



## Training service users to become community researchers for effective engagement within a Participatory action research (PAR) framework

The paper is a work in progress, presented by Jo Hobbs on behalf of all the people who participated and are involved in the project. When the paper goes to publication all those who participated will be formally acknowledged as co-authors. This presentation will highlight: facilitating collaborative working and community capacity building whilst simultaneously empowering and encouraging greater participation and employment of community researchers. This paper seeks to contribute to the wider remit around engaging service user researchers within health and social care services by focusing on detailing the delivery of high quality context specific as well as broad based training for a group of community researchers recruited by Manchester Metropolitan University.

In addition this paper will draw together the significance of inclusive interagency collaboration, recognising how this strengthens the relationship between university researchers and community researchers and facilitates the synthesis of a collaborative network of researchers working towards creating innovative approaches to research within community research agendas.

Participatory action research is a method of research in which creating positive social change is the predominant driving force. PAR grew out of social and educational research and exists today as one of the few research methods which embrace's principles of participation and reflection, and empowerment and emancipation of groups seeking to improve their social situation. Kurt Lewin is credited with the creation of action research (AR) 'Participatory Action Research: Getting the Job done' ( Seymour-Rolls & Hughes, 1995, P.10)

Participatory action research stresses the 'political aspects of knowledge production' (Reason, 1998, p. 268), as orientated towards understanding concerns for power and control, and powerlessness associated

with the role, production and ownership of knowledge.

It values the knowledge gained through people's lived experiences and aims to empower them, through a process of true collaboration, to co-construct knowledge to produce further knowledge and action that will benefit them directly (Reason, 1994).

Service user involvement is recognised as integral to useful health research, particularly as an activity that can have positive outcomes for individuals, research and service provision. Providing research training is fundamental and a key principle of successful involvement ensuring that community researchers are encouraged and supported to gain the specific skills, knowledge and understanding that will enable them to be actively involved and work effectively within the PAR process.

I am a researcher working on a project titled 'The impact of changing services for people with long term neurological conditions'. This research is primarily concerned with gauging the impact of current service delivery in terms of the health and wellbeing of people who have a brain or spine condition, which ranges from epilepsy to Parkinson's disease.

It was always part of the project's agenda to involve users of services throughout the research processes and PAR represents an approach which effectively supports the development of inter-professional working between academic researchers, health and social care professionals, service providers and service users as community researchers.

The research engagement principles we sought to work with in this respect were:

- equality of all stakeholders within the process

- open communication on all aspects of the research
- commitment to social justice for all
- development of a partnership with shared vision and expectations
- A willingness by all concerned to allow the PAR process to facilitate change both in themselves and in service delivery.

To ensure users of services played a full and active role in the research process from beginning to end, my first action was to bring on board 3 users of services as co researchers and co advisors. The project steering group agreed that it would be pertinent to expand the numbers of service users involved as there were times when the existing co researchers were either too ill to contribute, attending hospital appointments or unable to commit themselves.

In order for the project to deliver within a PAR framework, it was important that service users should be enabled to use effectively the skills gained in this collaboration to work on other projects. Therefore it was proposed that those brought on board would be assisted to organise themselves into an association of co-researchers and advisors and given appropriate training.

It was agreed that funding for the training would be provided by Manchester City Council, Manchester Primary Care Trust and Manchester Metropolitan University as a collaborative venture which would lay the foundations for establishing a network of multi-agency researchers who would then be available to contribute to future University and community based projects, particularly in the areas of environmental change, health and social care research. This would encourage the growth and development of more community led research projects within the context of knowledge and skills transfer.

Contact was made and established with 2 service users who have neurological condition's and 2 community campaigners working with local urban regeneration contexts as it was felt this would strengthen the breadth and depth of experiences and perspectives. Electronic communication with those brought on board identified the need for them to meet to foster and encourage a team spirit and to put together an agenda for their professional development thus an open day was organised at Manchester Metropolitan University.

At the open day introductions were made and those in attendance spoke briefly about why they were

interested in becoming involved in research projects. There were many different reasons but they grouped around an interest in research as a means of engendering change, remaining active, being involved in society, making a positive impact on services and living environment and remaining personally motivated.

All participants felt that this was an opportunity for them to:

- Widen their experiences and understanding of the world around them
- Widen their experiences and understanding of the formulation of policies
- Present opportunities for them to meet different people
- Present opportunities to get involved with different ventures
- Provide them with opportunities to broaden their knowledge and that of the people they met.

This seemed particularly pertinent as the 2 community campaigners working within the regeneration field expressed themselves as feeling dispirited and alienated from service involvement whilst those from the physical disability and neurological service field felt confident and optimistic about their involvement and contribution to service delivery.

The opportunity to form an association of cross disciplinary researchers and advisors was seen as a great opportunity for information and knowledge exchange.

To facilitate their ability to work within a PAR framework it was formally agreed that they would need to access suitable training. Training requirements were identified and it was felt that two half days of training should be attended solely by the users of services partly because the community activists were reluctant to work alongside professionals and that two half days of training should be attended jointly by themselves and health and social care professionals. The joint training days will focus on an agenda around challenging the barriers which impede service user's engagement, the inherent power differential and inclusive interagency collaborative working.

The open day ended with a discussion around how the group would like their roles to be referred to, eventually they resolved to refer to themselves as Community researchers and advisors, which they considered to be an empowering term of reference

and hence the use of this term throughout this presentation and in all subsequent papers.

