

INVOLVE

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

STRATEGIC PLAN 2007 – 2011

October 2007

INVOLVE is a programme of the National Institute for
Health Research (NIHR)

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1. Our vision

We work towards a world where public perspectives are integrated into the whole research cycle, enriching research and enthusing all those who participate in it.

We aim to develop our role as the leading authoritative resource on public involvement* in NHS, public health and social care research.

2. Our values and approach

- We encourage and support research partnerships between the public and researchers.
 - We seek to share knowledge and experience of public involvement.
 - We value learning from the work of others.
 - We believe in challenging assumptions regarding the potential of the public to contribute to the research and development process.
 - We believe in inclusion, diversity and equity.
 - We believe in supporting the active involvement in research of groups and individuals who are often excluded from research.
 - We seek to make the work of INVOLVE as accessible as possible.
 - We will build on existing work carried out by INVOLVE, to ensure that such work reaches the widest audience.
 - We value working collaboratively to maximise the opportunities to promote and support public involvement.
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3. Achieving our vision

This Strategic Plan is the result of our constantly developing role, building on our work over the last 10 years. The Strategic Plan was developed following discussions with INVOLVE Group members and revised in the light of a wide consultation with our stakeholders. This plan outlines the key challenges for

INVOLVE and specific strategies to take forward our overall aims. To achieve our vision, we will pursue the following seven strategies:

i) Influencing policy and practice

Over the last 10 years there has been a sea change in the approach and acceptance of the value of public involvement in research amongst policy makers, researchers, research funders and commissioners. However, amongst some, the value and contribution of public involvement is still controversial or not acknowledged. It is necessary to address the concerns of those yet to be convinced whilst sustaining and driving forward change, ensuring that public involvement is at the forefront of new initiatives, as well as maintained and developed within existing organisational structures.

We will do this by:

- proactively identifying and working with existing structures and networks where INVOLVE can seek to influence policy and practice. In particular, looking to identify opportunities within the social care and public health fields as well as the NHS
- working with relevant stakeholders to jointly develop strategies for influencing policy and facilitating the embedding of public perspectives throughout the research process. For example:
 - working with the Department of Health, National Institute for Health Research, the Policy Research Programme, Social Care Institute for Excellence and the James Lind Alliance around the identifying, prioritising and commissioning stages of research
 - working with the UK Clinical Research Collaboration (UKCRC), UK Clinical Research Networks (UKCRN) Research and Development Support Units (RDSUs), the National Research Ethics Service (NRES), and University Research Departments, to support the development of public involvement within research structures covering NHS, public health and social care research
 - working to encourage the dissemination and wider awareness of the contribution of the public to research
- developing strategic links with service user organisations and user researchers to share good practice
- working to explore strategies for promoting public involvement within industry research
- drawing on the expertise of existing INVOLVE Group members and their networks

- recruiting new members who have the potential to influence amongst wider networks

ii) Helping to create an environment that encourages and facilitates involvement

Increasing numbers of researchers and service users recognise the value and need for public involvement, but find it difficult to implement within existing work environments, and time constraints. Investment is needed to further support and encourage involvement if it is to be sustained.

We will do this by:

- exploring ways of encouraging reward and recognition for public involvement both for researchers and the public (e.g. funding to organisations to set up systems / networks to increase public involvement)
- encouraging the development of infrastructures to support public involvement including wider provision of training around public involvement for researchers, commissioners and the public
- working with journals and academic institutions to give credit to research that involves the public
- championing ways of making it easier for the public to get involved e.g. payment and support to get involved and financial support in the development of research applications
- considering ways of providing support to service user organisations to get involved in research
- encouraging greater diversity amongst those who get involved in research (including those who are often excluded from research)
- encouraging research funders and commissioners to promote, support and monitor public involvement (e.g. the development of performance indicators)

iii) Improving understanding of the extent, nature and effects of involvement

We need to further develop our knowledge of the extent, nature and impact of public involvement to improve our understanding of the benefits of public involvement, as well as to understand the best approaches to public involvement. There is a growing body of knowledge in this area, but considerable work still needs to be done to both synthesise existing work as well as generate new research.

