

Involving users in data collection: The findings of a systematic literature review

As part of a systematic literature review of user/carer involvement in research design we sought to find empirical studies giving detailed information regarding user involvement in data collection. Thus in this presentation we will address the conference theme of undertaking research.

Four electronic databases were searched (ASSIA 1987-2003; IBBS 1987-2003; CINAHL 1982-2003 and Medline 1966-2003) and these were supplemented by hand searching. Terms used to identify research which had involved users were: (1) involv* and research with carer; client; community (development; lay; patient; people; public' subject and users); (2) participation and research with participant feedback; benefits; feedback, financ*; financ* and benefit; incentive; money; pay and reward.

Although 81 relevant articles were found in only 15 papers were details provided regarding how precisely users or carers were involved in a research project. In eight cases information was given about how users or carers were involved in data collection. Notable was the small number of users participating in data collection, in several studies being less than 10 people (Stalker, 1998; Truman & Slade, 1999; Ramon, 2001; Rhodes 2001 and Roy & Cain 2001). The two most common types of involvement were in the development of questionnaires/interview schedules and in acting as interviewers. Little reference was found to any training provided for users and none was discovered regarding 'professional researchers' needs, although several authors' reflected on their own learning as an outcome of the project. While anecdotal accounts indicate that user involvement is

more extensive than suggested by this search, it highlights the need for projects involving users to be published in peer reviewed journals and for full details to be provided on methods of involvement.

Issues for Discussion:

1. Factors inhibiting users and carers involvement in data collection ? is this realistic?
 2. How can accounts of projects involving users best be disseminated?
 3. What type of education and training is needed by researchers in order to encourage and support users in data collection
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It's our project! People with learning difficulties managing and doing research

We are a group of people with learning difficulties called the Learning Difficulties Research Team. The Department of Health asked us to find out all about good ways to involve people with learning difficulties in research. We are doing this by looking at what's happened in 12 research projects funded by the government through the Valuing People white paper. We want to find out:

1. ?How people with learning difficulties got involved in these research projects.
2. What works and what doesn't work about involving people

with learning difficulties in research.

We are travelling around the country to meet people and ask them questions about their views and experiences. After we finish interviewing people we will put all our information together and publish a report, run a conference and do other things to tell people what we've found out.

This is an exciting project because we are the researchers and we are also running the project ourselves. We manage the money, make all the decisions and do the research.

We would like to tell people how we set up, manage and run a proper research project as a group of people with learning difficulties. We would like to tell people how we have learnt to do good, inclusive, empowering and accessible research and how we have overcome challenges and difficulties.

We can do this in the paper format, with questions and discussion or we can run a workshop. Both formats will be fully accessible. The workshop format would focus on what people with disabilities or other 'service users' can do to have more control over research and what non-disabled researchers can do to support us.

What do you think about your transport? A survey conducted by service users and carers

A survey was conducted on behalf of the Glasgow Learning Disability Partnership by a research team of people with learning disabilities, their supporters and carers on the

topic of transport arrangements. The respondents were people with learning disabilities, parents and carers who used a day centre service (Priesthill in Glasgow).

The paper will consider the experience of undertaking the survey, including the preparation needed and the learning we gained about how to maximise the response and obtain useful data. The benefits of having a partnership research team to undertake the research will be described. The paper will:

1. Explain the training people took part in to carry out the research
 2. Discuss the value of service users and carers collecting data from their peers
 3. Say what we learned about the differences in information gained from different methods – group interview, telephone interview, postal questionnaire and face to face interview.
 4. Describe the group's participation and how they have taken forward action from the findings.
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The development and evaluation of a collaborative model for Consumer Research Panels in Cancer Research Networks

The involvement of consumers in research is an increasingly important ethical and political priority. However, within

Cancer Research Networks initiatives to involve consumers are at present unco-ordinated and existing links need to be developed to establish ways of building sustainable programmes of involvement. This paper will report on a joint initiative by the National Cancer Research Network and Macmillan Cancer Relief to establish Consumer Research Panels in three Cancer Research Networks ? Humber and Yorkshire Coast, Central South Coast and Surrey, West Sussex and Hampshire. This collaboration will facilitate consumer involvement locally and regionally and help reinforce national initiatives. In this way, consumers will be able to be involved at all stages of the research process and at all levels. If successful, the initiative can be rolled out to the other Research Networks. The project will be independently evaluated by a team from the Patient and Public Involvement Research Unit, at Worthing and Southlands Hospital. Consumers are represented on the Project Steering Group and also in a Reference Group that will inform the evaluation.

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.