made use of guidelines on user involvement[33] and sought advice from INVOLVE (a Department of Health funded organization supporting public involvement in research). We thought that a service-user reference group set-up specifically for the review would enable a collaborative and interactive relationship to develop. We would support the group to develop terms of reference and ways of

working, and provide service users with information and orientation to the issues rather than research training. Our proposal included costs for 25 service users to meet three times with £100 payment per meeting and reimbursement for travel expenses and carer costs (estimated at £50 per person).

Conceptualizing membership

We developed a representation framework to serve as a guide to recruitment (see Box 1). We chose to align membership with representation of the client groups with which nurses, midwives and health visitors work, using priority clinical areas within their spheres of practice (as defined by National Service Frameworks).[34] In relation to the recruitment of individuals, our criteria for membership included interest and ability to attend the meetings (see Box 2). We drew up a list of target voluntary and consumer health organizations from our own knowledge, supplemented by Internet searches and putting

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Box 1 Representation framework

We recruited individuals from national consumer
  and voluntary organizations to participate in the Service
  User Reference Group. Our aim was for the group to
  reflect the diversity of nursing, midwifery and health
  visiting practice. To help guide the recruitment of
  organizations, we developed a simple framework based
  on the *client groups* with whom nurses, midwives and
  health visitors engage, and the *priority clinical areas*
  within their spheres of practice.
Nurse, midwife and health visitor client/patient groups
  Pregnant women, mothers and newborn babies
  Children and young people
  Older people
  People with disabilities
  People from minority ethnic groups
  Carers
Nurse, midwife and health visitor priority clinical areas
  Cancer and palliative care
  Cardiovascular disease
  Diabetes
  HIV/Aids
  Learning disability
  Mental health
  Neonatal and maternal health
  Public health

Box 2 Individual membership recruitment criteria

Membership of a service-user organization
  or voluntary group
Interest in user involvement in research
Ability to contribute general views on nursing, midwifery
  or health visiting but also to represent a specialist
  interest or client group
Commitment to attend three scheduled meetings
  over a period of 9 months

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out a call for interest in the INVOLVE newsletter (see http://www.invo.org.uk).

Negotiating ways into organizations

Identify a link person within target organizations (2 months prior to first meeting)

We approached the target organizations with the aim of identifying individuals who might be able to support recruitment. Generally, this involved contacting a main switchboard or information centre to find out about various sections of the organization. Usually, we were able to obtain details of someone to whom we could send further information; however, we quickly learnt to probe and pick up clues about teams or individuals whose remit might be appropriate to our purposes. Within split locality or multi-site organizations, different sections sometimes acted independently of one another. Staff working in headquarters of national organizations often wanted to put us in contact with regional offices, which conflicted with our intention to maintain a national rather than local focus. Some organizations were 'virtual' as opposed to being based in a discrete physical location, with staff working from home or other organizational bases, in academic departments or on health service premises. This made it difficult to identify where and when people worked, and how best they could be contacted.

Initial contact with link individuals (4–6 weeks prior to first meeting)

Having identified a link person for each organization, we sent them some information about the service-user reference group (a one-page leaflet outlining the aims of the review, the role

of the service-user group and what we were looking for in terms of individuals' experiences and interests). It incorporated a return slip that individuals could use to express their interest in participating, and it also directed readers to the project website for further information.

Follow-up and networking (2–3 weeks prior to first meeting)

In the case of non-response, we followed up with a second telephone call or a reminder by email. This was labour intensive and entailed negotiating access to nominated/interested individuals and having to 'sell' the project. We tried to emphasize the credibility of the study, explain the objectives of the review and how we envisaged users could contribute, and make a case for an organization's involvement. This direct communication did seem to work. For example, a director acknowledged that she had disregarded our information but, on hearing more about the project, it caught her interest. In one organization, we 'started again' with recruitment and pitched the project to another officer who subsequently directed us to its network of service-user members.

