

# **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 non-pharmacological intervention clinical trial**  
**Taking part in a steering group for a non-pharmacological 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.

---

## Getting started with involving the public in public health research

This information sheet includes information on who to involve and how to find the right people.

# **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.

---

# **Knowing how: a guide to getting involved in research**

Authors: Lisa Thorne, Rachel Purtell and Lisa Baxter

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.

No. of pages: 26