

# INVOLVE

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

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## Report of the work of INVOLVE 2003 - 2007

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October 2007

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

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### 1. Background

INVOLVE was established in 1996 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.

INVOLVE aims 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 help improve practice in health and social care. One of the main reasons why the public get involved in research, is to contribute to a process which can ultimately assist in improving practice.

INVOLVE is made up of a main Group and three working groups. Each of the working groups has a responsibility for leading on one of the strategic objectives of the main Group. The working groups are called:

- Strategic Alliances
- Empowerment
- Evidence Knowledge and Learning

INVOLVE includes a broad mix of individuals who use health and social care services, carers, representatives of voluntary organisations and health and social service managers and researchers.

INVOLVE is funded by the Department of Health and reports to the Director General of Research and Development. It is one of the programmes of the National Institute for Health Research.

The terms of reference of INVOLVE are:

1. To help develop an environment where people affected by NHS, Public Health and Social Care research have the opportunity, and are equipped to have an active role in determining what and how research is prioritised, commissioned, undertaken, disseminated and put into practice.
2. To develop and promote alliances with key groups, including the public, researchers, the Department of Health, and other research funders and commissioners in order to promote greater public involvement in research.
3. To create, gather, disseminate and promote the active use of evidence/knowledge on the inclusive involvement of the public in NHS, public health and social care research.
4. To report regularly to the Director General of Research and Development at the Department of Health on progress, and make recommendations to the National Institute for Health Research about the development of public involvement in research.

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## **2. The changing environment**

Since 1996, there has been a major shift in the Department of Health, the NHS, other public services and academic institutions, towards a greater acceptance of the value of public involvement in research. INVOLVE has made a major contribution to this shift and has become recognised as an important resource with increasing demand for its expertise.

INVOLVE works with a range of stakeholders to promote and support active public involvement in research. Since our last Strategic Plan in 2003, there have been some major organisational changes within health and social care research as well as in other related areas. In particular, some of the major changes have arisen from: the report of the Research for Patient Benefit Working Party (2004); the Government's Best Research for Best Health National Health Research Strategy (2006); the Cooksey Review of UK health research (2006); the recommendations of the Report of the Ad Hoc Advisory Group on the Operations of NHS Research Ethics Committees (2006); and A Stronger local voice (2006). These changes have resulted in the abolishing of various institutions and the establishment, planned creation, or variation to the roles of others, including:

- National Institute for Health Research (NIHR)
- Office for Strategic Coordination of Health Research (OSCHR)
- UK Clinical Research Collaboration (UKCRC)

- UK Clinical Research Networks (UKCRN)
- National Centre for Involvement
- Healthcare Commission
- National Research Ethics Service (replacing the Central Office for Research Ethics Committees)
- National Institute for Health and Clinical Excellence (merger of the Health Development Agency and the National Institute for Clinical Excellence)
- Local Involvement Networks (replacing Patient and Public Forums)

The social care research environment is also undergoing change as major bodies, including the UK Departments of Health, the Department for Education and Skills, the Social Care Institute for Excellence and the Economic and Social Research Council are working together on ways to improve capacity and develop infrastructure. A national consultation exercise was undertaken in the summer of 2006 which was designed to inform the production of a new, cross-national, strategy for social care research. Other, more specific, initiatives include:

- extension of the DH Research Governance Framework to the social care sector, with many Councils forming local governance alliances involving service user/carers;
- RDInfo extending its information services to cover the social care field;
- discussions with the National Research Ethics Service on ways to support social care research ethics review more effectively, including opportunities for wider public involvement;
- work by the Commission for Social Care Inspection (CSCI) on government proposals for the creation of centres of research excellence in social care;
- establishment of a new National Research Register for Social Care Research (NRRSC), hosted on the website of the Social Care Institute for Excellence ([www.scie.org.uk](http://www.scie.org.uk));

INVOLVE needs to respond to this constantly changing environment. The greater focus on a patient and service user centred NHS and social care services, creates opportunities for the work of INVOLVE and public involvement. Awareness and support for public involvement has continued to grow and there are many more people and organisations at both a national and local level involved in promoting public involvement. There are also far more opportunities for the public to get involved and contribute to research, and growing numbers of people are choosing to get involved in different ways.

However, for public involvement to continue, there needs to be further development of infrastructures to support involvement. Voluntary organisations, support groups and individuals need assistance to facilitate greater involvement in research, and an improved infrastructure is necessary to ensure that

researchers and research commissioners have the knowledge, understanding and resources to support and encourage involvement.

Wider acceptance of public involvement brings its own tensions, and there is the risk of involvement becoming diluted with the emphasis by some on engagement and consultation rather than active involvement and partnership.

