

# 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.

No. of pages: 2

---

## Who says service users want this research and what will they get out of it?

This workshop will provide short input for group discussion. It will consider how nationally service users' views can lead to the identification of a research topic and become the basis of a research project, exploring the complex issues that are involved in bringing about change nationally and locally, based on such research findings.

The focus of the project concerned was the relationship between receiving benefits and participating in research and other activities. It was carried out by Shaping Our Lives, a national user controlled organization. The workshop will examine both the complexities of initiating such user chosen research and of making change based on it, at the same time as ensuring that service users stay involved in the overall (often difficult) process.

- open up discussion about some of the issues/tensions

that arise when there is an aspiration to take forward user controlled research and address its commitment to making change.

- share experience, highlight complexities and ways of addressing them, by focusing on ways in which service users may make their priorities known and the sensitive response this requires.
  - support ways of thinking through and taking forward research which starts from the concerns of service users/consumers/public.
- 

## **A report on how the Medical Research Council Consumer Liaison Group has influenced MRC research in the early stages**

The MRC is a national organisation funded by the taxpayer. It promotes research in all areas of medical and related science. The MRC established the CLG in 2000 to: (1) advise the MRC Council on the public's perspectives on research, policy and strategy, (2) advise on how to involve the public in particular activities, and (3) to suggest activities that would benefit from public involvement.

CLG members have been involved in a wide range of research initiatives, and have focused on the early stages of research activities of national interest, for example, a Review of Autism Research, Chronic Fatigue Syndrome Advisory Group, MRC Draft Guidelines on Tissue Collection and BioBank UK. CLG

members have carried out their work by attending committees, advisory groups and working groups, and responding to documents and briefings.

In this presentation, members of the CLG and MRC will critically examine the influence of the CLG in making specific contributions to MRC research in the earliest stages of both applied and basic, research. We shall explore the challenges of making an impact in a large and complex organisation, and will discuss recent initiatives to extend the influence of the CLG to peer review processes, local networks, and MRC strategic activities.

---

## **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.

---

## **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.

---

# **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