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## **Include Me In: User involvement in research and evaluation**

By Tim Grayson, Yuet Hung Tsang, Dee Jolly, Kate Karban, Phillip Lomax, Claire Midgley, Ian O'Rourke, Caroline Paley, Jill Sinson, Kim Willcock and Paul Williams

### **Structured Abstract:**

*Purpose:* This paper discusses the experiences of a group of ten user and carer researchers from mental health and learning disability services who worked together in a research and evaluation project between 2009 and 2012. The research project aimed to identify changes that took place as over 300 people moved from hostel accommodation into independent tenancies in flats and bungalows. These moves were part of a three year project involving a partnership between a local authority and a housing association.

*Design / approach:* The paper describes the process of involving user and carers in the research process, identifying the challenges and benefits of involving users and carers. The ways in which people were trained and supported to take part and stay involved are outlined, as well as how the group felt they learnt new skills and increased their confidence.

*Findings:* User involvement in research can mean different things with different levels of involvement, from consultation through to user-controlled research. The collaborative study had a range of benefits for the lives of the co-researchers, as well as contributing to the development of a new independent living service. A number of factors contribute to the success of user involvement in research and these are listed.

*Originality / value:* This paper adds the voices of the co-researchers to the literature and provides 'lessons learned' for other researchers in this area.

*Keywords:* User involvement, research and evaluation, learning disability, mental health, independent living, housing, social inclusion.

*Article Classification:* Case Study

### **Introduction**

This paper describes the experiences of a group of ten user and carer researchers from mental health and learning disability services who collaborated in a research and evaluation

project. The project aimed to identify changes that took place as over 300 people moved from hostel accommodation into independent tenancies in flats. These moves were part of a three year project involving a partnership between Progress Care Housing Association and Leeds City Council Adult Social Care Department.

The plan to evaluate the move from hostel accommodation to people having their own flats/bungalows and tenancies was discussed at a number of meetings of hostel tenants. People were particularly interested to find out if moving out of a hostel improved social inclusion and helped people to feel more involved in the local community. Progress Care Housing Association led a bid for funding from the Big Lottery. This was successful and a research management group was set up including people from Progress Care, Leeds City Council and Leeds Metropolitan University. First of all three staff were recruited to work on the project, a senior researcher, a research officer and a part-time administrator. They were employed by Progress Care but based at the university and supervised by a university researcher involved in the original bid and who had relevant research and practice experience.

User and carer involvement in the evaluation was recognised as very important in the funding proposal and in the research design. The original plan stated that it would be important to involve people with experience of using services in doing the research. Some of the planning group were themselves involved in moving from a hostel to independent living.

Although the plan had been to involve 24 user and carer researchers, this was changed and an initial group of six researchers was recruited. A further four researchers later joined the group. The term 'co-researchers' was chosen by the group to describe the user and carer researchers and this term will be used throughout this paper. The term 'researchers' is used to refer to the senior researcher and research officer.

This paper will begin by reviewing some of the UK literature on service user involvement in research and evaluation. We will describe some of the difficulties faced in starting this work and how the co-researchers were recruited and trained. We will talk about the experiences of the co-researchers – the positives as well as some of the difficulties faced. Finally we will talk about what we have learnt from these experiences, the co-researchers' views on their experiences of being involved, and what might be helpful to people doing similar work in the future.

The researchers discussed how we would write this paper with ~~the eight~~ co-researchers who maintained their involvement throughout the project. ~~and t~~The decision to write this paper collectively was agreed by everyone involved. This included the decision to include everyone's names as co-authors. The experiences and views of the co-researchers provided the starting point, and drafts of the paper were read, discussed and changed by the group at each stage.

## **User participation in research**

Involving service users and carers in research is becoming more widely recognised as an acceptable way of doing research. The involvement of service users is emphasised by government policies, especially in health and social care (Department of Health, 1999; 2000; 2001; 2005). However, it still may not be seen as a priority and it can be hard to obtain funding. Also, while there is quite a lot written about user involvement in mental health research (Beresford, 2006; Faulkner & Layzell, 2001; Rose, 2001), there are fewer examples of research involving people with learning disabilities (Abell et al, 2007; Ham et al, 2004; Redmond, 2005).

User involvement may also mean different things. There are different levels of involvement in research – from consultation (where researchers may ask service users to comment on parts of the research), collaboration (the service users and researchers work together to make decisions), through to user- controlled or user-led research. In user-led research, service users control and lead all stages of the research process (Minogue et al, 2009).

Turner and Beresford (2005) have noted that when people talk about user involvement in research sometimes the users and carers don't really have any say over what happens. They argue for user-controlled research, where service users are the ones in charge of the research and decision making. This study is best described as collaboration - where service users work closely with professional researchers on all aspects of the research (Schneider, 2012).

Other commentators have stressed the importance of research being relevant to the lives of the people involved, not just carried out by outsiders. Taking part in research may help people make other lasting changes their lives (Flicker et al, 2008, Schneider, 2012).