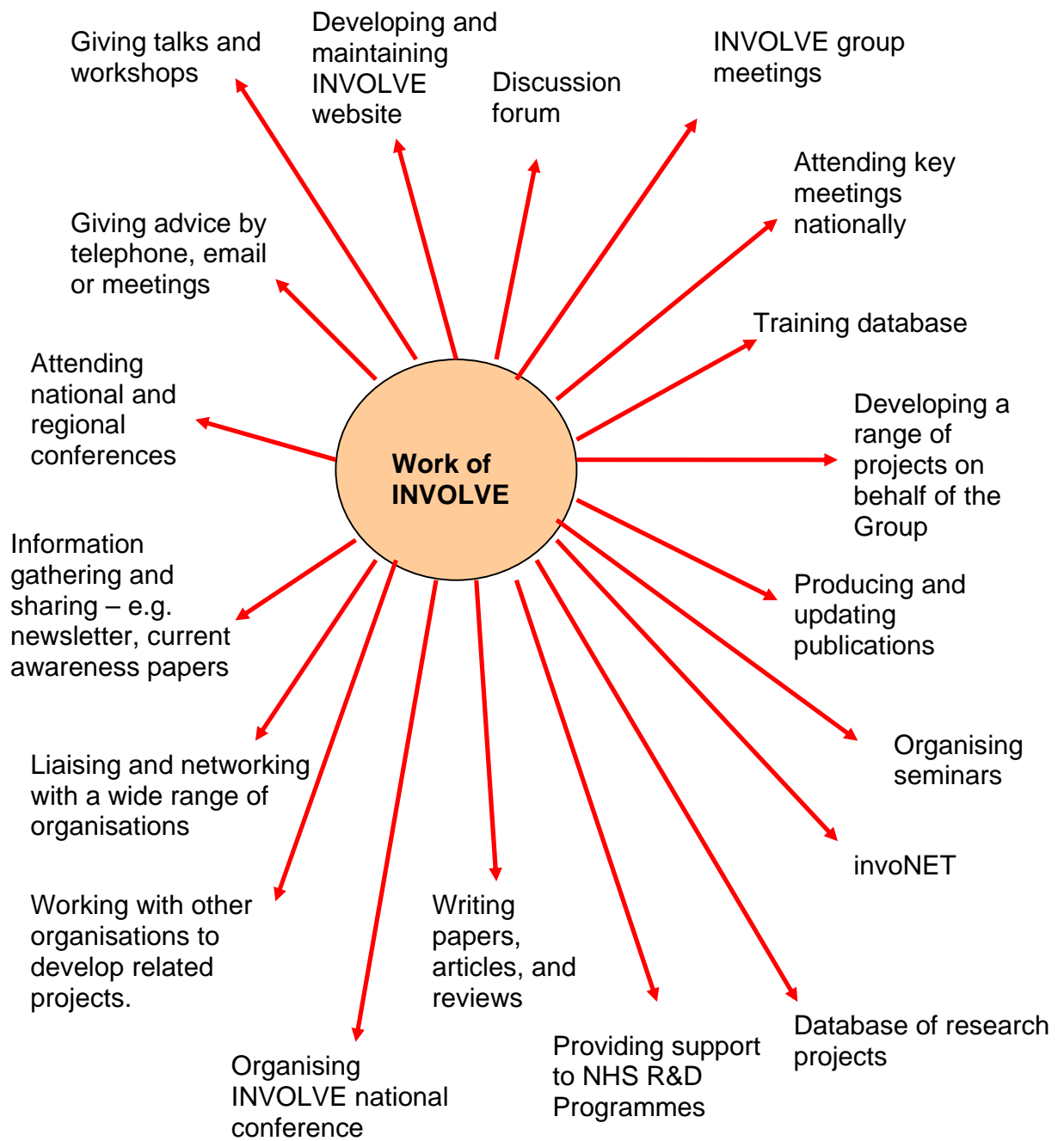
INVOLVE provides an important resource to the Department of Health and other stakeholders. It is uniquely placed to foster a culture of public involvement in research, through advising on policy, providing co-ordinated national support and advice, highlighting good practice, facilitating the sharing of knowledge and expertise, and establishing common practices.

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### **3. INVOLVE Activities**

INVOLVE's activities are concentrated around five operational objectives:

- Supporting the development of an evidence base to monitor the advancement, and assess the effects of, public involvement in research
- Raising awareness about the work of INVOLVE and the value of public involvement
- Developing and taking forward strategies for influencing policy and practice
- Providing advice and support for the public, researchers, research funders and commissioners
- Ensuring INVOLVE continues to develop as an effective organisation



The following sections outline the main activities of INVOLVE since 2003.

