

Report Summary - Training for service user involvement in health and social care research: a study of training provision and participants' experiences.

Lockey R, Sitzia J, Gillingham T, Millyard J, Miller C, Ahmed S, Beales A, Bennett C, Parfoot S, Sigrist G, Sigrist J., Worthing & Southlands Hospitals NHS Trust (2004)

Users of health and social care services bring unique and invaluable experience, knowledge and perspectives to research. However, sometimes people need to gain new and specific skills and knowledge to be actively involved in research, and so research training for service users is a key principle of successful involvement. The TRUE project, commissioned by INVOLVE and carried out by a collaborative service user / university / NHS team, aimed to explore the provision of this training. Through interviews and visits to training initiatives, the project found that:

- ❖ Training for service user involvement in research was not readily available. Only a handful of organisations provided open access training on a regular basis. Training was diverse in style and content, and often was developed for a particular service user group or project.
- ❖ Training was perceived as being most useful when it had a clear aim and purpose, and was centred around specific research tasks and real research problems that drew upon the participants' experiences.
- ❖ Participants wanted to be involved in creating and developing ideas in which they could become absorbed and take some ownership. Service users wanted their input to be creative and not just reacting to others' ideas, and wanted to be involved in both training and research from the start.
- ❖ A key aspect of successful training was exchange and sharing between people, both trainers and participants. This was mutually supportive, sometimes using ice-breaking exercises, small group work and role-play.
- ❖ Training helped affirm the strength and value of service users' experiences and understanding of health conditions and services.
- ❖ Confidence to contribute developed in a 'safe' environment. This is one where others show that they value what a participant is saying and that if they wish to challenge it, then that is done in a constructive and helpful way.
- ❖ Considerable time and space was needed to allow all participants to make a full contribution. Project timescales and funding should reflect this.

- ❖ Training had enormous value to participants' personal development and confidence. Almost without exception, training led to actual involvement in research and a desire to do more.
 - ❖ Language was a significant challenge for those providing training. Effective training 'demystified' research, providing a base from which stakeholders can understand one another's language and purpose.
 - ❖ Payment was a sensitive issue. Although training commonly was seen as a mutual 'exchange' of skills and knowledge, typically participants were not paid for attending training, whilst trainers and employed researchers were paid.
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Introduction

Service user involvement in health and social care research has in recent years become rapidly and formally recognised as a right, not a privilege, and as an activity that has positive outcomes for both the individuals and the research activity concerned. Training is a key principle of service user involvement, as it is recognised that people who are 'novice' researchers may need to gain some specific skills and knowledge in order to work effectively. The TRUE project aimed to describe training for service users in this context, to identify factors that constitute 'good' training, and to explore the impacts of training for the individuals involved.

Map of training for service user involvement in research

Training for service user involvement in research involvement is not so readily available. We found only a relatively small number of initiatives that actively provided training and most of these had been recently established. Many more people and projects we spoke to were developing plans for training, and commonly people asked us where they could get training. The training examples that we found were diverse, ranging from involvement in one aspect of a research process to user-led research. The majority of initiatives existed within a collaborative working environment. Universities were the most common training provider. Nine initiatives provided training in preparation for a specific research role or activity (such as for critical reviewing of research proposals). The other 17 initiatives provided training for several research roles, often for roles throughout a whole research project. Eight of the 26 initiatives (31%) provided training for all types of service users, a further eight (31%) were for mental health service users, and the remaining 10 for other specific groups.

Clear aim and purpose

Service users identified two key questions that they ask of training: Why do this? Why me? Training was most valued when it had a clear purpose, when it was centred around specific research tasks and real research problems, and above all when it was linked to a defined and real research project or role. Of key importance, in highly rated initiatives, service users' contributions/roles in the training and research clearly and explicitly drew upon their experiences as service users. These contributions ranged across a large part of the research process, but in all cases there was a clear purpose to the contribution. For example, the research topic in

some cases was prompted by participants' experiences; or recruitment or interview methods were informed by these experiences. The clear identification of this 'added value' helped ensure that involvement was constructive and relevant, rather than vague, confused and ultimately despairing.

