

INVOLVE

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

(formerly Consumers in NHS
Research)

INVOLVE RESPONSE TO THE REVIEW OF UK HEALTH RESEARCH JULY 2006

We welcome the opportunity to respond to the Review of UK Health Research. INVOLVE (formerly Consumers in NHS Research), was established by the Department of Health in 1996 to promote active public involvement in research, in order to improve the way that research is prioritised, commissioned, undertaken, communicated and used. The remit of INVOLVE, includes NHS, social care and public health research. Our response largely concentrates on the review in relation to the relevance and importance of UK health research to the public (see note below).

We believe that UK health research should have patients at the centre of any plans, which is why we welcomed the new NHS R&D strategy which places high value on health research which is for the benefit of patients and the wider public. Whilst the science of research is critical in decisions about funding, so too is the relevance and importance of the research to the potential end users (i.e. patients, carers, service users).

The Department of Health plays an important role both in funding the infrastructure for research (for example the newly established UKCRC and UKCRN) as well as directly funding applied research. Research that is rooted within the NHS, facilitates a greater understanding of the needs of patients.

There is a vital role for biomedical basic science but this should not result in us losing sight of the importance of translating that research into practice oriented, applied research, if it is to have an impact on patients health and wellbeing.

The well established national R&D Programmes have a strong history of independence and established peer review processes for the funding of their research. These programmes have also ensured public involvement in the decisions about funding, through membership on advisory boards, encouragement of the public to highlight priorities for funding, and through public involvement in the peer review process. The newly established National Institute for Health Research, including the Central Commissioning Facility, is also taking measures to ensure that the public are actively involved in decisions about research that is funded. These mechanisms have enabled the public to have a voice in research funded by the Department of Health, and have helped in ensuring that health research is relevant and appropriate to the end users of much of the research.

Since 1996, there has been a major shift in the Department of Health, the NHS, and academic institutions, towards a greater acceptance of the value of public involvement in research. The work of INVOLVE has made a major contribution to this shift in awareness and acceptance of the value of public involvement, and INVOLVE has become recognised as an important resource with increasing demand for its expertise (See Appendix A for a summary of recent work of INVOLVE). Whilst INVOLVE is under the umbrella of the National Institute for Health Research, INVOLVE provides independent advice both to the Department of Health and researchers.

Active public involvement in research is critical if research is to answer the real questions that face people about health, and if health research is to be truly responsive to the needs of patients. Thus one of the organisational challenges facing health research is the need for renewed support and commitment to public involvement within research. Any new structures for the funding of research, should ensure the continued support for active public involvement in research.

We believe that if active public involvement in research is embedded into research practice it can contribute towards improving levels of public confidence and understanding of research as well as to the quality, relevance and acceptability of research. It is important to look at the needs of patients holistically in the context of the lives that people lead and thus a public perspective to research helps to ensure that research addresses both health and social care needs. Research that is more relevant, appropriate and acceptable to participants is also likely to encourage greater participation in research.

INVOLVE believes that the public should be actively involved at all stages of the R&D process, including deciding what research should take place; commissioning and undertaking research; as well as communicating the findings. These principles are embedded in the Research Governance Framework.

There is the risk that the creation of a new larger body to manage and administer research funding within the UK, could result in the public becoming more remote

from the heart of its work. Thus any new structures need to ensure that we do not lose sight of the long term goal of health research as being for the benefit of patients. The public should be key in advising on the priorities for health research and in ensuring relevance, appropriateness and accountability of that research.

NOTE:

We use the term '*public*' to include:

- 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 services 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.

By '*involvement*' we mean:

An active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research. Active involvement may take the form of consultation, collaboration or user control. Many people define public involvement in research as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public. This would include, for example, public involvement in advising on a research project, assisting in the design of a project, or in carrying out the research.

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INVOLVE

The role of INVOLVE

The three main strategic objectives of INVOLVE are:

- To develop strategic alliances among key groups in order to maximise effective public involvement in health and social care research.
- To empower people to play an active role in research.
- To monitor the advancement, and assess the effects of, public involvement in NHS, social care and public health research.

Members of INVOLVE come from non statutory organisations, the user movement, research, health and social services management. INVOLVE meets four times a year. Sub group members are largely recruited via open advertisement. Members of the main group are appointed from the sub-group membership by the Director of Research and Development at the Department of Health. The work of INVOLVE is supported by a small support unit. The total budget for INVOLVE is approximately £550,000 per annum.

In recent years, awareness and interest in public involvement has continued to grow. INVOLVE is uniquely placed to provide co-ordinated national support and advice on public involvement in research. INVOLVE provides a resource to researchers, research funders and the public, to facilitate the sharing of knowledge and expertise and to reduce unnecessary duplication of effort.

The work of the Group has increased year on year. This is in large part due to a growing awareness of the work of INVOLVE and the resources available being increasingly utilised by health professionals and the public, coupled with a greater demand for support and advice on the practical issues associated with actively involving the public.

INVOLVE works with a range of different stakeholders to promote and support active public involvement in research and is flexible in responding to new organisations and initiatives and adapting to the constantly changing environment.

The work of INVOLVE

The following section highlights some of the key areas of work undertaken by INVOLVE.

Advice and Support

Providing advice and support through:

- Talks and presentations
- INVOLVE workshops and conferences
- Personalized information and advice on public involvement
- Production of a quarterly newsletter, providing information on the work of INVOLVE and providing updates and examples of initiatives involving the public in research (3,500 individuals / organizations on mailing list).
- Provision of a broad range of information and advice on the INVOLVE website (Approximately 17,000 visits to our website per month)
- Database of training providers
- Web based, publicly available database with information on over 200 research projects which have actively involved the public
- Ongoing networking with statutory, voluntary and service user organizations
- Production of reports and guidelines for researchers, research funders and the public (e.g. Guide for researchers on involving the public, guidance on payments)
- Development of a network and information resource (invoNET) for researchers interested in the nature, contribution and impact of public involvement in research

Influencing policy and practice

In addition to working with individuals to encourage and support public involvement, INVOLVE also seeks to influence policy and practice through developing alliances with various initiatives and through membership of national committees and organisations. For example:

- UKCRC and UKCRN
- NHS R&D Forum
- Medical Research Council (Advisory Group on Public Involvement)
- James Lind Alliance

New initiatives

- Scoping study planned for 2007 to look at the body of literature available on the evidence of the impact of public involvement in research
- Development of website to include a discussion forum for researchers, research funders and the public

- Joint work with the UKCRC including a web based resource to facilitate links between the public and research organisations
- Joint work with the NHS R&D Forum to provide advice and support to the public on the legal liabilities and responsibilities of public involvement
- Revision and development of a guide for the public on getting involved in research
- Guidelines on public involvement in commissioning