

Public Involvement in Research

Lucy Simons
INVOLVE

Irene Douglas & Suzanna Rose
Patient, Public & Carers Partnership
in Research and Development,
Berkshire Healthcare Foundation
NHS Trust

www.invo.org.uk



INVOLVE

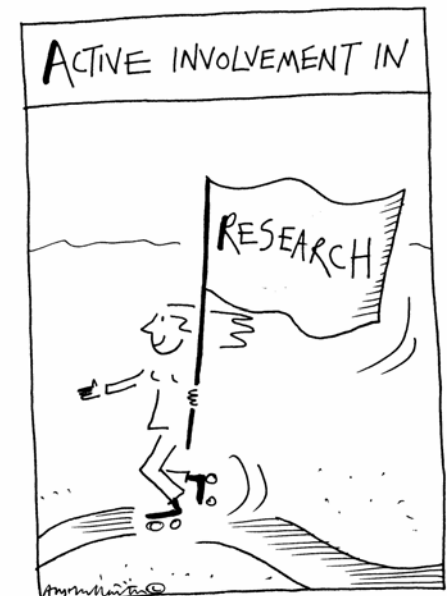
**National advisory group established
in 1996. Funded by the National
Institute for Health Research**

**Promoting active involvement
of the public in NHS, public health
and social care research**

We use the term ‘public’ to include patients, service users, carers, and representatives of people who use services

Research carried out ‘with’ or ‘by’ the public rather than ‘to’, ‘about’ or ‘for’

Involvement can take many forms from consultation and collaboration through to user controlled research



Why is public involvement in research important?



Why?

- **People should have a say in research that is potentially for their benefit**
- **It can improve the quality of the research:**
 - **Helps to improve the relevance of research to patients and carers**
 - **Helps to improve the quality of research design, methods and findings**
 - **Can assist in the dissemination and implementation of research**

Relevance of research

- **Highlighting issues of importance to public**
- **Identifying outcome measures reflecting concerns of patients and the public**

Quality of research

- **Influencing research design and methods**
- **Improving information provided to participants**
- **Helping to increase participation in research (recruitment and retention)**

Dissemination and implementation of research

- **Disseminating findings in accessible language and format**
- **Disseminating to wider audiences**
- **Encouraging the implementation of findings**

Public Involvement and the NIHR

- **Best Research for Best Health (2006)**
- **Research Governance Framework (2001 & 2005)**
- **Requirement for evidence of involvement in funding applications**
- **Public involvement in review process e.g. peer review, commissioning boards**

Requirement for evidence of involvement in funding applications

- **Details of plans for involvement in grant applications**
- **Criteria for assessing applications**



So how can this be translated locally?

– At Berkshire Healthcare Foundation NHS Trust we started to think about PPI in Research and Development formally in June 2009

- The drivers for this: Service user involvement in a NIHR portfolio RCT starting January 2010
- The need to offer appropriate competency based training
- An overall enthusiasm for the work



- At the group’s request we do not differentiate externally between patients, public and carers. This is perceived to reduce possible stigma
- It is termed the ‘Involvement in Research and Development Group’
- In research terms we are very much a developing Trust and we also see this group as developing alongside



- Researching the work itself including any possible adverse effects of service user involvement
- The recently published useful literature review ‘Exploring Impact: Public involvement in NHS, public health and social care research (Staley 2009) Available via www.invo.org.uk

INVOLVE

Promoting public involvement
in NHS, public health and
social care research



So why did I join up?

– Irene Douglas

Talk with your neighbour...



- If you have experience of public involvement, what would your advice be to someone doing so for the first time

or...

- If you have not had direct experience of public involvement, what are your top two or three questions about how to ensure successful involvement?

Help and support -

INVOLVE

- website (www.invo.org.uk)
- newsletter
- research project database
- publications
- enquiries
- building an evidence / knowledge base

Research Design Services

- public involvement leads
- remit to advise on public involvement