

Involving service users with intellectual disability in research: experiences from the STOP Diabetes Study

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Conflicts of interest

The authors declare no conflicts of interest

Article statement

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ABSTRACT

Background: The involvement of service users (people who use health and social care services) in research is central to UK policies, is an integral component of many research funding programmes and improves the quality and uptake of research. People with intellectual disability are often excluded from research involvement.

Aims: The purpose of this article is to describe how adult service users with intellectual disability were involved in the early stages of a diabetes screening study conducted in Leicestershire, UK.

Method: People who volunteered were involved in five key areas: publicity; study documentation and process development; acceptability of measures; recruitment of research staff; and training of staff.

Findings: Service users helped with logo selection, publicity materials, designing art work, raising awareness of the study, study documents, rehearsing clinics and recruiting and training research staff.

Conclusions: Our findings demonstrate that with careful planning adults with intellectual disability can meaningfully be involved, and benefit from involvement, in research. We look forward to continued involvement with service users with intellectual disability in future research studies.

INTRODUCTION

During the last two decades the involvement of service users (people who use health and social care services) in research has become central to UK policies (Department of Health, 2005; Department of Health, 2010), is an integral component of many research funding programmes (National Institute for Health Research, 2013; Medical Research Council, 2013), and is becoming increasingly common both nationally and internationally (Ennis & Wykes, 2013; Holmes *et al.*, 2002; Mosavel *et al.*, 2005; Schneider *et al.*, 2004).

A number of benefits of involving service users and carers in applied health and social care research have been proposed. First, there is the 'consequentialist' argument that involvement produces a good outcome so it is intrinsically 'morally right'. Service users can provide valuable knowledge and insights to research (Beresford, 2005; Chalmers, 1995; Entwistle *et al.*, 1998; Goodare & Smith, 1995; Oliver, 1995; Smith *et al.*, 2008), encourage recruitment through publicity (Chalmers, 1995; Goodare & Smith, 1995; Oliver, 1995), improve quality, relevance and impact of the research (Boote *et al.*, 2002; Brett *et al.*, 2014a; Nilsen *et al.*, 2006; Staley, 2009; Thompson *et al.*, 2009) and potentially help to meet recruitment targets (Ennis & Wykes, 2013). Second, from a moral and political perspective, it is argued that service users contribute to public-funded research and are part-owners of the National Health Service in England (Thompson *et al.*, 2009) so all research should be transparent to those affected by it (Martin, 2008). Finally, it is proposed that involvement can benefit the service users themselves (Staley, 2009), providing personal development, and increasing satisfaction and service users' knowledge of their own condition (Brett *et al.*, 2014a; Thompson *et al.*, 2014)

Despite the benefits, various challenges to the successful involvement of service users have been reported. These include contrasting priorities (Boote *et al.*, 2010; Stewart *et al.*, 2011;

Brett *et al.*, 2014a), public understanding of health research methods (Boote *et al.*, 2010), language and jargon (Boote *et al.*, 2010) and lack of time and resources (Boote *et al.*, 2010; Brett *et al.*, 2014a). This is particularly true of vulnerable groups, such as people with intellectual disability (Kiernan, 1999). It takes additional time and resources to effectively communicate and collaborate with people with intellectual disability (Booth & Booth, 2003; Garbutt *et al.*, 2009; Palmer & Paterson, 2013; Rapley, 2003), which can be at odds with researchers' own demands and priorities (Stalker, 1998). Instead, researchers often turn to 'sympathetic others', such as parents or carers (Atkinson, 1997) who may have different perspectives.

Yet evidence suggests that people with intellectual disability want to discuss health issues (Rodgers, 1999), want to be treated fairly (Garbutt *et al.*, 2009) and can improve the quality and relevance of the research (Stalker, 1998). Disability academics have argued that, if research is to fully reflect the experiences of people with disabilities, they should be involved in the research process at the outset (Farmer & McLeod, 2011). So, rather than being denied the opportunity to be involved in research because involvement poses more challenges, the emphasis should be on overcoming the challenges so that people with ID can be meaningfully involved (Booth & Booth, 2003; Garbutt *et al.*, 2009).