Prior to training taking place, I consulted with the community researchers and read widely around service user's involvement in research projects, from their input and my reading I established those principles which would guide the training sessions. The training agenda recognises the importance of empowering community researchers through encouraging their participation within research and also in providing a level of training which builds confidence and capacity to conduct research successfully and which are fundamental to the PAR agenda. These are:

- 1) That the trainer is well-informed and aware of service user involvement within research
- 2) That they well versed with service user participation and what it entails.
- 3) That the service users involved are consulted with regard to planning the training agenda and the means of its delivery.
- 4) That the learning environment allows trainees to feel relaxed and equipped to gain the requisite knowledge
- 5) That the training methods employed ensure trainees take on board factual information and hands on practical research skills.
- 6) Ensuring that the training environment provides trainees with informal learning opportunities and the time and space for people to share their experiences with each other
- 7) That training is tailored to the roles that the trainees will be undertaking upon completion of training
- 8) That the language used during training is unambiguous, uncomplicated, and jargon free.
- 9) That the trainees are aware of and agree with the aims and objectives of the training programme.
- 10) That the training schedule should help generate a cooperative learning forum that encourages personal and professional development, seeks to enhance confidence and self-esteem, build up critical thinking and reflective practice.

#### **Aims and objectives of the training session**

AIMS:

- 1) To establish an association of community researchers and advisors and assist them to build a rapport amongst themselves.

- 2) To empower them as individuals and build community capacity

- 3) To equip them with the necessary research skills to be able to work alongside university and practitioner researchers on diverse projects.

Objectives:

- 1) To generate greater understanding about the role of research in bringing about changes in the provision of services.

- 2) To highlight the role of community researchers in the context of research and community advisors as members of steering committees which oversee research projects.

- 3) To generate greater communication about the different understandings and experiences that community researchers and advisors can bring to existing research practices and procedures.

#### **Reflections**

Community researcher reflections on the training sessions was highly positive.

Bringing on board a trainer from mental health, a service industry area at the fore front in conducting needs-led, user-controlled services involvement in redesigning services was a positive factor in the success of the training sessions.

*"I really enjoyed the training sessions. A (the trainer) can take the credit for that.*

*He wasn't patronising, know it all or boring, his own experience I found were very valuable to the sessions and to us the trainees and I learned a lot."*

The trainer had himself been a user of mental health services and thus had an appreciation of the problems that users of services from other areas may have experienced and thus could talk with knowledge and awareness of issues within user involvement around power differential, input into changing services and challenging health and social care professionals.

*"Since taking part in the training sessions I've questioned my own little prejudices which previously I wasn't aware of, prejudices that relate to gender and or disability. It's raised my awareness of how part of me has been 'closed off' and that I'm not as open minded as I thought I was. It's certainly been a learning curve for me and made me aware of the need for my own self development. I am please to be part of – however small -- this project and hope to develop the*

*skills needed to become a community researcher.”*

Informal and formal communication with the Community researchers and advisors with regard to evaluating the usefulness of the training sessions has identified that the training enabled people to:

- Work closely together
- Allowed them all the opportunity to share their experiences
- Enable them to consider their positioning within a broader research context
- Enable them to think beyond their previous horizons
- Enable them to share aspects of their understandings and experiences. Began the process whereby they learnt to appreciate the listening skills required by researchers
- Encourage an acceptance of and sensitivity towards other people's views.

Community researchers and advisors also began to appreciate the fundamental aspect of PAR, which is being able to learn through personal reflection as well as in discussion with other co-researchers. They felt this had helped them to derive insights for future development both as a people and as members of the association of Community researchers and advisors.

As the association progresses, the extent to which personal, social and professional development encourages a mutually co-operative and understanding environment will be assessed as part of group development activity. It is to be hoped that the experience and understanding they have gained as a user of services will be acknowledged as a strength that they bring to the research process.

## **Conclusion**

Training community researchers for effective engagement within a PAR framework requires us as training providers, commissioners and consultants who are likely to be working alongside those recipients of the training to be more aware of and to draw up training agendas that strive to implement research which tends more towards needs-led, user-controlled services.

In order to address the problem of bringing on board people from hard to reach and diverse backgrounds the training agenda needs to acknowledge that trainee's knowledge may differ from other forms of knowledge acquisition being based as it is on lived experience rather than research findings and is likely to have been amassed through informal exchanges of

ideas. Training must also take into account the potentially diverse nature of trainee's capabilities in terms of levels of awareness, understanding, familiarity with research agenda's, and must also take into consideration age, ethnicity, culture, sexuality, class, gender, disability, etc.

The training process therefore needs to be inclusive and take into account access requirements which ensure that training engages and reaches out to those people who services might otherwise fail to take account of. In this way the research process will endeavour to explore future opportunities for their assimilation and involvement within service re-design and facilitate collaborative working and capacity building within both the research community and service provision.

Whilst service users may feel confident that they are experts on their own experiences, and that what they know is equally valid as professional knowledge, if they are placed in a research situation for which they are ill-equipped by training they are likely to become disengaged from the process.

When considering the training requirements of users of services we need to be more aware of and use methods which will encourage and inspire more needs-led user-controlled services. In order for service provision to incorporate community researcher's experiences and understandings into service planning, their knowledge must be given the accord which professionals accord their own knowledge. This process needs to be inclusive and take account those requirements which will ensure it reaches and engages as many of the hard to reach users of services as possible.

These measures should help to strengthen the relationship between university, practitioner and community researchers and facilitate the synthesis of a collaborative network of researchers working towards creating innovative approaches to research within community research agendas.