

Memorandum of evidence

To: House of Commons Health Committee

From: INVOLVE, Promoting public involvement in NHS, public health and social care research

Re: New Enquiry – Public and Patient Involvement in the NHS

1. Introduction

INVOLVE is funded by the Department of Health and is one of the programmes of the National Institute for Health Research. The INVOLVE group meets four times a year and the membership includes service users, carers, researchers, research managers and practitioners from both the voluntary and statutory sectors. INVOLVE has been promoting active public involvement* in NHS research for the last 10 years. Since 2001 our remit was extended to include public health and social care research taking place outside the NHS.

We believe it is vital for members of the public to be actively involved in research. Research which reflects the needs and views of the public in this way, can lead to more relevant research and is more likely to produce results that can be used to improve practice in health and social care.

To this end INVOLVE aims to:

- develop strategic alliances with key organisations
- develop the evidence base for active public involvement in research
- empower service users, carers, patients and members of the public to take an active part in research

INVOLVE has a full time Support Unit which undertakes the practical aspects of the INVOLVE's work. This includes:

- producing guidance and information on active public involvement in research
- providing advice to researchers, research managers, research commissioners, and members of the public on active involvement in research.
- holding conferences and seminars, and giving talks and workshops for a variety of organisations

Our role is to promote and support involvement within research rather than service delivery. However, many of the arguments for the value of public involvement in research are transferable to public involvement in service delivery more generally.

Below are our responses to two of the questions raised by the Committee.

2. What is the purpose of patient and public involvement?

Over the last 10 years there has been an increasing emphasis by the Department of Health on a patient centred NHS and social care services which recognises the contribution patients and the public can make to both research and service provision. This has been reflected in various documents, for example: Strengthening accountability: Involving patients and the public (2003); Creating a patient led NHS: Delivering the NHS Improvement Plan (2005); Research Governance Framework for Health and Social Care (2005); and the Best Research for Best Health: NHS R&D Strategy (2006).

Patients and the public are the end users of NHS research and services and therefore it is important that they are at the centre of NHS plans. One of the strongest motives service users and carers give for getting involved in research, is to help bring about improvements to health and social care and to improve existing services and treatments. Patients and the public can bring a unique perspective, by offering a view from the 'outside looking in', which is different to that provided by health professionals.

Public involvement can help to:

- identify issues that are important from a patient perspective
- influence the way services are planned
- improve services from a patient perspective
- improve the experience for people who receive services
- make it more likely that services are provided in user friendly and acceptable ways

3. What form of patient and public involvement is desirable, practical and offers good value for money?

Our experience of public involvement in research, provides us with an understanding of the nature and scope of public involvement, which has relevance for public involvement in service delivery.

The public has been involved in research and development for a number of years and in a variety of different ways. For example, this includes:

- identifying and prioritising research topics
- being part of research advisory groups and steering groups
- undertaking research projects
- reporting and communicating research findings

Public involvement can range from being consulted about some aspect of a piece of research, through to collaboration in a research team, to research which is actively controlled, directed and managed by the public.

INVOLVE has produced various documents in consultation with the public and researchers which highlight good practice in public involvement, as well as practical issues to consider (e.g. Hanley, 2004; INVOLVE, 2006; Steel, 2006; Steel, 2004; Tarpey, 2006) There is also an increasing body of literature highlighting principles of involvement in research (e.g. Telford, 2004; Faulkner, 2004; SURGE, 2005). Much of this work is transferable to public involvement in service delivery. For example:

- avoiding tokenism
- involving people with direct experience of a condition or service relevant to the area of work
- taking into account diversity and equality issues
- working with communities and groups
- allowing time to build relationships
- negotiating and clarifying levels and types of involvement of most value
- offering people a choice about how they want to be involved
- involving people as early on in a project as possible
- planning for sufficient time and resources to support involvement

Whilst there is a growing acceptance of the value of public involvement both in research and service delivery, systematic research to evaluate the nature, scope, cost effectiveness and impact is relatively limited. As a first step, we are currently developing a web based database of research to identify research that has been carried out in this area as well as other research whose primary focus is a research analysis or reflective analysis of public involvement in NHS, public

health or social care research (www.invo.org.uk/invoNET.asp). This will help us to gain a better understanding of the value of different types of involvement.

NOTE:

*** active public involvement**

Active involvement in research is different from simply taking part in a study. It is about research that is done **with**, members of the public, not **to**, **about** or **for** them.

When we use the term 'public' we mean this to include:

- patients and potential patients
 - informal (unpaid carers)
 - parents/guardians
 - people who use health and social care services
 - disabled people
 - members of the public who are the potential recipients of health promotion programmes, public health programmes and social service interventions
 - groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services
 - organisations that represent people who use services
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4. References

Faulkner, A (November 2004)

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Joseph Rowntree Foundation

Hanley, B et al (2004)

Involving the public in NHS, public health and social care research: Briefing notes for researchers. INVOLVE

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SURGE (Service User Research Group England) (2005)

Guidance for good practice: Service User Involvement in the UK Mental Health Research Network. Mental Health Research Network.

Tarpey, M (2006)

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Telford, R et al (2004)

What does it mean to involve consumers successfully in NHS research? A consensus study, Health Expectations, 7, page 209-220

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