

# 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.

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# 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.

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# 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.

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# 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.

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# **Creating a dialogue: Helping researchers put user involvement into practice**

The North West Users Research Advisory Group (NWURAG) has been meeting regularly since 2000 with the aim of promoting the NHS policy of User involvement in R&D in the North West region. The Group comprises 50% lay members and 50% professionals (a mix of academics and health service personnel). The Group is supported by Health R&D North West and has a paid facilitator.

The group felt there was a need to produce material that would give guidance to local researchers and organisations on the practical issues of User involvement, particularly at the design and management phase of the research cycle. Great emphasis was given to the format of this information so that even the most reluctant of researchers would be encouraged to involve Users in health research.

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## **Best practice in involving service users and carers in research: Confronting the**

# issues and doing it for real

We aim to tease out the discrepancies between theory and practice when involving service users and carers in research and to make participants discuss the issues behind the reality of “meaningful involvement”. In order to achieve this, we will use our own involvement in collaboration with the local university. We are very aware that we are probably experiencing best practice but also that issues are not quite so clear-cut and that there are potential limitations and barriers to involving users and carers fully. Through a group exercise using an imaginary research project concentrating around designing and undertaking research, we hope to make participants think about the range of practical issues at stake (funding, training, professional support, honorary contracts, CRB checks etc.), about the meaning of involvement for both service users and professionals (making positive use of service users’ research skills, cultural differences, addressing the fears of professionals, etc.) and the question of recruitment (who?, how?). We aim to tackle these issues productively and to generate a positive exchange of views hoping that participants, thinking about their own projects, current or future, will take ideas and solutions back to their groups and teams... and do it for real!

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## **Patient involvement and research ethics: Experiences**

# from the Macmillan Listening Study

This paper reports the experiences of setting up the Macmillan Listening Study. The study is commissioned and funded by Macmillan Cancer Relief and aims to explore the attitudes people affected by cancer have about cancer research and to identify their research priorities. The study is participatory in design and thus involves cancer patients and carers as co-researchers or advisers throughout the research process.

The paper focuses on a fundamental aspect of the research cycle ? the process of ensuring ethical approval. Multi-Centre Research Ethics Committees, Local Research Ethics Committees and local R&D exert a significant influence over research, ensuring that studies are conducted in a safe and appropriate manner.

Research generates specific ethical challenges when people affected by cancer are involved in developing the study design and delivering the project. These challenges include, the consideration of the psychological and other support needs of co-researchers, ensuring the confidentiality of research information, ensuring co-researchers are not over-committed, and responding to potentially prejudicial views of patients by committees. The paper will therefore raise issues of how to ensure that involving people affected by cancer as co-researchers is ethical, as well as indicating the concerns ethics committees may raise when reviewing studies of this nature.

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# 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.