Voices of experience: service users as advisors in a research project on the needs of homeless women

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Abstract: Whilst researchers are increasingly required to demonstrate patient or participant involvement in the design, implementation, and dissemination of their research, very often that involvement is lacking in continuity, is defined by the researchers themselves, and is subject to the criticism of being tokenistic. This paper discusses the role played by service users in advising on a longitudinal study of the health and social care needs of a cohort of homeless women in a major city in England. It explores the experience and impact of including service user advisors within research from the perspective of the advisors themselves and researchers. Although it was a steep learning process for all concerned, the advisors became a valued part of the research team and valued the experience themselves.

Keywords: service users; advisors; homeless; women; participation; research methods; engagement; impact.

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Joe James is an ex-service user who currently works in the third sector supporting those with complex needs. She has acted in an advisory capacity on a number of different academic research projects.

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Karen Morgan is an experienced researcher with a wide range of interests relating to gender based violence, speciesism, violence, and theoretical understandings of the re-presentations of structural and symbolic violence.

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Lorna Henry worked as a Research Associate within the School for Policy Studies on a number of externally funded projects which included a Department for Children, Schools and Families (DCSF) funded Evaluation of the Social Pedagogy Pilot Programme in England. She was previously a researcher for evaluation of the role of the Virtual School Head for Looked after Children (also funded by DCSF). Her PhD focused on protecting children and protecting family privacy. She has extensive experience as a researcher in academia and as a voluntary sector project worker facilitating service user involvement.

1 Introduction

Over the past few decades, there have been significant changes in the way researchers have approached projects which affect the lives of individuals. Rather than research being seen as something which is done to, on, or for, sections of the population, active participation in the design, execution, implementation and dissemination of research is now seen as important in many areas, particularly in health and social care research (DH, 2001). It has also become a required element in the consideration of applications by many funding bodies, The National Institute for Health Research, UK, for example, asks that
full details of ‘the appropriate involvement in the proposed research and/or outputs of service users are in the research proposal’. The UK Government’s establishment in 1996 of a national advisory group (INVOLVE) to support greater public involvement in research within the National Health Service, public health, and social care shows the extent to which patient and public involvement (PPI) has become embedded in research policy.

Participatory research, as it is generally termed, can take many forms, ranging from consultation before and during the research process, collaborative research, where researchers work with participants, to totally user controlled projects. It has become a powerful force for social and political action and emancipatory change in less well developed countries (Fals Borda, 2001) and also among groups of disadvantaged, vulnerable or marginalised people within mainstream society (Lewis, 2001; Dickson and Green, 2010).

Participatory research should be characterised by a collaborative, non-hierarchical approach, mutual respect and support, and a transparent and reciprocal attitude to sharing knowledge (Reason, 1994). Not all those concerned will wish, or be able, to take part in the research in the same way but there should be an open acknowledgement of the extent to which each partner is involved and the value of their contribution (Heron, 1981; Reason, 1988). There are strong affinities here with feminist research practice (Williamson, 2000; Oakley, 2000; Kaspar, 1994) which can be seen as concerned with issues of power and control and a commitment to collaborative working with participants, who are seen as the experts in their own lives and able to share their experience and give informed opinion.

Genuinely involving service users¹ in research projects can be demanding and time consuming. It requires careful attention to every aspect of the process, from the choice of vocabulary to the provision of practical and emotional support to participants. Where research sites are temporary locations for participants, such as in domestic violence refuges, hostels, or hospitals, continuity of participation in research can present major problems and additional resources are needed to maintain contact (Cotterell et al., 2007). Perhaps for these reasons, it can be all too easy for involvement to become tokenistic, with the agenda set by researchers which can leave participants feeling exploited or marginalised (McLaughlin, 2010; Carey, 2011; Beresford, 2002). It could be argued that the mere fact of reducing involvement to a set of initials (PPI) can be seen as symptomatic of this approach to involvement.