The purpose of this article is to describe the way in which adults with intellectual disability were involved in the initial stages of a research study and to share experiences of our methods. The main aims of the research study were to: (1) assess the feasibility of screening people with intellectual disability for undiagnosed Type 2 diabetes and impaired glucose regulation (high risk); and (2) to develop an education programme for the prevention of diabetes (and cardiovascular disease) in this population. As well as service users being participants in the research study, we wanted to involve them more fully in the research process as has been achieved with the rest of the population in relation to diabetes research (Lindenmeyer *et al.*, 2007; Lowes *et al.*, 2011).

METHODOLOGY

The methodology for this work was loosely based on the principles outlined by the National Institute for Health Research (NIHR) Research Design Service for incorporating patient and public involvement in the design, undertaking and management of research (Research Design Service, 2014). These included: assisting in creating a research strategy; reviewing and commenting on proposed questions and data collection methods; assisting in writing the patient information and consent forms; and aiding in the design of the protocol/conduct of the study.

The research team comprised academic researchers, healthcare professionals (medical and nursing staff) and senior staff from local community intellectual disability services. Prior to initiating recruitment, four members of the research team visited three local intellectual disability partnership boards. Such boards are tasked with decision-making and setting priorities in relation to intellectual disability locally; their members include a wide range of professionals and public members, including councillors, commissioners, clinicians, charity representatives, community support and safety officers, staff and students in further education, police officers, family and paid carers, and people with intellectual disability. The research team discussed the study at the board meetings, invited feedback and discussed ideas around how adults with intellectual disability could be involved in the research.

Researchers in the study team subsequently approached two self-advocacy groups in Leicestershire to discuss how service users might help with the research study. Both groups were led by an experienced facilitator/supporter whose role was to ensure that all of the adults understood what was being discussed and that they had every opportunity to give their views and contribute to the discussion. Most of the service users in the groups

expressed an interest in helping with the study; the role of one of the groups was primarily to discuss health issues and we found that service users in this group had a particular interest in being involved. In addition, the manager and residents of a communal care establishment were approached through the lead research nurse's contacts; the residents agreed to help with the study with support from their key workers and manager of the home. We approached service users from different locations to encourage a diverse range of views, minimise burden and also to potentially identify a pool of interested service users for future collaborations.

Once we had established that service users were interesting in helping us, the research team met to discuss how individuals could be involved to benefit both the research and potentially the service users themselves, without making excess demands on their time. Although a common way of involving service users in research is through regular representation on steering group meetings (Barber *et al.*, 2007), both researchers and individuals with intellectual disability dismissed this option at the outset. Past experience suggested that the meetings were lengthy, using conference call facilities and with researchers often having lengthy discussions over complex methodological issues, which would isolate the service user. Instead, the research team agreed to feedback key points from the steering group meetings to the service user groups and that there would be 'ad hoc' attendance by service users (with support) at steering group meetings. In addition, we agreed on five further areas where individuals could realistically become involved. We then worked with service users, facilitators and support staff to devise ways in which this input could be achieved. The five areas chosen were:

- (i) Publicity;
- (ii) Study documentation and process development;
- (iii) Acceptability of measures;
- (iv) Recruitment of research staff;

- (v) Training of staff.

Publicity

The intellectual disability partnership boards were involved at the developmental stage of the research study to advise on reasonable adjustments and practical considerations. These included tailoring information leaflets to a larger font and modifying the size and colour of the paper and text for those with visual impairment, using pictures as well as text, and using a staged, step-by-step approach to delivering information. Subsequently, we met with the boards to discuss progress and any recruitment difficulties. Their involvement also served as a means of raising awareness about the research. The study involved a Leicestershire-wide screening programme, so it was important to publicise the research as widely as possible to give all adults with intellectual disability in Leicestershire (n≈3800) the opportunity to take part.