Gaining an understanding of internal communication structures was essential. Some organizations communicated with their members using newsletters. For example, in one organization for people with a long-term condition (which provided training for members interested in getting involved in research), we were offered space in their monthly newsletter to advertise the project. If we had not begun the process of recruitment 2 months before the first meeting, we would have been unable use this opportunity. Some large 'umbrella' organizations had well-established email networks and distributed information to all members the same day. In more than one organization, this generated high levels of interest far beyond that which we could accommodate in the project. Although we could have asked organizations not to approach all their members, we and they had no way of predicting the number of responses we would receive. We also appreciated that for some organizations, providing equal opportu-

nities to participate and inclusiveness were part of organizational ethos.

Engaging with individuals

Selection of individuals (6–1 week prior to first meeting)

In some instances, the selection process was straightforward, for example, when we had just one organization that matched a client group/area of practice in our representation framework from which one person was nominated. However, as we had targeted more organizations than we had places for and the process of establishing interest was progressing at different rates, decisions around selection became complex. At one point, we were simultaneously liaising with three organizations for the same client group/area of practice, even though our representation framework only allowed for one place. Similarly, there were difficult decisions to be made about selection when we were contacted by a number of individuals from the same organization (an issue discussed below).

Providing confirmation and information (2 weeks prior to first meeting)

Two weeks before the first meeting, we wrote to 25 individuals to formally confirm their place within the group. Throughout the recruitment process, work was simultaneously being undertaken to plan for the first meeting, which also had implications for the time we could dedicate to recruitment. We sent participants an outline agenda and general information about the event, and sought to find out about any individual needs, for example, in relation to physical or sensory impairment, and dietary requirements.

Informing those respondents not selected (4–2 weeks prior to first meeting)

The high number of expressions of interest meant we had to turn down many people (over 80 including enquiries made by email). We felt an ethical responsibility to provide a good reason for why individuals had not been selected. We explained that we were trying to

gain a range of views (on nursing, midwifery and health visiting) by recruiting from different organizations, that we had limited numbers, and that individuals had not been turned down for any personal reasons or for anything they had or had not written on their 'expression of interest' form. We thanked people for their time, apologized that they could not be involved and offered to send them a summary of the findings. We contacted most respondents by telephone or email to let them know of our decision quickly and before they made arrangements to attend the first meeting.

Learning points

Representation has multiple meanings and implications

We chose to develop a representation framework to serve as a guide to recruitment and to provide us with a way of justifying who was and was not involved. We could have chosen to apply alternative concepts of representation. For example, one form of democratic model would be to award one person one vote, however, defining who should vote and on what issues would have been too prescriptive. A similar political model, proportional representation, would have worked on the same basis but we would have had to make decisions about relative influence of votes, and again what exactly people were being asked to vote on would be difficult to define. A model of statistical representation, for example, randomly selecting individuals from patient lists, would have not allowed us to identify individuals with the relevant knowledge, skills and interests. Given that we wanted to gain service-user views on the work of nurses, midwives and health visitors, it was necessary to develop an alternative model that incorporated 'nominated membership' (members were sometimes nominated by their organizations to participate), 'dispositional representation' (some individuals were involved by virtue of job role/organizational membership), representation of 'shared interest' (including members from lobby groups) and 'personal representation' (some individuals had personal

experience of receiving care from nurses, midwives or health visitors).

Our approach to recruitment placed responsibility for selecting candidates on organizations, not all of which were prepared for this. For example, three members of a mental health organization contacted us by phone on the same day, having received details of the project by email from their group's administrator. We explained that, as places were limited, we could only include one representative from their organization. One person asked, 'How do we know who you will choose?' and another, 'Who is the best person of the three of us to attend?' We passed the decision back to the administrator and asked that the organization nominate someone, reminding them of our recruitment criteria. It was extremely difficult for us to 'reject' individuals who were keen to be involved whilst, at the same time, pursuing organizations that were initially less enthusiastic. In contrast, a member of an organization for a long-term condition offered his candidacy as someone with multiple networks in the community who could 'fill several gaps' if we had a perspective missing. These events and others like them fed into our learning about how particular forms of representation can be a facilitator or a barrier to the involvement of some individuals. Being selected to represent an organization and being selected by virtue of one's membership of an organization constitute different approaches to recruitment and mean different things for who can be involved. It would have been helpful if we had provided more detail about what we were asking individuals to represent in terms of the types of experiences, interventions, roles and relationships, issues and trends we were interested in exploring.

