

INVOLVE

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

STRATEGIC PLAN 2003-2006:

**CREATING THE EXPERT
RESOURCE**

July 2003

INVOLVE STRATEGIC PLAN 2003-2006:

CREATING THE EXPERT RESOURCE

1. INTRODUCTION

In 1996 the Director of Research and Development in the Department of Health set up Consumers in NHS Research, as a standing advisory group on consumer involvement in the NHS. In 2001 the Group widened its remit to cover public health and social care research commissioned by the Policy Research Programme of the Department of Health. The Group has now been renamed 'INVOLVE – Promoting public involvement in NHS, public health and social care research,' to better reflect its extended remit.

INVOLVE was established to promote public involvement in research, in order to improve the way that research is prioritised, commissioned, undertaken, communicated and used. We believe that the active involvement of the public in the research process leads to research that is more relevant to people and is more likely to be used. Research which reflects the needs and views of the public, is more likely to produce results that can be used to improve practice in health and social care.

We use the term 'public' to include:

- consumers;
- patients and potential patients;
- people who use health and social services;
- informal (unpaid) carers and parents;
- members of the public who may be targeted by health promotion programmes;
- organisations that represent the public's interests;
- communities that are affected by health, public health or social care issues;
- groups asking for research because they believe they have been exposed to potentially harmful substances or products (e.g. pesticides or asbestos).

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.

INVOLVE meets four times a year and includes a broad mix of service users, informal carers, representatives of voluntary organisations, health and social services managers and researchers. Members of the main Group are appointed by the Director of Research, at the Department of Health. INVOLVE reports through the Steering Group for National Programmes to the Director of Research. INVOLVE is supported by a Support Unit based in Eastleigh, Hampshire which is managed under the umbrella of the National Cancer Research Network (NCRN) at the University of Leeds.

2. TERMS OF REFERENCE

The terms of reference of INVOLVE are:

- to promote the empowerment of the public to become more involved in research;
 - to develop and promote alliances with key groups, including the public, researchers, the Department of Health, and other research funders and sponsors in order to promote greater public involvement in research;
 - to monitor public involvement in research in the NHS, public health and social care;
 - to encourage the evaluation of the effects of public involvement in research in the fields of NHS, social care and public health;
 - to report regularly to the Department of Health on progress, and make recommendations about the development of public involvement in research;
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3. WORK UNDERTAKEN BY INVOLVE SINCE 1999

Since the establishment of INVOLVE there has been an increasing acceptance of the value of involving the public in research, and much greater interest in understanding how best to involve them. Below we outline some of the activities undertaken by INVOLVE over the past three years.

3.1 EMPOWERMENT

Guides for the public and researchers

- We have published two documents, one to guide researchers wishing to involve the public (Hanley et al, 2000), and one for members of the public wishing to become involved in research (Royle et al, 2001).
- In 2002 we published a guide to paying the public (Steel, 2002)

- In 2003 we produced a consultation document on involving vulnerable and marginalised groups (Steel, 2003)

Accessibility of information

- In 2000 we produced an Induction Pack for new members of INVOLVE. This was then published on the website in order to be transparent about how the group works.
- In 2002 / 2003 we have been seeking to make our publications more accessible. In consultation with service users, and informal carers, we are looking at improving the format, readability and presentation of documents as well as making our documents available in different formats such as large print and audio tape. This has included the establishment of a readers panel.

Training

- In 2002, we commissioned some research to find out about training that is currently being provided to support public involvement in research, and to identify what is helpful. This research is due to be completed at the end of September 2003.

Public involvement in research in related areas

- In 2000, we commissioned a piece of research to look at ways in which the public have been empowered to become involved in research in other areas, for example social care, education and the environment (Baxter et al, 2001).

3.2 DEVELOPING STRATEGIC ALLIANCES

National conferences

- Since 1999 we have held two successful national conferences, with between 300 and 400 people attending each event. Those attending included researchers, health and social care practitioners, service users, and informal carers.