By presenting the different aspects of the research process from the perspective of the different agents involved in the research, this paper explores the ethical and practical dilemmas which arise when including service user advisors within a research team. This paper explores these issues in order to examine how participant involvement can be better enacted within the research community.

2 The TARA² project

TARA was a longitudinal study which has followed a group of homeless women over the past years in order to identify how their experiences and needs changed over time and to gain a fuller understanding of their complex needs, including their social care and health needs. It also sought to identify the barriers that service providers, and therefore researchers, face in engaging with homeless women over a sustained period and to
understand how best to support women themselves to access, and maintain engagement with, support services.

3 Why recruit service users as advisors?

Our past research (Williamson et al., 2010; Henry et al., 2010) showed that women who are homeless, or at risk of becoming homeless, often have complex social care and health needs including drug, alcohol, and/or mental health issues and sexual or other forms of abuse. As a result, the chaotic nature of homeless women’s lives can result in barriers to accessing services, including inability to remember or attend appointments, confusion at being passed from one agency to another, poor mental and physical health, and a lack of resources (such as credit to make phone contact). As a consequence, researchers too face difficulties and inherent dangers in finding, engaging with, and maintaining contact with this group of women over time.

To gain a robust and meaningful understanding of the lives of homeless women, we recognised the need to talk directly to those who were living that experience whilst being aware that the problems outlined above meant that it would be difficult for participants to be able to sustain the demands of full participation in design, research and implementation. We were also acutely aware of the potential for emotional damage that might be caused to already vulnerable individuals (Wright et al., 2004; DVRG, 2004). As our previous research showed, without a secure base, women are less likely to be able to deal with their other issues alongside research participation. Such roles might also place advisors in a difficult position in relation to service providers engaged in the research and who, as service users, may well be in daily contact with service providers engaged in advisory roles within research.

Given that research indicates that women who have begun to emerge from traumatic events are often eager to reach out to help others (Kirkwood, 1993; Abrahams, 2010) asking women who were now in stable accommodation and who had a wide experience of statutory and voluntary agencies to join us as service user advisors, to assist in the design and execution of the research, provided a way forward.

4 Process

4.1 Recruitment

At the end of the previous project, four participants co-presented the findings with us at the final dissemination conference. At this time we asked if they would be interested in taking part, as potential advisors, in any future research we conducted about homeless women. All of them agreed that we could contact them again if funding was obtained. Once funding was secured, we were able to re-establish contact with three of the women, and they met a member of the TARA team for face to face discussions about the new project, what their role would be if they decided to take part, and any anxieties they had about potential involvement. It was clear, from later comments, that they were pleased to be approached, but also surprised that the research would be going ahead.

“J: I remember doing the presentation ... you could see what kind of feedback you got from the audience ... and then try and get the money together to do a
As this quote from J. illustrates, she had little faith that the research team would come back on the basis of broken promises in the past which highlights the need for researchers to be honest about the limitations of possibilities when discussing advisory roles.

4.2 Training

Before taking part in the dissemination of the earlier project results, we held confidence building sessions and training in presentation skills with a number of service users. The purpose of this training was to give women the confidence to take part in the conference event, if they chose to do so.

“J: I think I was only about a few months clean, I’d just found recovery again, and then I was a few months clean ... and I was a bit apprehensive. But what I was looking forward to was just being with women. I remember thinking that, it’s going to be all right, it’s just women. Yeah, I was looking forward to that... and then when I got there and like the exercises that you done and ... it was like a team building thing really wasn’t it? And kind of you know give us the skills to do the presentation. I thought them three days were good. Good lunch. (laughter)

L: Lovely lunch. And there was no real pressure, it was a very therapeutic approach, it was really lovely... that first experience made me realise how important it is for my opinions to be heard. It boosted my confidence massively, you know it started something off in me. It was a huge audience.

