

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.

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.

Undertaking palliative care research: Service users involvement

This paper will discuss a research project being undertaken in palliative care that includes the experience, knowledge and perspectives of service users throughout the research process. This inclusion is achieved via a research User Advisory Group that work with the researcher influencing all stages of the research. The research itself is concerned with the accounts of local men and women with a range of life limiting conditions about what they need and experience from palliative care.

In the current health and political climate user involvement can easily be seen as an unproblematic, must-do activity, and service user involvement in research has followed suit (Beresford, 2002). It has been seen as an approach to counter marginalisation some service user group's experience (Northway et al, 2001), however ownership and purpose of such projects can be a contentious issue and this research is no exception.

We will question the process of involvement for researcher and service users and concentrate upon how the research has been undertaken and produced. Some of those involved in this research will question how we have worked together on this research and how the service user contribution has influenced the research.

A survivor – led evaluation of a survivor-led service

This workshop will present some information about the evaluation of the Leeds Survivor Led Crisis Service carried out by the team, under the following headings:

Training: a developmental approach was taken to training to take into account the previous experience and skills of all team members;

Mutual support and teamwork: we shall explore the issues we considered in working together and supporting each other in carrying out the evaluation;

Interviewing: we shall explore the ethical issues we discussed about how to interview people (often based on our own experiences of being interviewed), and some of the practical issues that we needed to address.

It is not easy to fit this project into one single theme! But we have chosen to address 'undertaking research' in order to explain what we did and how we did it, as well as enabling workshop members to hear about a survivor-led approach to an evaluation.

With thanks to the Leeds Survivor Led Crisis Service, who funded the evaluation.

Making decisions about how to

apply what you've found out: Involving people with learning difficulties in a European research project

'I like, I love' is a research project that covers 6 European countries, looking for a new resource for people with learning difficulties around sexual health that is useful in all partner countries. This report from the researchers involved in the project will consider the professional involvement of people with learning difficulties. The report will address undertaking and implementing research with people with learning difficulties. Joyce Howarth will talk about the importance of people with learning difficulties being employed on the project. Sally Hillman will give her experience of being a researcher with learning difficulties. Kerrie Ford and Val Williams will talk about meeting all the partners in Mallorca and how Kerrie helped to decide on the way forward.

Issues for discussion will be:

- The importance and added value of including service users in research about sensitive topics.
 - Methods for including service users in professional, mixed teams of researchers.
 - Doing research in an inclusive way in Europe.
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Knowing how: a guide to getting involved in research

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The aim of the project was to find out how much lay people are actively involved in research outside the health service, and to use what was learned to make recommendations for health research.

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