Building links with research commissioners and research funders

- In June 2000, we held a seminar for research commissioners and research funders, to promote shared learning and the development of public involvement in the research commissioning process.
- We are developing greater links with NHS R&D Programmes and the Policy Research Programme.
- In 2003, we held a workshop for those with experience of public involvement in commissioning, to assist us in developing further guidance and support.

Developing alliances with NHS R&D regional offices, NHS Trusts and Primary Care Trusts

- In 2000, we worked with the four northern regions to organise a series of seminars on involving the public in R&D.

- We are observers on the NHS R&D Forum Representatives Group.
- We are developing links with staff in NHS Trusts and Primary Care Trusts (PCTs) through informal discussions and contributing to workshops and seminars.

Other work to promote alliances

- In 2000 we organised a seminar jointly with the Clinical Trials Unit at the Medical Research Council. The seminar aimed to encourage the sharing of experience of researchers and the public about public involvement in Randomised Controlled Trials (RCTs), and to discuss how to promote and develop public involvement in RCTs.
- We were involved in the development of the Research Governance framework. In 2002 / 2003, the Support Unit also facilitated consultations with service users and informal carers on behalf of the Policy Research Programme around ethics and the implementation of the Research Governance framework in the social care context.
- We have also supported regular meetings of those with a lead for public involvement across the national NHS R&D programmes, the Medical Research Council and the National Cancer Research Institute (NCRI). We will be developing these meetings further over the coming year.
- We have held meetings with individuals from various organisations to share learning about public involvement. These include the Joseph Rowntree Foundation, the Social Care Institute for Excellence, the College of Health, the Economic and Social Care Research Council and COREC (Central Office of Research Ethics Committees).
- We are observers on the MRC (Medical Research Council) Consumer Liaison Group, and the NCRI, (National Cancer Research Institute) Consumer Liaison Group.
- In 2002 we held a workshop to explore how to effectively involve the public in public health research.
- In 2001 and 2003 we held workshops with users of social care services to explore how we could support their involvement in social care research.
- We have worked closely with Folk.Us in Exeter, since it was established in 2000. Folk.Us is an initiative funded by the NHS which aims to promote a research culture which is meaningfully controlled and influenced by service users, disabled people and informal carers in North and East Devon.

3.3 MONITORING AND EVALUATING PUBLIC INVOLVEMENT IN RESEARCH

- In 1998 we commissioned the development of two databases of health research projects in which the public were actively involved. During 2000/2001 we updated these databases to produce one unified version which is available via the Support Unit website.

- In 1999 / 2000 we carried out research to examine the nature and extent of public involvement in research activity managed by the Department of Health Regional offices (Buckland and Gorin, 2001)
- In 2000, we carried out some research to identify those research units involving the public in randomised controlled trials (RCTs)
- We are currently producing a booklet illustrating the ways that the public can be involved in trials.
- In 2000, we developed draft guidelines for grant assessors and grant applicants about consumer involvement in research (Buckland and Entwistle, 2000)
- In 2001, we commissioned a scoping study to explore the most appropriate way to produce and disseminate information on the quality of randomised controlled trials for potential participants (Campbell et al, 2002).
- We are currently developing plans to monitor the nature of public involvement within PCTs, NHS Trusts and the National NHS R&D Programmes.

3.4 ESTABLISHMENT OF THE SUPPORT UNIT

In 1999 a Support Unit was established to support the work of INVOLVE and to provide information, advice and support to the public, researchers, and research funders and those working within the NHS and (more recently), the Policy Research Programme (PRP).

- The Support Unit has a website which enables people to download copies of all our publications and provides current news around public involvement in research (www.invo.org.uk).
- We produce a quarterly newsletter which is distributed to nearly 3000 people who are on our mailing list or with whom we have contact at conferences and events.
- We produce a monthly current awareness bulletin to update members of INVOLVE on relevant news.
- We give regular talks about public involvement to researchers in NHS Trusts, PCTs, Universities and other organisations, as well as give presentations at conferences and workshops.
- We produce and update publications on involving the public in research.
- We take routine enquiries and requests for advice through email, telephone and by post.

4. CHANGING ENVIRONMENT

Since the establishment of INVOLVE in 1996, there has been a major shift towards the greater acceptance of the value of public involvement in research.