J: And the people in the audience as well were all professionals, commissioners, providers, all that type of things, so that caused us all a bit of anxiety.

L: It caused us a bit of anxiety, but on the plus side there were a couple of familiar faces for me ... who said ‘Just look at me, talk to me, it’ll be okay’ and it was… you know and the positive feedback that we got from the presentation and how we put ourselves across was lovely. Again it was more confidence.

J: And I think the other thing, we’d to work out ... what them three days did, they managed to draw out each of our strengths, so we drew on each other’s strengths didn’t we, so that was really cool.

L: And supported each other. Felt quite important actually in the room and doing the photos afterwards.

J: I felt like we were taken seriously, you know. And I remember particularly one particular agency that I ... I engaged in ... came up to me after the meeting and said she’s going to make some changes around certain guidelines for vulnerable women.

L: And the university ... you know, you supported us really well. It was brilliant. The confidence building, speaking to us on a level, it really was really inclusive, really important ... I loved it actually, thinking back.

J: Yeah, I was thinking back and I was thinking ‘Oh ...’ And it’s weird that, cos I’d do that now, it’s weird that I have ever experienced ... of course I could do it now, but I don’t think maybe I’d feel the same way about it.
Subsequently, following discussion with the service user advisors about any types of training they felt that might benefit them in carrying out their advisory role, background training in research methods and ethics was arranged and this was also considered helpful. The event was tailored to the advisory roles being carried out by women advisors to two projects focused on provision to women. The comments also illustrate the importance of considering the best way to facilitate attendance at meetings and training days.

“J: I thought it was well organised, you know ... you know everything that you said you’d do you’ve done. I thought that research training was really useful … and interesting. Cos I’m part of a drugs project doing a bit of research, so I just had a little bit of knowledge and understanding, cos I’m dead curious ... I’m asking lots of questions. So um ... it was really interesting like that, the research. And I think you know that you’ve been really helpful. So like silly little things that make a difference, you know, paying parking and finding parking ... and you underestimate just them silly little things, how important they are ... to support people in coming to meetings, making sure there’s lunch. All them little things help the engagement of ... specially people like us service users.”

4.3 Ethical considerations

Asking service users to be involved in research can risk emotional harm to them. There is also a danger that they can become too close to those they are interviewing, wanting to help and blurring the boundaries between research and action (Wright et al., 2004). This had been one of the considerations in asking service users to act as advisors to the project, rather than carry out research themselves. Because of their desire to reach out and help other women, this was not an easy concept for them to grasp, but both Joe and Lucy recognised the implications, as the project developed.

“J: I think it’s been a very gentle process and I’ve really appreciated that. It hasn’t been … you know there was a bit of me that wanted to get involved in the interviews and be a bit more present and vocal and everything, but then that wasn’t my role, it was to advise, it wasn’t to do ...
so, you know, had to remember that.

L: It definitely sparked something in me as well you know. Helping women and the whole subject it’s just so ... it’s really triggered off how important it is to me. And I wanted ... the same as Joe, I wanted to do the interviews, I wanted to do it all (laughs) ... I suppose because I identify so much with the research that you’re doing, you know ... it’s really important.

[Int] So were you unhappy that you couldn’t do the interviews?

L: No, I’m really glad now with hindsight.

J: Yeah, yeah, same as that, with hindsight. You need a particular level of experience and skill and I don’t think I would ... I don’t think it would be possible to get that ... not with a history like mine, I’d be doing a disservice to the person I was interviewing to be honest.
L: And it would probably affect the research as well. Because I’d want to help everybody. You know I couldn’t … yeah.

J: I might struggle maintaining them boundaries and that, I might struggle with that. So in hindsight yeah, it wouldn’t … not at that particular stage in my life anyway… maybe later on that could happen, but not at that point … not with the history what I’ve got.”