Whenever users and carers get involved in research, it is important to think about who makes the decisions and says what is going to happen. This may vary at different stages of the research. Sometimes different people will be involved in different activities. For example, while some commentators have written about the benefits of involving users as interviewers (Bengtsson-Tops & Svensson, 2010), service users can also be involved in research design and management, data analysis and dissemination. In our project, this happened with some people choosing to focus on doing interviews, some preferring to be involved in analysing data, and others in talking at meetings about the research. People also took part in devising interview schedules and contributed to the 'Together in Research' newsletter, as well as choosing the name of the project group 'Include Me In'. The main thing was that people could make choices and feel part of the whole project. More information about the range of activities can be found on the website mentioned at the end of this paper.

## Identifying the challenges

### *Recruitment of user and carer researchers*

The first step in recruiting service users and carers to the research team involved attracting people with experience of living in the hostels that were being replaced by individual flats. The researchers produced an information leaflet that was sent to all the hostels. This was followed by inviting residents and staff to meetings in each hostel. At these meetings the researchers talked about the evaluation project, sometimes using pictures and playing a game of 'research bingo' especially developed by the researchers. Anyone interested in getting involved was asked to fill in a brief application form to show their interest and then invited to an interview. Fifteen people applied and six of these applicants were successful. The group included two people with learning disabilities, two with mental health difficulties and two carers (one of whom also had learning difficulties). Everyone from the group took part in weekly training sessions held at the university over five weeks.

Compared to similar research projects which have promoted the inclusion of all those who want to get involved (Faulkner, 2004), the recruitment process might appear formal and perhaps off-putting to potential applicants. However the form and the interview were designed to be as straightforward as possible. All applicants were encouraged to seek help in completing the form and also offered the opportunity to bring someone with them to the interview.

An important sign of the success of the first stage of the project was the high level of commitment shown by the co-researchers, with most people attending all of the training sessions. Nine months later when more co-researchers were recruited, some of the original group were involved in interviewing the new applicants, showing a very positive and confident demonstration of their knowledge of the project. From these interviews, a further four co-researchers joined the team, one of whom already had some experience of similar work. This was a critical point for the research team, in terms of new people joining an already established group. One of the new members, however, commented that:

*For people who have been there from the start they have seen things change; for me, coming in later, I have been welcomed and my views listened to.*

### *Training and support:*

The weekly training sessions were planned to help the co-researchers understand the research process and to introduce them to basic research activities and skills. This has led on to involvement in a range of activities including questionnaire design, interviewing and data transcription and analysis.

Many commentators have written about the importance of support for service users involved in research projects. The co-researchers were a diverse group and some needed support to attend sessions at the university. Support needs varied from needing reminders of the date and time of the next session, having taxis booked, and being met on arrival at the university. Over time people became much more skilled and confident. This included finding the way around the university campus to attend meetings and using university facilities such as the coffee bar.

Although the original plan had been to recruit 24 user researchers, it was later decided that a smaller number would ensure enough support was available for all individuals. This point has also been made by Faulkner (2004) who advises against being carried away by enthusiasm and recruiting a large group, only to find that there are not enough resources to provide support. A smaller, more intimate group may also contribute to a sense of belonging and peer support. One co-researcher commented on the 'warm and friendly atmosphere' and a sense of 'fun' when the team were together.

#### ***CRB checks:***

Other commentators have written about the potential problems associated with undertaking Criminal Record Bureau (CRB) checks for user and carer researchers (Repper et al, 2007). Some of the co-researchers didn't have the papers and documents that were required. An alternative suggestion that co-researchers could go to the police station and be finger printed to confirm their identity was not felt to be acceptable and no one chose to do this.

#### ***Payments:***

The question of payment for the co-researchers presented a number of problems. The original budget included enough money for the recommended payment on an hourly basis for those taking part (Scott, 2008). A local Welfare Benefits Advisor was invited to talk to the co-researchers as a group and everyone was also offered a one-to-one meeting to talk about their individual circumstances. Most people accepted this as everyone was anxious not to have problems with their benefit payments or tax.

At the start the plan was that a local advocacy group would be responsible for making payments to the co-researchers. However, this didn't work out and the university agreed to take this on. As a result arrangements for payments involved close working with the university finance department where people already had some experience of making payments for service user and carer involvement. However, as other similar projects have

found (McClimens et al, 2007), there were some difficulties trying to organise this within the systems of a large organisation.

### ***Ethics / Acceptability of user involvement / resistance***

Ethical approval for the evaluation was given by the University's Ethical Committee, however this was a long process. Others have also found this to be difficult. Smith and Bailey (2010) have written about the challenges they faced in gaining ethical approval when working with user researchers. They found a lack of understanding about the role and contribution of the user researchers and had to change their plans as a result. Others have written about user researchers with intellectual difficulties applying for ethical approval (Ham et al, 2004) and the amount of time involved in preparing materials necessary for a successful application.

Involve and the NHS National Patient Safety Agency (2009) emphasize that the involvement of service users in research design, data analysis and dissemination does not usually raise any particular ethical issues for those involved. However, where there will be direct contact with service users as participants, for example in carrying out interviews, it is important to pay attention to the well-being of both interviewers and those who will be interviewed. In particular there is a need to ensure that training and support is offered to the user researchers, and that there are no extra risks for the people being interviewed.

