

Public Involvement in Research

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Family Group**



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National advisory group established in 1996

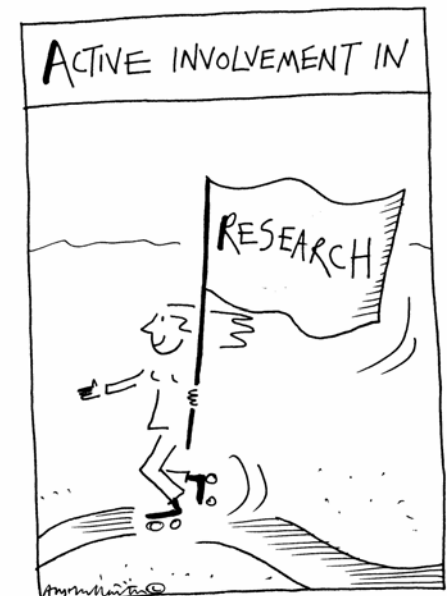
**Funded by the National Institute for Health
Research**

**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-led/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

Requirement for evidence of involvement in funding applications

- Details of plans for involvement in grant applications
- One of the criteria for assessing applications

Public involvement in commissioning research

- Priority setting
- Lay review
- Commissioning boards / selection panels

User-led research in stroke? Reflections on an experience

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Background

- Patient and public involvement in research has been promoted in the UK for at least a decade.
- Involvement can take a number of forms - consultation, collaboration or user-led.
- User-led research is defined in National Institute for Health Research documents as that where “members of the public lead the research and are in control of the research.”
- Turner and Beresford (2005) have argued:
 - ❖ that “user-controlled” research is less likely to lead to tokenism in user involvement;
 - ❖ that service users who lead and control research are particularly committed to making changes;
 - ❖ that this will promote more equal research relationships; and that it will make involvement in research a more positive experience for participants.
- They identify a number of barriers to user-controlled research including scientists' perceptions of such research, and access to training for users keen to undertake research.

Aim

We report our experience of attempting to initiate user-led research in stroke.

Applying for funding

The idea for a study of stroke risk factor self-management was generated by a stroke service user (NP), drawing on his personal experience of stroke risk factor management and his professional experience as a teacher using self-directed learning methods.

The proposal was developed with the support of professional researchers and submitted to a funding body, with NP as lead applicant and professional colleagues as co-applicants.

How the application was assessed

Importance of the question and originality

Reviewers judged the proposed study important and novel.

The quality of the science

Reviewers had some questions about specific aspects of methods and provided useful suggestions about how the study might be improved. Overall, they thought that the study would be able to answer the question posed.

Reputation of the applicants

Reviewer 1: “The team supporting (NP) have a solid reputation and good links with patient groups...”

Reviewer 2: “[Co-applicants] have held substantive research grants... and are clearly familiar with the area and have a history of publications on the topic. I am slightly concerned that, from the CV of NP, he appears to have little research experience... Although he clearly has experience in the area of stroke he will need to be adequately supported by his colleagues and I believe it will be important that [co-investigators] provide advice and support as detailed...”

Discussion

In the highly competitive arena of research funding we were unlucky on this occasion. Perhaps we neglected to explain why it was important that this study was user-led.

Our experience suggests that users wishing to carry out funded research need to be embedded in an established research team; and that they may require an established track record in relevant research. This is not acknowledged in policy promoting user-led research.

User-led study proposals will be judged like any other, within the parameters of the orthodox scientific grant application.

This promotes good science but does it overlook Turner & Beresford's assumption that user-led research will bring something novel to research?

- What is this *something novel*?
- How should it be incorporated into the assessment of proposals?

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