4.4 Payment

The question of payment to interviewees has been a contentious one for many researchers. On the one hand, monetary incentives may attract those in urgent need of cash, but who have no intention of staying with the project long term. It has also been argued that payment might compromise the quality of the research and undermine the voluntary nature of consent. Additionally, it may adversely affect benefit payments and an individual’s tax situation. On the other hand, payment to participants can be seen as a tangible acknowledgement of their involvement in the project and the time, skills and expertise they contribute (INVOLVE, 2010; Wright et al., 2004).

An alternative method of incentive, used in our previous research, was the provision of vouchers as a way to limit where payments could be spent. In asking women to join us as service user advisors, however, this seemed an inappropriate gesture towards women who would now be working as part of the research team. As Joe pointed out, we were now in a different relationship; and in the new situation, vouchers could be seen as being patronising and lacking in trust. It was decided that a nominal payment fee would be made for attending all meetings, to cover attendance, travelling costs and the time to read papers and respond.

4.5 Working together

In working with service user advisors, our policy was to be transparent and honest in our discussions and decision-making, involving them in the design of the research and methodology. Because we had worked together before, a basis of trust had been established, but it was important to build on this if the collaboration was to be fruitful. The use of abbreviations and jargon as a kind of shorthand is endemic in the research community, but we tried to avoid using terms which might appear to marginalise or exclude them. This turned out to be a two-way process, however, since their involvement with a variety of situations and agencies had given them a jargon and idiom which we had to learn.

Involvement in meetings with the full advisory group, comprising academics, commissioners of services and senior members of service providing agencies, was a further area where policy and practice had to be negotiated. We had concerns that the advisory group meetings might be alienating and/or feel impersonal and abstract to the service user advisors given the subject of the research. However, as our intention was that service user advisors should be full and equal members of the advisory group (Tarleton et al., 2004), measures were introduced to try to alleviate these potential problems. This included incorporating small group working within the meetings, in order to break up the agenda and encourage discussion, and pre-meetings to answer any questions the advisors might have about the agenda for the meeting.
We were, however, surprised that some wider members of the advisory group expressed concerns about service user advisors being full members of that group. Concerns were expressed about confidentiality, as well as in relation to potential discussions of the internal policies of different agencies. There was also concern expressed against payment as some group members saw a potential conflict between the role of advisors on our research project for which they were to be paid, and the normal process of service user feedback undertaken within services, which were not paid. Finally, there was a fear that practitioners might be present who had worked directly with a service user advisor, possibly resulting in embarrassment for both parties. This attitude towards service users, can, perhaps, be seen as symptomatic of the reluctance, in practice, to share power, even by those who accept this in theory (Dickson and Green, 2010; Barber et al., 2011).

Following a lengthy discussion about the training and guidance which had been given to service user advisors, and an understanding that the process would be reviewed, the agencies agreed to attend the meetings and no such problems arose. Before each full meeting, we met with service user advisors to discuss the previous meeting and the new agenda. We checked by texting after the meeting that there had been no adverse emotional problems. In fact, after some initial hesitation, the meetings went well, with service user advisors playing a full and active part in proceedings.

We were concerned to ensure that none of the steps we had taken to enable participation could be seen as patronising or excluding the service user advisors from any part of the research. The response to this question was emphatic; our approach had been inclusive and accepting of them. While Joe appreciated that we had probably made changes to enable them to work with us, they had never felt less than full members of the team.

“[Int] One thing we’re always concerned about is do we come across as patronising?

J: Not at all. No. No.

L: No. Friendly ...

J: Yeah. Friendly, supportive, encouraging ... and you always ... it’s like you’re just now asking me how my job was ... do you know what I mean? ... little things like that. That you remember things, you’re kind of compassionate, you know, you guys show a lot of empathy ... no I’ve never felt patronised or kind of ... you’ve always been inclusive, you know. And I’ve got no doubt in my mind that maybe you’ve had to be mindful of your vocabulary for instance and not ... and all them things don’t go unnoticed.”