The study logo that we used needed to be easily recognisable and understandable to all, and the publicity materials had to be suitable for our target population. The research team suggested several names for the study; we did not use acronyms as the service users did not like them. The creative director devised four corresponding logos. One of the researchers then visited the first self-advocacy group, discussed the names and logos, and asked the service users their preference using a feedback form with a scale and pictures. The preference was relayed back to the research team before a final decision was made. The second self-advocacy group was then approached during one session and shown the study logo to discuss possible ways of publicising the study to service users with intellectual disability (and/or their carers). The researcher also discussed other publicity materials, such as posters and fliers, in this latter session. Once all means of publicity had been discussed, the researcher took the ideas back to the research team for further discussion, and to determine if sufficient resources were available to implement them.

Study documentation and process development

The study involved gaining informed consent from participants. Under English mental capacity legislation, an adult is considered able to make a decision unless all practical steps have been made to help them to do so without success (Mental Capacity Act, 2005).

Information about the study needed to be available using simple language, free from jargon and with visual aids, so that potential participants had every opportunity to understand what we were doing and reach an informed decision about whether to take part.

Research documentation, including the initial invitation letter, patient information sheet and consent form, were initially written in easy-read format (symbols and words) by the research team, with support from local intellectual disability services, which included a speech and language therapist. The team then sent the draft paperwork to the partnership boards and local intellectual disability services for feedback on the symbols, text and whether additional communication aids might be necessary.

Acceptability of measures

Data collection involved the administration of a number of questionnaires. We wanted to assess whether, in combination, they were acceptable to participants. Service users at the participating communal care establishment helped the research team to pilot data collection processes.

Recruitment of research staff

Research nurses played a central role in the study. They needed to assess capacity, explain research procedures, obtain consent, take measurements, administer questionnaires and

undertake venepuncture. Patience, sensitivity, responsiveness to participants' needs and excellent communication skills were essential in this role. Two of the service users offered to help us with the interview process for recruiting nurses for the study. With their group facilitator, they devised two questions on how good the nurses were at communicating with people with intellectual disability and how they might adapt their communication if that person did not understand them. Supported by their group facilitator, the service users asked the nurses these questions in a separate room on the day that they were interviewed. Later, they rated the nurses' responses using a feedback form that scored the responses on a scale of 1 to 4. This feedback form was given to the interview panel as part of the recruitment decision-making process.

Training of staff

Service users were crucial to the training of staff for the study by allowing the staff to practise communication-based interactions, consent taking and to obtain measurements, such as height, weight, blood pressure, and waist and hip circumference. As part of the induction and training process for newly appointed study research nurses, staff received initial training and instruction in study procedures from the lead study researcher. Service users from one of the advocacy groups were invited to attend a follow-on staff training session so that nurses could put their new skills into practice. Service users gave their feedback on the nurses' skills and discussed what they liked and what they did not like. This enabled staff to gain confidence and develop competency in various procedures.

RESULTS

The first self-advocacy group chose a preferred logo for the study. The second self-advocacy group discussed printing the logo on note pads, study documents (information leaflets, consent forms) and pens. One of the service users suggested printing the logo onto fridge magnets, which had not previously been considered by the researchers or other service users. As this suggestion was positively received by the rest of the group, the research team added fridge magnets to the publicity materials.

The service users of the second self-advocacy group identified that holding a poster competition might also be a good way of publicising the study. This would serve the dual purpose of raising awareness about the study as well as potentially creating interest in being a participant. As a result, service users were invited to enter the competition via local day centres (local services managed by social services, NHS or voluntary/private bodies), health clinics and other organisations, using brief easy-read information distributed by staff at the relevant sites. Individuals were asked to design a poster that incorporated their ideas and pictures about health checks, healthy foods and exercise. All service users who entered the competition were given a certificate and a small award of art and craft materials. The research team collectively then determined the best artwork, and the service users were involved in deciding which artwork was displayed on the promotional materials.

