

Involving people with dementia and their carers in research

People with dementia have largely been excluded from all stages of the research process, mainly because of the perceived challenges to verbal communication and understanding. A 'user panel' consisting of people with dementia and their carers was developed as part of a wider research study examining quality of life outcome measures for people with dementia and their carers.

Active partnerships between people with dementia and researchers through consultation and collaboration were used to empower people with dementia to become more involved in research; to monitor and evaluate the effects of their involvement; and to develop models for identifying and prioritising relevant and appropriate outcomes. The group explored exactly how and when members would like to be involved; methods for communicating with people with dementia; identifying and prioritising topics for investigation; and was involved in designing and evaluating the content and form of available outcome measures.

The user group has successfully involved older people with dementia and their carers in the research process. It has guided the development of research tools, and ensured that the voice of people with dementia is directly incorporated in the research project.

Funding issues will be addressed.

Making a difference in the mental health services

This paper provides an account of an action research project undertaken by Suresearch, a Midland based user-led network of people using mental health services and their allies involved in research and education. This project, commissioned by the Birmingham and Solihull Mental Health Trust, was designed to promote user involvement in clinical governance in the Trust. Building on work previously undertaken by Suresearch on what service users valued in mental health services in Birmingham, this project focused on three service sites in the Trust. Suresearch researchers worked with service users and staff on those sites to audit the service being provided from a users' perspective and identify changes that could be made to make the services more effective in supporting users mental health and recovery. The paper describes the project and reflects on lessons learnt in its dissemination and implementation phases.

Implementing the Statement on Consumer and Community Participation in Health and Medical Research in Australia

This report focuses on disseminating and implementing research, based on an Australian pilot. In 2004, the Consumers' Health Forum of Australia (CHF) and the National Health and Medical Research Council (NHvIRC) are collaborating to implement their joint Statement on Consumer and Community

Participation in Health and Medical Research.

CHF's membership comprises over 100 Australian health consumer organisations. It provides a consumer perspective on national health issues to balance the views of health care providers, government and industry. NHMRC is Australia's leading funding agency for health and medical research.

This action-research project focuses on two pilot sites, the National Ageing Research Institute in Melbourne and the Queensland Institute of Medical Research. These sites vary in their size, type of research and consumer links. The former has an identified consumer group of older people whilst the latter faces greater challenges in engaging consumers due to its diversity of research interests. Materials being developed include a model framework for consumer participation, resources for consumers involved in research and educational material for the NHMRC's Human Research Ethics Handbook.

This report discusses relationship building between researchers and consumers who are sharing information about research through seminars, community events, and other methods of joint engagement.

Collaborative research with older gay men and lesbians

This paper examines a recently funded project into the needs of older gay men and lesbians in the Bournemouth, Poole and Dorset area, funded via a Community Fund grant. This is a joint project between Bournemouth University and Help and Care, a local voluntary sector agency working with older people and their carers.

The paper will provide an overview of the existing literature in this area and will add to this by providing practical examples experienced in the first year of this project. The paper will examine issues relating to the recruitment of volunteers, the identification and prioritising of themes and the tensions relating to this type of research. This project is using a collaborative model through a Participatory Action Research methodology. The importance of approaching research with minority groups of older people in an inclusive way, and the implications of participatory research will be also be explored.

Discovering the research priorities of people with type 2 diabetes

This paper describes a piece of research in which diabetes service users collaborated at every stage.

A reference group of health professionals and service user representatives was set up to define our research question. We wanted to find out what the important areas of diabetic people's lives were. We aimed to define and prioritise some research questions from these important areas and compare these with the Department of Health's research priorities.

On the reference group's advice professionals who understood the language, dialects and culture of the minority ethnic groups that made up the local diabetic community joined the research team. Six focus groups were run to discuss the issues that people with diabetes considered important areas to research. Representatives of the focus group participants were

involved in the analysis and dissemination of the findings.

This method of determining research priorities in diabetes finds very different results to more traditional expert based methods. The potential advantages and disadvantages are explored. The difficulties encountered in carrying out this study and the issue of representation of service user views are also discussed.

Service user involvement in forensic mental health research

Although substantial work has been undertaken in developing methods of involving service users in research, the forensic mental health context does present a number of unique problems associated with access, the need to maintain security, confidentiality and the protection of individuals.

The UK Department of Health's Forensic Mental Health Research and Development Programme commissions research on the management of people with personality disorder or severe mental illness within settings of differing levels of security, from maximum secure hospitals to those in community settings. It also commissions work related to the mental health of prisoners.

The Programme has taken a variety of approaches to involving service users in the research process

- Commissioning an expert paper "User Involvement in Forensic Mental Health Research and Development" by

Alison Faulkner and Brigid Morris.

- Inviting service users to sit on the Programme's Advisory Board
- Involving service users in the peer review process including a pilot study being undertaken within Rampton High Secure Hospital to involve patients from forensic settings in peer reviewing
- Commissioning research projects which address service user involvement in forensic mental health research

This paper will describe the problems and solutions of service user involvement in forensic mental health research and will raise issues around meaningful service user involvement in research commissioning.

Public perspectives on assessing what works in health care

We have gathered public perceptions on assessing 'what works?' in health by asking people what is most important to assess and how should this be done. We have done this with people working with the Cochrane Collaboration and the NHS Health Technology Assessment Programme.

Here we shall present perceptions from the public on testing 'what works', how we have developed systems and resources to help people comment at the stages of commissioning and publishing research, and how we are evaluating those systems and resources.

We shall describe:

- ideas that have come from members of the public that can be incorporated into health technology assessment;
- how these relate to ideas from health professionals and researchers;
- how members of the public are central to the development of resources to support public involvement;
- how members of the public have responded to systems and resources to support their involvement
- methods for describing what the public has to offer health technology assessment

We shall raise for discussion the need to balance sufficient guidance for public peer review of health technology assessment without constraining their contributions.

Involving users in NHS research

This paper will provide a model for involving users in the NHS research process as a mechanism of improving quality of research. The chosen conference theme will be addressed through discussion of the development and implementation of the model. The issues are:

- Identifying and involving users: The Cardiothoracic Centre ? Liverpool NHS Trust (CTC) has established a Service Users Research Awareness Sub-Group (SURASG) – bringing together service users with an interest in research issues at the CTC.
- Establishing a meaningful role: The group critically review lay summaries and patient information sheets for all research which is proposed at the CTC. It has been agreed that all recommendations made by the SURASG will

be accepted by the Trust's research project review group; to the best of our knowledge this is a unique feature of the group at SURASG.

- Enabling involvement – research capacity building: A prerequisite for being a member of the group is to have undertaken a two day workshop in basic principles of research delivered by Health R&D North West, the local DoH support unit.
- Benefits: The initiative has provided clear benefits to the institution, the individual SURASG members and the wider population of NHS users.