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 -observationreflection-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 coordinated 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 nonpharmacological intervention

clinical trial Taking part in a steering group for a nonpharmacological 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.

User controlled research: its meanings and potential

Authors: Michael Turner and Peter Beresford

User controlled research has been developed by service users and their organisations as a new approach to undertaking research and evaluation. The aim of this project was to find out more about the definition, nature and operation of user controlled research. It was carried out both through a literature review and through information provided directly by a wide range of service users and service user researchers in a series of individual interviews and group discussions.

An easy read summary of the report is also available.

No. of pages: 136

What user controlled research means, and what it can do

This is an easy read summary of the report <u>User controlled</u> <u>research: its meaning and potential</u> by Michael Turner and Peter Beresford.

No. of pages: 14