We are now working in a very different environment both in terms of this shift in acceptance amongst researchers, and changes that have taken place and which continue within the NHS and social services. We have also widened our remit to include public health and social care. In the area of social care there is a long history of public involvement in research (e.g. Baxter et al, 2001) . This is experience that we are learning from.

Some of the most recent changes which will affect the work of INVOLVE, include the Research Governance Framework for Health and Social Care, and the work of the following agencies:

- Commission for Patient and Public Involvement in Health (CPPIH);
- Commission for Social Care Inspection (CSCI);
- Commission for Health Care Audit and Inspection (CHAI);
- Health Protection Agency (HPA);
- National Patient Safety Agency (NPSA);
- Social Care Institute for Excellence (SCIE);
- National Institute for Clinical Excellence (NICE);
- Central Office for Research Ethics Committees (COREC).

The increasing emphasis by the Department of Health on a patient centred NHS and social care services, creates opportunities for the work of INVOLVE and its future development. **Within this changing environment we should aim to become the expert resource on public involvement in research, within the NHS, public health, and social care fields.**

STRATEGIC DEVELOPMENT 2003 - 2006

5. WORKING PRINCIPLES

We have developed a number of working principles that underpin our strategic plan. These principles signify our commitment to involve the public, researchers, policy makers, research funders, and practitioners in our work, and share our learning with them. They also underline our commitment to ensure that people from groups which are often excluded from research, are included in the research process.

- Wherever possible we will encourage and support research collaboration between the public and researchers.
- We believe in inclusion, diversity and equity and in challenging assumptions regarding the potential of the public to contribute to the research and development process. Throughout our work we will make specific efforts to involve those groups which are traditionally excluded from the research process. These will include, for example,

people with learning difficulties and those from minority ethnic communities.

- We will seek to make the work of INVOLVE as accessible as possible.

6. STRATEGIC OBJECTIVES

We have three strategic objectives to enable us to achieve our terms of reference (Section 2). These are:

- to develop strategic alliances among key groups in order to maximise effective public involvement in NHS, public 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.

6.1 Developing strategic alliances among key groups in order to maximise effective public involvement in NHS public health and social care research

We recognise that although there is significant interest and enthusiasm amongst the public, researchers, research commissioners and the Department of Health for the whole subject of public involvement, there are also some concerns. Some researchers, research managers and commissioners are unsure about the best ways of involving the public and some service users are concerned about improving mechanisms to best facilitate their influence on research and practice. We want to promote alliances and partnerships between different groups to enable public involvement to improve quality at every stage of the research cycle. It is important to raise awareness and knowledge, and encourage a commitment to public involvement amongst a wide audience. This audience includes government departments, non-statutory organisations, individual service users, informal carers, members of the public, communities, researchers and research communities.

Proposed work 2003 / 2004

- To develop plans for a 4th national conference in 2004 to facilitate the sharing of experiences and knowledge.
- To continue to develop alliances with government agencies and NHS Trusts and Primary Care Trusts, through informal meetings, presentations, workshops and joint working.
- To continue to explore ways of ensuring that alliances are developed with those involved in the areas of public health and social care.

- To develop mechanisms for providing support and guidance to those involved in the commissioning process of research, including research funders, researchers, and the public.
- To facilitate further consultation with service users and informal carers around ethics and the implementation of the Research Governance framework in the social care context.
- To explore mechanisms for widening the membership of INVOLVE

6.2 Promoting and supporting the empowerment of the public to play an active role in research

We recognise that some members of the public need additional support, knowledge or skills to enable them to become more actively involved in the research and development process. We are also aware that some members of the public and communities are traditionally excluded from the research process. We are keen to ensure that people from these groups have opportunities to become more involved in research, in order to ensure that the outcomes of such research are relevant to a wide range of the population.

