

Partnership research: researchers with and without learning difficulties working together

In 2005 a group of 20 researchers with and without learning difficulties came together for three residential workshops to learn – from each other – about how to plan research together. At the workshops we worked together designing, planning and piloting research projects ‘in partnership’. We held a small conference in June to tell people about the work we had been doing together.

The project, which was funded by the Economic and Social Research Council, was extended so we could hold a final residential workshop looking at funding for research. We invited ten extra people (with experience of obtaining funding) to this workshop, to help us turn our ideas into research proposals.

The presenters of this paper attended all of the workshops and conference. Our paper will talk about our experiences of working together.

People with learning disabilities’ and carers’

research questions for investigating health risks

Most people with learning disabilities, family carers, and care-workers do not get the chance to decide about research projects. Anita Young asked 20 people with learning disabilities and 20 carers / care-workers about the big questions for doing a research project. The project was about making things better for health.

Anita will talk about how she spoke to the 40 people using stories and pictures. Two stories told different kinds of harm about heart disease. Everyone was asked to give a question for each story. Seventy-eight questions were given, and from these came six big ideas to study.

Anita talked about the six big ideas with other groups of people with learning disabilities, carers and care-workers. All groups agreed that the six big ideas were the right ones.

Then the 40 people chose their top big idea.

The study showed that people with learning disabilities and carers can make up questions to study what they feel is important. Also they can decide what to study first.

You will have the chance to discuss how professionals may feel about research questions made up people with learning disabilities.

The Research Assessment Exercise (RAE) and public involvement in research: can the tensions be reconciled?

The Research Assessment Exercise (RAE) determines funding allocation for university research – a major location of research activity. There are concerns that the RAE's orientation is not consistent with increasing interest in public, patient and service user involvement in research/evaluation. Different RAE panels and subpanels approach this issue in different ways. Clearly it is important for such an exercise to be consistent with wider policy if research is to reflect and address current thinking in research, research priorities and research funding more generally.

This paper will explore this issue and examine the implications of the RAE process for user involvement in research and emancipatory research approaches. Are barriers likely to operate? How can these be challenged helpfully? Can we learn from the approach of different (sub) panels? What role can researchers, service users/patients and public play in this? How can people working in the university research sector particularly, ensure that a commitment to public involvement does not disadvantage their work, but rather may be valued?

The Comensus Project

The Comensus Project has been established in the Faculty of Health at the University of Central Lancashire. The aims are to provide for systematic participation of health and social care service users and carers in all aspects of the Faculty's work: practitioner education and training; research; and strategic planning. A key element of the project is the development and support of a group of service users and carers. They are networked into the wider community provide a forum for information exchange, consultation, negotiation and influence within the university, such that service user and carer's views and perspectives are more thoroughly engaged with across the variety of activity in the Faculty. This forum has been named by the participants as the 'Community Involvement Team'.

The initiative has been conceived as a modified participatory emancipatory action research project, using a spiral process of iterative cycles of planning-action -observation-reflection-planning. This presentation will present findings to date.

Taken as a whole, the project aims to deliver a number of reciprocal benefits between the university and the local community. The anticipated benefits for the university include a range of enhancements to course provision and research quality, and a shift away from previously piecemeal involvement of service users towards a more systematic and co-ordinated enterprise. The forms of user involvement which are developed should have the added value of being credible, organic and independent. The process of community engagement and involvement should ensure associated beneficial impact upon the university's public image and standing within the local community. Potential community benefits involve employment opportunities, opening up access to university resources and, importantly, the opportunity to make a

difference.

The aim of this paper is to inform participants of our project, its development and to report on the process of action research. We hope that people will take away the message that service user and carer led projects have enormous value, are worthwhile and should be encouraged.

Research Jargon Buster

Research (and the NHS) can be full of jargon and very confusing when you don't understand what the words mean. One group of people who found exactly that decided to write a jargon buster for other people trying to find out about and do research. The poster will describe the background to the Direct Impact Research Group and how the group came to develop their own jargon buster. It will show the jargon buster that the group wrote and which has been published in a peer reviewed journal.

The poster shows that research can be made open to everyone and can be shown and presented in an understandable way. Copies of the jargon buster will be available for people who want one.

The Direct Impact service user and carer research group was established in May 2001. Service users and carers have taken part in a number of research projects across the Trust and have developed their own research projects. The group aims to ensure that the views and experiences of people receiving mental health services (either directly or indirectly as carers) influence local research and development at all levels. They won a West Yorkshire Modernisation Award in 2004.

Listening to the voices of service users and carers and making them count

Last year Bec and Kristina worked with Macmillan Cancer Support. They tried to find out how different organisations listened to the views of service users and carers, and then how these views were made to count. They also looked at how people with cancer had listened to the views of other people with cancer.

The poster will tell you about what they learned about how to listen to the views of service users and carers.

What will people learn?

This poster could give people useful ideas about how best to listen to the views of service users and carers, but more importantly how to make these views count in an organisation.

Society's contribution to the development of the Strategic Plan of the Health Care

Region of El Hierro (Canary Islands)

Vinita Mahtani works for the Canary Islands health care services in Spain. She was asked to identify the needs of health care services of the local people of the Island of El Hierro .

The goal was to develop a specific plan for health care services development for the island of El Hierro. This is an island with 8.000 population where the health care services include primary care and basic hospital care, but that relies for some health care services on the Hospitals in the island of Tenerife. Frequently policy makers manage decisions about health care services organisation independently. In this case, public opinion was included in the report for planning health care services for this island. People who lived in this island were involved in the research process.

Vinita will present in the poster the degree of involvement of the people of El Hierro in the research process. She will show the type of information that was achieved through public opinion that could not have been understood otherwise.

Taking part in a steering group for a non-pharmacological intervention

clinical trial Taking part in a steering group for a non-pharmacological intervention clinical trial

The Alzheimer's Society funds research through the Quality Research in Dementia programme (QRD) which, through the QRD Consumer Network, involves consumers in all stages of the selection and administration of the funded research. A proposal to address management of challenging behaviour in care homes for people with dementia was selected by QRD in 2002 and subsequently funded by The Big Lottery Fund.

Three QRD consumer network members joined the project steering group. Our experience:

- The researchers were just as nervous of us as we were of them, but we soon developed a working relationship based on mutual trust
- We felt we had a real input to the discussions
- Although we each had experience from having people we cared for in homes, we were still surprised by some of the events related to us during the meetings and moved by some of the case stories
- We feel we have been part of a project that has the potential to change lives for the better in care homes.