We will do this by:

- documenting existing knowledge on the value and experience of public involvement

- supporting the development of meaningful outcome measures of ‘successful’ public involvement
- encouraging researchers, research funders and research commissioners in the building of an evidence base to improve our understanding of involvement and its effects on the broad range of different research methods
- facilitating a national research network (through invoNET), to help build the evidence / knowledge base for public involvement

iv) Encouraging further understanding of the value of genuine involvement

Increasingly, researchers are being asked by funders to involve the public in their work, but not all are convinced of the value and are sceptical of involvement. Building the evidence base on the impact of public involvement can help, but we also need to demonstrate in other ways the added value of involvement.

We will do this by:

- further developing useful support and guidance on good practice
- supporting and encouraging champions to assist in promoting involvement (including academics and clinicians)
- developing examples of involvement for others to learn from
- encouraging educators to incorporate training about public involvement as part of the mainstream teaching curriculum for researchers
- raising awareness through encouraging researchers who have involved the public to include this information in publications they produce
- continuing to raise the profile of public involvement, and the avoidance of tokenism
- continuing to raise awareness of the contribution and value of different types of involvement including user controlled research

v) Increasing understanding amongst researchers, commissioners, funders and the public, of the practicalities and opportunities for public involvement

Whilst some still question the value of public involvement, for many the questions have shifted to the need for more practical and detailed advice on how best to involve the public in their work. We need to develop and respond to these needs. In addition, we need to continue to explore how we can best support the public who wish to get involved and contribute to research.

We will do this by:

- continuing to support and advise researchers and research commissioners
- providing practical knowledge and support

- identifying and highlighting good practice
- identifying common mistakes and poor practice
- raising awareness and understanding of the research environment and potential opportunities for the public to get involved in research

vi) Developing our role as a conduit of expertise identifying and sharing good practice and increasing awareness of the remit of INVOLVE

One of the major functions of INVOLVE is assisting in the sharing of good practice about active involvement. This is an activity that INVOLVE should continue to develop, both to assist and broaden understanding but also to minimise duplication of effort, particularly with the increase in organisations providing guidance and support on public involvement.

We will do this by:

- developing and widely disseminating new resources
- collaborating with others to develop and share resources and facilitating joined up working across organisations
- identifying models of good practice, and criteria for monitoring the effectiveness of involvement
- sharing knowledge on the contribution of public involvement to research
- improving communication about the work and remit of INVOLVE as well as its values and approach
- helping clarify the distinction between the remit of INVOLVE (to promote active public involvement), and the work of others focusing on engagement and participation in research
- linking with organisations focusing on engagement and participation to encourage active involvement within their work

vii) Regularly reviewing our processes to improve the work of INVOLVE

For us to maintain our role as an effective resource we need to be aware of the diversity of perspectives and interests around public involvement, as well as ensure that we operate in a way that enables people to contribute to, and benefit from, the work of INVOLVE.

We will do this by:

- constantly striving to achieve diversity within our membership, to ensure that we consider the wide range of perspectives necessary to fulfil our role
- continuing to reflect on, and seek to improve the accessibility of INVOLVE materials, events and processes

- developing strategic relationships with similar or allied organisations internationally
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4. Conclusion

We recognise there have been significant changes over the last 10 years in the acceptance of the value of public involvement in research. We now need to build on these changes and fully develop the potential for public involvement throughout the research process. This is an ambitious Strategic Plan which will require close links with all our partners. We will be working to annual Operational Plans to monitor delivery against our Strategic Objectives. We have recently recruited 17 new members to the INVOLVE working groups to help us develop and take forward this programme of work.

*Public involvement

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

- patients and potential patients
- people who use health and social care services
- disabled people
- informal (unpaid) carers, parents and guardians
- organisations and communities that represent the interests of people who use health and social care services
- members of the public and communities who are potential recipients of health promotion programmes and social care interventions

The term 'the public' also embraces the rich diversity of people in our multi-cultural society whether defined by age, colour, race, ethnicity or nationality, disability, gender or sexuality who may have different needs and concerns. These need to be taken into account in our policies, procedures and practices.

By '**involvement**' in research we mean:

An active partnership between the public and researchers in the research process. 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 prioritising research, advising on a research project, assisting in the design of a project, or in carrying out the research.

Further information about the work of INVOLVE and our publications can be found on our website.

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