For this study, ethical approval required a statement about the need to assess the capacity of service users to give consent to be interviewed. This had to be undertaken by the 'professional' researchers rather than the user and carer researchers.

At the start of this project, a small number of the residential staff questioned the involvement of users and had concerns about the possible impact of payments on benefits. However the majority were positive and supported service users to get involved.

### **Motivation for involvement**

The co-researchers described their reasons for getting involved in a number of ways and these are shown in Figure 1 below.

**Figure 1: Reasons for getting involved**

- To find out what research is, and how you can use it to find out what you want to find out.

- To learn about the Independent Living Project (ILP), find out about people's views and experiences of the ILP, see what works and what doesn't work, and if it is a change for the better.
- To learn about social inclusion.
- To have a purpose and a challenge, to be involved in something stimulating.
- An employment opportunity, experience to add to your CV.
- To be involved in something that changes people's lives for the better.
- To 'give something back' to the system that has supported us.
- Closure - a significant and meaningful end to personal involvement in the ILP.

These motivations can be grouped into three main areas. Firstly, people thought the research would help with their own development and learning, in building skills towards finding employment in the future. Secondly, the co-researchers were committed to improving services and keen to find out if changes in service provision changed peoples' lives for the better. Finally, - for some of the co-researchers there was a more personal reason for being involved. This included, for one person, giving something back to the service and for another, a sense of personal closure on their use of the services being studied.

Some of this is summed up in the words of one of the co-researchers:

*..... I've been a service user for a long time and have seen a lot of changes, and the ILP project sounded interesting. I also wanted to give something back and to use my experiences to try to help other people. I have been on the board of a housing project, done lots of training and feel I have a lot to offer people.*

She added:

*It is also important that [people's] voices are heard. It makes you feel important, valued as a person, you are not just a service user ...*

## **Benefits of involvement**

The co-researchers have described a range of benefits from being involved in the research project and these are described in Figure 2 below. There is a sense that the co-researchers have, at least in part, realised their hopes as expressed in their reasons for getting involved.

## Figure 2: Benefits of involvement

- Getting a certificate for completing the training programme.
- Financial gain - getting paid for doing research activities.
- Research skills – interviewing skills, how to put a questionnaire / interview schedule together.
- Job skills – time-keeping, keeping appointments / diary-keeping, learning about responsibility (through respecting confidentiality and handling confidential information and data).
- Learning about processes – how to get things to work (often through trial and error).
- Meeting people from similar backgrounds with similar interests, having fun, coming together to have a laugh, making friends with the other researchers.
- Supporting each other, enjoying each others' company, having a relaxing time - a kind of support group for each other.
- A therapeutic experience.

Other feedback from the group also emphasizes the importance of the learning process. One of the co-researchers stated that:

*There is a lot to learn as most of us have no past experience of research. The researchers teach and guide us, helping the group to learn all the different aspects of research and helping co-researchers reach their potential.*

One of the co-researchers who had joined the group after it had been established had previous experience of interviewing service users and staff. However, when reflecting on undertaking the interviews, he acknowledged how complex the issues involved are and the need to be aware of the different situations that might be encountered:

*..... there is no room for complacency when meeting residents because you never know what to expect. People can change their minds easily and moods can impact on the interview process and what information you end up with.*

## The end of the evaluation

-In this study everyone who was involved knew that this was a three year evaluation. It was important to consider what could happen after the end of the research. The researchers

arranged for contacts to be made with local volunteering groups as well as looking for other research opportunities. This included making contact with the local universities and the local NHS Trust. Some of the co-researchers are planning to follow up these ideas and there are also plans for the group to stay in touch with each other.

A final conference provided an opportunity to celebrate the achievements of the group with senior managers from the organisations that were involved, staff and other users and carers. The co-researchers also received framed certificates. A final celebratory lunch for the co-researchers was organised, as it was important to emphasise how much people's contribution has been valued (Read & Maslin-Prothero, 2011). Most people had mixed feelings about the ending, feeling sad that the work was finished, but also looking forward to the future.

## **Conclusion**

The experience of this study has illustrated some of the challenges, as well as the benefits of involving service users and carers in research. This collaborative study has made a difference to the lives of the co-researchers as well as contributing to the development of a new independent living service. Reflecting on our experiences reveals both the success of this work, but also the way in which we would do things differently if we were embarking on another project. These are summarised as lessons learned and are listed here:

### *At the beginning:*

- Taking time to recruit researchers and to create a supportive group
- Building relationships with staff and others to increase understanding of the value of service user and carer involvement in research
- Resolving issues about payment to co-researchers
- Recognising and addressing potential tensions in obtaining ethical approval

### *During the research:*

- Maintaining the group and supporting each of the individuals in an appropriate and flexible manner
- Preparing people for challenges such as CRB procedures

### *At the end of the research:*

- Seeking out potential opportunities for co-researchers after the work has finished

- Involving co-researchers in dissemination
- Celebrating the end of the work

**Further information:** Further information about this study including a short film about the evaluation is available at: [www.progressgroup.org.uk/include-me-in](http://www.progressgroup.org.uk/include-me-in).

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