The service users we approached did not report any difficulties with understanding the easy-read invitation letter, patient information sheet and consent form for the study. However, they wanted there to be additional methods of communicating the study to the potential participant. They chose flash cards, story cards and an interactive CD rom as additional methods of communication. One of the service users in the group assisted the team by taking photographs to help illustrate the information leaflet, flash cards and story cards.

Three service users from the group modelled for some of the photographs. Another service user from a different self-advocacy group, who had previous experience of helping with health promotion materials, assisted with production of the interactive CD by recording the “voice over”. This latter method was eventually not adopted as a means of communication because of technical issues and because there was very little demand for it.

Piloting the questionnaires and clinics helped the researchers to determine how long appointments might take and how many visits may be needed. Service users, including those with borderline intellectual disability, reported that some of the questionnaires were far too lengthy and complex. As a result, the research team met to discuss the difficulties. It was agreed to make changes to reduce the burden to potential participants; for example, one of the questionnaires (the PAS-ADD [Moss, 1994]) was changed to a shorter, simpler version (Mini PAS-ADD [Moss, 2002]) and two questionnaires were removed (DINE [Roe *et al.*, 1994] and IPAQ [Craig *et al.*, 2003]) from the data collection entirely. Researchers were, therefore, able to plan how best to organise the research process to be as time-efficient as possible but also to be responsive and flexible to the needs of participants.

The two service users involved in recruiting research staff for the study said that they enjoyed devising and asking the applicants their questions. The scores on the applicants that were fed back to the interview panel closely favoured the same applicants (several staff were needed for the study) that had been preferred by the panel. The service users’ input helped to reinforce the panel’s decision and we feel that it was particularly valuable in assisting the panel’s decision between two similar applicants.

DISCUSSION

This article describes the way in which adults with intellectual disability were involved at the early stages of a research study. We would like to share our experiences and encourage others to involve and engage people with intellectual disabilities in applied health research.

As with most service user involvement initiatives, the impact of involving service users in this research study is difficult to quantify. Evidence on the effectiveness and impact of service user involvement remains relatively weak (Mockford *et al.*, 2012; Brett *et al.*, 2014b) and largely depends on the perspective of the researcher, service user and clinician. From a researcher perspective, we propose that involvement of service users improved the quality of our study, but we do not know what would have happened had we not involved them. Recruitment into the STOP diabetes study was 29% and it is known that recruiting people with intellectual disability into research studies is challenging (Lewis, 2014; Oliver-Africano *et al.* 2010). However, we are not able to draw any meaningful comparisons, as this is the first and largest study of its kind in the UK.

Service users' involvement in the study was essentially collaboration between researchers and adults with intellectual disability, with support from self-advocacy group facilitators and support staff. As such, the research does not fall into the 'emancipatory' framework first described by Oliver (1992) and perhaps favoured by many disability academics (Farmer & McLeod, 2011), which would involve the research arising from and being steered by the service users themselves. In our study, the power balance favoured the research team and final decisions on the study issues raised were always made by the lead investigator. Chalmers (1995) describes some excellent examples of highly productive research questions proposed by lay people, such as a mother of a child with Edward's syndrome (trisomy 18) who hypothesised that a low level of maternal serum α fetoprotein concentration might be a marker for the condition. Despite this, we have shown that adults with intellectual disability can make a considerable contribution to research and can increase their own knowledge-base in doing so. In line with previous research (Rodgers, 1999), we found that

the service users valued the opportunity to discuss health issues and appeared to enjoy their participation.

We recruited most of the service users for involvement through self-advocacy groups.

Although still perhaps lagging behind other disadvantaged groups, people with intellectual disability are increasingly finding a voice through the self-advocacy movement. Such groups allow adults with intellectual disability to take control of issues affecting their lives and are a useful resource for engaging service users in research (Rodgers, 1999). The benefits of groups in developing participation in intellectual disability research have been highlighted in a number of studies (Burke *et al.*, 2003; Gilbert, 2004; Palmer & Paterson, 2013; Rodgers, 1999). For this study, the established group dynamic was valuable as service users were not intimidated to voice their own opinions and could refer to the group facilitator for help to express their views when needed. However, some academics are justifiably critical of the way in which self-advocacy groups are increasingly becoming inundated with requests for support (Apsis, 1997) for what is often perceived to be a tick-box exercise. As service user involvement becomes increasingly common in the intellectual disability field, involvement through invitation is likely to become more prevalent, but we anticipate that this may raise further ethical concerns; it is vital that individuals understand what they are being asked to do and this requires effective communication and potentially additional support.