5 The role of service user advisors

The role envisaged for service user advisors in this research developed during the funding application and was discussed with them during the recruitment process. This included giving the advisors a written role description as both advisors and members of the advisory group. As other researchers have found (Barber et al., 2011; Staniszewska et al., 2011; McLaughlin, 2010), the involvement of service users in the design and methods of a research project greatly improved the research tools and procedures. The work that the advisors did on the interview schedules, the explanatory leaflets and the consent forms
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had a major impact on the content and appearance of the material and, in fact, made them easier to work with. Excess words were stripped away, explanations were made clear and succinct, and advisors asked direct questions and challenged our assumptions about how women would react to the research questions. They suggested areas to explore that we had not considered, because they were beyond our experience, but which added depth and understanding to the research. The advisors also suggested that there were questions we should ask when we were reluctant to include them.

Involvement also extended from design to recruitment. Because of their wide range of experiences and knowledge, the advisors were able to interpret actions to us and offer insights as to what potential participants might be feeling and advise on what might be termed 'street etiquette' such as when to contact potential participants and when it might be dangerous to do so. When other efforts to contact women failed, they were able to suggest avenues of approach which we might not have been aware of and which facilitated keeping in contact with our cohort of interviewees. And, in a poignant reversal of what we had expected, they were protective of the members of the research team, checking that we were able to debrief after difficult interviews, and that the emotional stress was not becoming overwhelming.

6 Impact

Participatory research has been used as an instrument for action to create change in ways of working and outcomes and can also have an empowering effect on participants.

6.1 On the outcomes of the project

Our previous research with homeless women had resulted in positive changes in some areas; a number of services had changed their procedures and commissioners of services had insisted, on the basis of our research, that tendering services provided increased emotional support to women and that women only services were to be retained wherever possible. It is too early to say if there will be changes as a result of the current research.

We asked Joe and Lucy to look at how they felt the project had worked in terms of influencing outcomes. There was considerable disappointment that some agencies they had felt should have been involved were not willing to take part, but an understanding as to why this might be. And as the research progressed, the service user advisors realised that the project was not going to be able to improve services in the same way that the previous project had done.

“J: I wished ... some services’ lack of motivation to participate in the research. I think that’s what really disappointed...

L: I was incredibly disappointed, because the service that I was representing in my initial contact really didn’t engage. The people that they could have referred would have been really vital to the research.

J: I … wondered what that was about to be honest. And I’m never going to know the answer ...

L: What I found quite difficult actually was the accepting the fact that the outcome of the research is not going to be that everything’s rosy. You know and especially with the financial climate ... you know we had the financial
climate change quite dramatically from the start of the project to where we are now, and services ... we’ve lost services. When we were actually expressing where the needs for services were ... and now even the services that were in place at the start of the project aren’t there.

J: Prospects for homeless women are not good. Outcomes for homeless women are not good, you know. [...] I’m not hopeful at all at the moment ... specially with the current climate ... you know mental health are changing, they’re being re-commissioned, mental health services are being re-commissioned, drug services are being re-commissioned. Just recently the housing support has been re-commissioned

L: And benefits have been changed, you know. The chance of a woman breaking free from any one of the things that we deal with are getting slimmer and slimmer.”

This discussion highlights the importance of being realistic and honest about the potential for research to have wider impacts in the provision of services, the policy field, and wider society. Whilst the advisors, and the research team, were disappointed that the financial constraints might limit the possibility of implementing the research findings, we had been realistic throughout the research process about its potential to make an impact and as such, the advisors did not feel that the research, as a result, was unjustified or disappointing.