Involvement in the research process

Service users did not want to have knowledge 'handed down' by trainers, but wanted to be involved in creating and developing ideas in which they could become absorbed, and take some ownership. Trainers were praised for getting the ball rolling and then taking more of a back seat, only giving a steer if the work was going off at a tangent. Participants welcomed this approach because it put them at the centre, allowing them to be proactive, driving the ideas forward as well as determining the route. To achieve this, trainers did not simply cease to do anything, but rather they set up ways in which participants could be enabled to take things forward with others that facilitated interaction, and exchange of ideas.

Exchange and sharing between people

Strategies for enabling people to work together, such as small group work and role-play, appeared to be particularly significant in these training initiatives. These strategies allowed participants to share their experiences, enabling them to feel that they were not alone, and then placed these into a broader research context, so that participants were 'thinking bigger than ourselves'. During the sharing of experiences, the skills of listening to others and being heard oneself enhanced feelings of self worth. Participants were able to bring out what was described as 'a wealth of knowledge, experience and expertise' that may have lain dormant.

Strength of the service user's experience being recognised

The process of listening to and valuing individuals' experiences reinforced – and sometimes redefined – for the individual that their experience and understanding gained as a service user was a strength that they brought to research. Non-service users could not and did not have this body of knowledge and insight.

Safe environment

Confidence to contribute develops in a 'safe' environment. This is one where others show that they value what a participant is saying and that if they wish to challenge it, then that is done in a constructive and helpful way.

Time and space for contribution

It takes time for service users to make a full contribution to research and successful involvement cannot be done under pressure. The time needed to involve people meaningfully and provide good quality training was frequently underestimated. Time for planning is particularly important: service users need to be involved from the start, for example to identify facilities and support needed, to identify training needs and to ensure that the training style and language is appropriate, and to plan for continuity.

Outcomes of training

A key message is that, without exception, the training had enormous value for the participants' personal development, confidence, motivation and skills, and generally had a positive impact in their lives. Service users from at least 21 of the 26 initiatives went on to be active in research and utilised the training in practice.

The language of research

Language is a real consideration for those providing training. Several trainers said that one of their aims was to 'demystify research', demonstrating that research is an activity that we all undertake in our daily lives – and therefore have skills in. It is not the 'concepts' of research that cause difficulty for new researchers, but the 'language'. Research language appeared more of a problem issue in 'scientific' quantitative research as opposed to qualitative research, research about peoples' lives and experiences. Training is vital to identify strategies to bridge the 'language gap' between scientists and the public, as can the requirement by commissioners that researchers write in as accessible a language as possible.

Payment

For the majority of training initiatives we identified, participants were not paid for attending training, thus raising the question of inequality with trainers and with employed researchers attending training. The participants were however usually paid for resulting research activities undertaken. In most cases all participants' expenses were paid; there was a strong sense that if people were participating on a voluntary basis then good refreshments and other forms of 'hospitality' – such as social events – should be provided. It must be recognised that unless *all* expenses are paid, then the activity will exclude some service users.

Conclusion

In conclusion, without exception the participants in this study felt the training was hugely valuable, worthwhile and empowering. Training increased people's knowledge and skills, and boosted participants' confidence in their ability to understand and undertake research. We recommend that training should be an integral, vital part of any research activity if service user involvement is to be effective and meaningful.

About the project

The project was undertaken by Worthing & Southlands Hospitals NHS Trust and funded by INVOLVE. It was conducted from July 2002 to October 2003 by a collaborative team of 11 researchers from service user, NHS and academic backgrounds.

Information was collected through 31 telephone interviews with 26 training providers, and through follow-up visits to and interviews with six examples of training.

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