It is important to stress that not all service user involvement is a positive experience. Brett and colleagues (2014a) reported that lack of preparation and training led some service users to feel that they could not contribute to the research; some also felt overburdened with the work involved. Similarly, researchers reported finding it difficult to involve service users in meaningful ways owing to lack of resources. Although funding bodies highlight the importance of paying service users appropriately for their time, there are often restrictions from academic institutions in the UK with regard to approving such payments (Pickard & Purtel, 2011). In our study service users were also worried about potential loss to their

benefits, which meant that we paid them for their expenses and refreshments only, but not for their time. In the future we have discussed more innovative ways in which to recompense service users, such as funding day trips or the cost of a coffee machine or water cooler. Another criticism of service user involvement is that its overarching aims are not internally coherent because lay people who are trained and 'empowered' can no longer bring 'layness' to the research process (Ives, 2013); we do not think this poses as great a risk in our population because we did not train the service users.

Service users' input was perhaps most valuable in contributing to easy-read information sheets and visual communication aids. The literature recognises the importance of using simple language, avoiding jargon and providing alternative pictures or images when communicating with people with intellectual disability (Farmer & McLeod, 2011; Garbutt *et al.*, 2009; Rodgers, 1999). Researchers do not always write as effectively as they think in this respect and sometimes phrases or pictures can be misinterpreted. When considering involvement, ensuring that easy-read information is available to participants throughout the study should be a priority.

Although the overall aim of this article is to share our methods of involving service users in the research, our experiences allow us to make some recommendations. First, we highlight the need to involve service users early on in the design of the research, before applying for funding. Owing to tight funding deadlines, our service user involvement was restricted to input from the intellectual disability partnership boards at this stage of the study. Further involvement is likely to have improved the quality of our application and have reduced the need to make changes once the study had commenced. In line with previous studies (Booth & Booth, 2003; Garbutt *et al.*, 2009; Palmer & Paterson, 2013; Rapley 2003), we found that additional time was needed to effectively communicate with the service users. We also needed to travel to service users in their own homes or group locations because many also had co-existing physical and/or psychosocial difficulties, so travel costs, making suitable

venue arrangements and the availability of facilitators/supporters are all important factors to consider. We approached service users through a number of sources because people with intellectual disability are not a homogenous group; we would recommend this approach to obtain a range of views and feedback, and to minimise the burden of involvement. In addition, we found some organisational restrictions with regard to paying people for their time and we would recommend that government health bodies work with academic, NHS and other relevant organisations to facilitate this process. However, even with such restrictions, it is always worth considering whether service users can be involved in some, if not all, aspects of the research.

Finally, we would like to emphasise that this article describes merely a snapshot of service user involvement at the early stages of a research study. Involvement is still on-going and will continue beyond study completion. Service users have already been involved in testing subsequent study procedures and informing the development and structure of the lifestyle education programme. We are currently presenting and disseminating easy-read findings via the links we have now established. In the meantime, we look forward to continued involvement with service users in the future.

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SUPPLEMENTARY MATERIALS

Interview questions and scoring form

STOPdiabetes

Leicestershire PartnershipNHS Trust

Name:

I

1. How good is the person communicating with us?

Please tick in a box below

Bad


1


2


3

4

Good







2. How good is the person at saying the ways they change their communication if the other person doesn't understand them?

Please tick in a box below

Bad


1


2


3

4

Good







STOP Diabetes logo chosen by service users



Artwork for fliers and posters



Flash cards, story cards and fridge magnets