6.2 Impacts for the service user advisors

Researchers have recorded increased benefits for service users participating in research (Dickson and Green, 2010; McLaughlin, 2010; Cotterell et al., 2007). Key findings were a realisation of their own strengths and values, a growth in self-esteem and confidence, which enabled them to speak out on issues that affect them and an increase in personal skills and an involvement in other projects. For Joe and Lucy, it was apparent that being a full part of the project had enabled them to put feelings previously in the background into words and ideas about the best way to work with women and also the confidence and ability to take action and challenge decisions effectively. Participation had also developed skills and experiences which could support applications for paid and unpaid work.

“L: It’s difficult to put into words. But getting involved in the TARA project has helped me get involved with other projects. It helped me use my voice, my experience, I’m a lot less afraid to speak out. Sometimes I don’t ... conduct myself in the right manner, it was a real lesson in building my confidence that I could do it, rather than just going in all guns blazing and defensive … I’ve got involved with loads of other projects. … it’s made me realise that everything that’s happened and everything that I’ve experienced it’s … if I can make one difference to one person’s experience, make it a more positive experience for them, then it won’t have all been for nothing. And that is what has really brought it home to me.

J: For me, what the TARA project’s done is to bring home ... like I’ve got personal experience of problematic drug use, of being homeless, I’ve got a history of mental health problems, and domestic violence. And I haven’t come across one woman who doesn’t have one or more of those issues going on. Usually more – there’s usually multitudes, a lot of things going on. And I’m really passionate about encouraging services to develop ways of working with all them problems, instead of separating them out and sending us to lots of
different places, you know. They’ve got to work with us ... holistically, with all the problems, with all that stuff. And you know, like Lucy, I’ve been involved in lots of different, women only projects that attempted to encourage that view about working with a person as a whole, not sending us off to different services hoping for the best. As if you know if you get rid of one problem then the others will take care of itself, that’s not my experience. You have to manage all of them, have to deal with you know all of them.”

6.3 Researchers’ perspectives

So far this paper has focused on the experience of service user involvement from the perspective of the service user advisor. As the discussions above have illustrated, this is a two way relationship which requires reflection on the role of the researchers. The following are summaries about this relationship from the perspective of three of the research team.

6.4 Hilary

Working with service users advisors has been an amazing experience. I had used action research before, but always under a top down agenda. Here, we were inviting women in to be a part of the team and it was new and unpredictable and initially, I was as nervous as they said they were. Having met them during the earlier project, I knew that they were women who had come through difficult situations and were essentially pragmatic and realistic in their approach to problems. Would we understand each other? Could they manage the constraints of the academic process? Would we be able to change and adapt? As the designated contact point for service user advisors I made the first approach to them to join TARA and was delighted at their positive reaction. As we grew together, it became easier to remember not to use jargon and to consider the constraints they were under. We had fun together and they taught me so much that has broadened my life and understanding. And I was so moved by the way they cared for us.

6.5 Emma

One of my main concerns throughout the project was the concern that we were patronising the service user advisors and being tokenistic. It is such a difficult balance to enable service users to equally participate in the research process without causing them harm, or without excluding them in some areas. I am proud of TARA because I think we managed to achieve that. I am sure the advisors got fed up of me asking for their reassurance that they were ok, that they felt able to contribute, and not patronised, but it is so important from both sides to be honest about that fear. Hearing their feedback about the whole process brings home how important it is to involve service users, whilst providing them with whatever tools they feel they might need, and recognising the additional benefits of doing so. Seeing generic attempts to provide PPI involvement in research I find problematic. Too often I think that researchers make assumptions about participants and service advisors alike. Certainly at the start, the advisors in this project would not have come to a university on their own, and they would not have felt confident to just turn up at a meeting where they did not know someone. By really being there, meeting with them beforehand, meeting them at the door, sorting out transport, being
clear about what was happening, and why, we managed to alleviate those fears and we benefited as a result.