An invitation to participate provokes a range of responses

We had not sufficiently anticipated the emotional responses that the notion of joining the group on behalf of an organization could provoke. This was made apparent in telephone conversations with some individuals who

questioned their own authority, ability or worthiness to represent their organization. One person told us they were interested but feared they were 'too old'; another person described himself as being 'too stupid'. In these instances, we reassured potential participants by saying that our aim was 'to make the experience accessible and informal, even enjoyable'. We were also aware that, for some individuals, such reassurance was not necessary and could be perceived as being patronizing.

We were surprised at how often involvement was seen as opportunity. One person wanted to nominate a friend whom they perceived to be deserving of the opportunity, explaining:

> I've got a 26 year old friend who has never worked. He is addicted to drugs and could do with a break but he might not be able to attend all three meetings. (Mental health service user, telephone response to the initial call for participants)

This again required sensitivity. We thanked the person for their suggestion and explained that we would prefer individuals to express interest themselves rather than be nominated by another person.

Principles have to be balanced with pragmatism

We originally planned to set the cut-off date for receiving expressions of interest at 2 weeks before the first meeting. This timeframe would maximize the recruitment period but still give us time to select and notify members of the group. However, a few weeks into recruitment, we decided to allocate some places as we were uncertain how much interest would be generated and it seemed reasonable to capture the enthusiasm of the early responders. It also meant that individuals would keep the meeting date free and be able to make travel arrangements. Then, as interest began to build, we decided to hold places for organizations that might fit particular categories of our representation framework. This change in procedure felt manipulative because it was difficult to decide which organizations we should hold places for and for how long, yet we were also concerned that these

places might not be filled. One person, who contacted us a week before the group met, was dissatisfied with our explanation that we had already allocated places for her area of interest and maintained she had a right to be considered. For us, this highlighted the tensions of being consistent with selection processes and recruiting a group of service users.

A representation framework was useful for judging success

Members of the reference group had a high level of expertise including knowledge of research strategy and management, consumer representation and research networks, user-controlled research, practitioner education and development, service-user and carer needs, statutory service provision in relation to specific clinical conditions, patient and public involvement initiatives, and developing research training for service users. It was evident that members' skills, abilities and knowledge surpassed the categories of our representation framework. However, the representation framework helps us to perceive those who were not there: most notably the difference being between organizational representation and direct representation of service users themselves. This was a particular point of reflection for one member of the project team:

> I think it is very important to distinguish between people there as service users and those there from organisations that work with service users who do not identify as service users themselves ... there are big issues in taking what non-service users say as indicative of what service users say. (Member of the project team)

Our experiences suggest that, in the context of systematic reviews, representation frameworks need to take into consideration how informed or skilled service users need to be in relation to the task at hand. This ultimately relates to the purpose of the review but it also provides a way of highlighting circumstances where involvement of particular groups has been problematic. For example, in our review, children and young people were not directly involved in the review,

although two members of staff from an organization working with children did participate. Discussions with these organizations helped us to appreciate the ethical implications and recognize that it was not feasible to facilitate the involvement of children in this particular review as we did not have adequate time or resources. Nor did we specifically aim to recruit individuals who are not affiliated to an organization. An important point here is that greater awareness of such 'structural' barriers to involvement could help to avoid the systematic reproduction of health inequalities.[29]

Creating an environment conducive to involvement

Getting ready for user involvement involved setting a positive tone and developing a sense of reciprocity, mutuality and respect. These aspects were not always as straightforward as we hoped. From the outset, we wanted to engage with service users quickly so that they could influence the review but we had not accounted for a complex process of gaining ethical approval for their involvement. Our aim for the group to work with us in a collaborative partnership was contested by the ethics committee's requirement that we obtain informed consent, and further compounded by the use of a consent form predicated on the signatory as a study subject. It was important to discuss expenses and payment details early on because this can affect social security payments.[35] Also it took time to set up payment mechanisms and to discuss people's preferences for payment. Getting these formal aspects of involvement right was vital for the administration of the project but this was not conducive to a sense of partnership:

> The formalities of the research process, for example registering and consenting people, created an immediate division between the project team and those we were asking to be equal partners in the project … It was unpleasant to focus on getting consent and financial details from participants rather then being able to spend this time welcoming people and making them feel their attendance was valued. (Member of the project team)

Making personal contact was beneficial for building respect before involvement formally began. We were sensitive to balancing the need to provide information and an agenda before the first meeting with being open to users directing the work. We had prepared working papers (operational definitions and a project flow chart) but held these back initially. Subsequently, some members said they would have liked more information about the project and interpreted the lack of detail as the team being ill-prepared. Other members felt it was appropriate to 'tackle the issues together' and had not expected to receive detailed information. Either way, it would have been better to explain our approach beforehand.

Implications for future reviews

It has been suggested that user involvement could be a quality indicator for systematic reviews.[7] Given the topic of the review presented here, involving users was relevant and appropriate for defining its scope and shaping the process and benefits were gained (see section on previous studies). However, for us, getting ready for involvement required dedicated thinking time at proposal stage and an application for ethical approval that would not usually be required for a systematic review. Recruitment required additional staffing (two researchers working full-time for 6 weeks) and finances, which might not always be supported by review commissioners. Others have spent over 2 months recruiting to a service-user advisory group.[32] The overall process of creating opportunities for user involvement was very much dependent on the researchers' ability to communicate the purpose and intentions of the review. It was also vital to help people feel at ease, respected and acknowledged.

Although it worked for us, our approach might not fit other systematic reviews. There are alternative ways to be responsive to users, such as including service-user perspectives as data in a review, by undertaking consultations about specific issues or emergent findings, or disseminating review findings to user groups.

The issues for user-led[36] reviews may be somewhat different and this requires specific attention. The main point that we can add is that developing a representation framework can help researchers to reflect upon the concepts of representation they are using, plan an approach to recruitment, identify potential access or exclusion issues and evaluate how their approach influences *who* is invited to participate and *which* individuals become involved.

Establishing the service-user reference group saw us starting at a theoretical level, conceptualizing membership of the group in terms of the diversity of nursing, midwifery and health visiting practice. We constructed and sought particular categorical notions of users by translating our ideas into recruitment strategies targeted at patient/client groups. Members recruited through particular organizations often had links to other organizations, networks or user groups. This exceeded our original ideas about what individuals and the group collectively might represent. It was also significant that we were liaising with different types of organizations (in terms of their remit, structure and links with members) as this had a direct impact on *how* we were able to recruit and *who* was recruited.

In the context of having to seek ethical approval to work with a service-user reference group, representation became a research governance issue as we attempted to argue that members' status was different from the traditional research subject role. Despite this ambiguity, involvement as manifested through the service-user reference group meant that a variety of perspectives was represented and service users' stake in the issue was recognized.

Engagement between individual members of the project team and the service-user group continues. For example, three service users have joined a reference group for a project led by one of the team on governance and incentives in primary care. These types of 'grown relationships' raise new questions for research about when to develop existing relationships and when to begin new ones.

Conclusions

Our experiences demonstrate that recruiting service users to a systematic review can be achieved but there are theoretical, ethical and practical issues associated with 'getting ready' to work together. An overarching theme is that user involvement is about relationships and that these extend beyond the boundaries of any particular systematic review. In our own study, the invitation to participate provoked a range of responses in organizations and individuals, and our engagement with users was not confined to those we selected to participate in the reference group. We have shown that decisions made at the conceptual level and in the early stages of research design can impact on users and researchers in complex and personal ways, hence researchers have responsibilities even in embryonic and episodic relationships with service users.

Contributorship

All of the authors contributed to conception and design, analysis and interpretation of data through team discussions and writing. FR had overall responsibility for the project. SD and ES undertook the recruitment of the service-user reference group and drafted the paper. Other authors critically revised it and gave approval for publication.

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