We are committed to:

- improving accessibility
 - in the provision of our information materials
 - to training and skills development
 - to membership of INVOLVE;
- improving access to information about:
 - research and research opportunities
 - training and support available
 - involvement in research;
 - involving or becoming involved in research
- promoting good practice about public involvement within the research community;
- addressing barriers to involvement;
- working in partnership with 'the Monitoring and Evaluation Sub-group' to ensure that involvement leads to meaningful results;

Proposed work 2003 / 2004

- To develop guidance to promote the involvement of young people in research
- To evaluate the availability of training to promote public involvement as well as the needs of the public for training
- To develop strategies to promote and support training
- To continue to improve the accessibility of materials produced by INVOLVE

6.3 Monitoring and assessing the effects of public involvement in NHS, social care and public health research

We believe it is important to monitor the nature and extent of public involvement in research funded by the Department of Health, to enable us to identify areas where involvement could be improved, as well as to monitor over time the effects of government policies to promote public involvement. We also recognise that it is important to assess the effects of public involvement in research and development, to emphasise the value added by public involvement and to usefully inform future involvement initiatives.

Proposed work 2003 / 2004

- To explore and encourage approaches to evaluating the impact of public involvement on research
 - To monitor the extent and nature of public involvement in research commissioning and research projects within the NHS and social services
 - To improve understanding of user controlled and user led research amongst researchers and research commissioners
 - To produce documents to illustrate the effects of public involvement in research (e.g. randomised controlled trials)
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7. FUTURE DIRECTION FOR INVOLVE

- To build on existing work carried out by INVOLVE, to ensure that such work reaches the widest audience.
- To learn from the work of others by sharing knowledge and experiences.
- To continue to develop our understanding of the different levels of public involvement
- To ensure that where practicable, work initiated by sub-groups of INVOLVE is followed through and acted upon both by INVOLVE, and by others.
- To ensure that the work of INVOLVE achieves a balance between NHS, public health and social care.
- To work with others within the Department of Health to develop strategies for influencing Department of Health policy and practice on public involvement in research.
- To develop our work with both communities and individuals to support and encourage public involvement in research.

- To seek to influence commissioning agendas in health, public health and social care to fund research to evaluate the effectiveness of public involvement in research.
 - To review the appointment and membership of INVOLVE and its' sub-groups, and continue to develop methods of working for INVOLVE in line with the changing environment in which we work.
 - For example to consider alternative mechanisms for recruiting members, the need for transparency in the way that members are recruited, and how decisions are made.
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REFERENCES

INVOLVE publications:

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- Buckland S. and Gorin, S (2001) *Involving consumers? An exploration of consumer involvement in NHS R&D managed by the Department of Health Regional Offices*
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- Royle, J et al (2001) *Getting involved in research: A guide for consumers*
- Steel, R. (2002) *A guide to paying consumers actively involved in research*
- Steel, R. (2003) *Consultation Document for Involving Marginalised and Vulnerable Groups in Research*

Research commissioned by INVOLVE:

- Baxter, L. et al (2001) *Small Voices, Big Noises*. Lay involvement in health research: lessons from other fields. Folk.Us, University of Exeter, Washington Singer Press.
- Campbell, M. et al (2002) *RCT Scoping study to explore the most appropriate way to produce and disseminate information on Randomised Controlled Trials*, Health Services Research Unit, University of Edinburgh.

ABBREVIATIONS

CHAI	Commission for Health Care Audit and Inspection - from April 2004 (Commission for Health Improvement - www.chi.nhs.uk Audit Commission – www.audit-commission.gov.uk)
COREC	Central Office for Research Ethics Committees (www.corec.org.uk)
CPPIH	Commission for Patient and Public Involvement in Health (www.cppih.org)
CSCI	Commission for Social Care Inspection (www.doh.gov.uk/csci)
HPA	Health Protection Agency (www.hpa.org)
MRC	Medical Research Council (www.mrc.ac.uk)
NCRI	National Cancer Research Institute (www.ncri.org.uk)
NCRN	National Cancer Research Network (www.ncrn.org.uk)
NICE	National Institute for Clinical Excellence (www.nice.org.uk)
NPSA	National Patient Safety Agency (www.npsa.nhs.uk)
R&D	Research and Development
RCT	Randomised Controlled Trials
SCIE	Social Care Institute for Excellence (www.scie.org.uk)