6.6 Karen

I became involved in the project a bit later than everyone else, by which stage the preliminary phases of the research had been set up and the interview schedules for the first stage had been agreed. This was my first experience of working with service-user advisers and I was a little apprehensive; not really being sure what to expect, nor, if I am honest, whether their involvement would be tokenistic. As soon as I met them, however, it was obvious that they were truly engaged in and enthusiastic about the research and their knowledge and experience was invaluable. Talking to them inspired confidence to carry out interviews with our research participants, knowing that with their insight, the interview schedules had been carefully developed and we were not going to be asking silly or inappropriate questions. The three service-user advisers were an integral part of the team, and I cannot imagine that we would have been able to conduct the research half as well without their advice. Their feedback about the process as a whole was moving and inspiring – and, I hope, can help provide a model for service-user engagement in future research projects.

7 Key themes

Probably the most important aspect of working with service user advisors is the need to ensure they are treated with respect at all times. This means being honest and transparent in all our actions and ensuring that we keep our promises. This includes being realistic about what can and cannot be achieved through the process. It also means clarity in our actions, including not using jargon and explaining why we are taking a course of action, which may not be immediately obvious. Above all, respect demands an ability to listen and learn from our co-researchers.

Respect also demands that we keep in touch on a regular basis. Because they are not present in our work environment, it is essential to keep them informed of any changes and the progress of the research. Without this, there is a danger that they will not feel part of the project and feel alienated from the rest of the team. This was clearly illustrated when we held a joint training day with service user advisors from another research project. Here, contact had been intermittent, the participants had felt excluded from the project, not all of them knew what ‘their’ research was about and they felt that their contributions were not valued.

We decided, from the outset, that our service user advisors must be treated as full members of the team and included in events and meetings. Although we faced some opposition in doing this, we felt that it added immeasurably to the knowledge and outcomes of the research project.

All of this, as other researchers have noted, is time consuming and resource intensive (McLaughlin, 2010; Wright et al., 2004). Flexibility is also an important element in understanding the constraints on participants and the ability on the part of organisations and individuals to change and compromise to enable them to contribute (Faulkner, 2004). If participatory research is to be genuine, time must be allowed to ensure that the necessary elements are put in place.
8 Conclusions

Participation in research in an advisory capacity is not always positive, particularly where involvement does not lead to change or where advisors feel their engagement is not valued. Genuinely involving service users as participants in the research process takes time and effort on the part of all those involved. Consideration needs to be given as to the extent to which involvement is needed, the purpose of involvement, the aim of doing so and the expected outcome. Preparation for service user involvement needs to take place well before any approach is made to prospective participants; it should cover issues such as contact, payment, clarity as to their role and an understanding of the need for flexibility. It is essential that both time and financial resources are included in costing, that funders who want genuine service user involvement recognise these costs, and finally, that institutional processes are flexible enough to enable them.3

Service user involvement in research is not always appropriate nor positive, and a tokenistic approach is damaging both to the research and the individual. However, undertaken with honesty and respect, it can lead to a deeper understanding of the issues involved, mutual learning and be beneficial to all those involved and the research project.

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References


Notes

1 McLaughlin (2010) and others have argued that the term ‘service users’ can be seen as conferring an inferior status – that of someone who accepts or receives a service passively and is inherently less powerful than a service provider. Other terms which are in current use include consumer, patient or participant. While respecting this view, service user appears to be most commonly understood and is the term we have chosen to use.

2 The name Tara was adopted as a result of a suggestion made by a member of the research team. The full title of the project was considered cumbersome and also likely to be seen as stigmatising to participants. Tara is regarded as a member of Buddhist pantheon, and also prominent in Hinduism. She is traditionally regarded as being the Mother of liberation, Founder of the Buddhist feminist movement and a committed feminist who symbolises compassion, healing, serenity, mercy and success in achievement. The name seemed to resonate from the outset with all our interviewees, whether or not they had any religious views.

3 For example, our own institution wanted participants to send in an invoice for their participant payment before we explained that the women were homeless, often with multiple problems related to complex trauma, and not therefore in a position to do so.