### **3.1 Supporting the development of an evidence base to monitor the advancement, and assess the effects of public involvement in research**

There is increasing interest in the need for evidence and knowledge on the impact of active public involvement in research. In 2006, we launched invoNET, a network of people with an interest in developing the evidence base on public involvement. As part of this work we have developed an area of our website to encourage networking and to provide access to a database of references. We are currently further developing the invoNET electronic library of references. This library includes references to articles that explore the extent, nature and impact of public involvement in research. We have also held two workshops to discuss the development of invoNET and issues around building the evidence base. In 2007, we plan to map and analyse work which looks at where public involvement in research has worked well or made a difference.

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### **3.2 Raising awareness about the work of INVOLVE and the value of public involvement in research**

Much of the activity to raise awareness about the work of INVOLVE and the value of public involvement is through the publications we produce, and events that we hold. In addition, our work with a range of national and local organisations focuses on the value and need for public involvement, and directly promotes awareness of the work of INVOLVE. See Section 3.4 for details of our publications.

#### **INVOLVE Conferences and workshops**

INVOLVE continues to organise successful events. Almost all of these have been oversubscribed, and all have been well received. These have ranged from our national conferences held biennially, where between 300 – 400 people attend, and smaller events of between 20 – 50 people. The smaller events often have the purpose of bringing people together to advise us on how we should proceed in certain areas, and / or to assist in the development of guidance documents, as well as to share knowledge. Reports are usually produced following our events, which are available on our website.

#### **2003**

- Commissioning workshop, for those with experience of public involvement in commissioning, to assist us in developing further guidance and support (July)
- Workshop with young people – developing guide to involving young people in research (July)

- Facilitated 2nd consultation on ethical review in social care research
- 2nd workshop with users of social care services to explore how to support their involvement in social care research.

#### **2004**

- Seminar to discuss the findings of the TRUE report – exploring training needs for public involvement (April)
- INVOLVE national conference, University of Nottingham (November).

#### **2005**

- Meeting to discuss the development of a discussion forum for researchers with an interest in researching the influence of public involvement in research (March)
- Training day for research commissioners on public involvement in research (May)
- Workshop on the impact of public involvement in research (June).

#### **2006**

- Workshop to develop the INVOLVE guide for the public on getting involved in research (January)
- invoNET event to discuss building the evidence / knowledge base for public involvement (March)
- INVOLVE national conference, University of Hertfordshire (Sept).

#### **2007**

- 2nd invoNET event (February)

### **Presentations and workshops**

We give regular talks about public involvement to researchers in NHS Trusts, PCTs, Universities and other organisations, as well as giving presentations and having stands at national and local conferences and workshops.

**Table 2 – Presentations and workshops April 2004 – Feb 2007**

|  | <b>April 2004 – March 2005</b> | <b>April 2005 – March 2006</b> | <b>April 2006 – March 2007</b> |
|--|--------------------------------|--------------------------------|--------------------------------|
| Presentations at conferences and workshops | 28                             | 25                             | 18                             |
| Exhibition stands                          | 28                             | 22                             | 14                             |
| Total                                      | 56                             | 47                             | 32                             |

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### **3.3 Developing and taking forward strategies for influencing policy and practice**

Our membership and representation on national committees has increased over the last three years. In addition, we meet with individuals from a wide range of organisations. On-going networking with a wide range of stakeholders is an important part of our work. This gives us opportunities to initiate and strengthen our influence and knowledge as an organisation. We are continuing to expand our networks with people who use services who might otherwise be excluded from the research agenda.

#### **Meetings and committees**

We are continually seeking to develop links both locally and nationally to support and influence policies within those organisations. Many of the meetings we have are initiated by others who wish to discuss the implications of public involvement in research for their own organisation. We also have regular meetings with groups to share and update on activities.

Examples of national organisations we have met with include: the Joseph Rowntree Foundation (JRF); the Social Care Institute for Excellence (SCIE); the Economic and Social Care Research Council (ESRC); National Research Ethics Service (NRES formerly COREC); Shaping Our Lives; the National Institute for Health and Clinical Excellence (NICE); the Disability Rights Commission (DRC); and the National Patient Safety Agency (NPSA). Local meetings have also been held with staff in NHS and Primary Care Trusts (PCTs), Strategic Health Authorities (SHAs), Research and Development Support Units (RDSUs), primary care research networks, and local self help groups.

In addition we facilitate the Public Involvement Collaboration Group meetings. These are quarterly meetings of those with a lead for public involvement across the national NHS R&D programmes, the Medical Research Council (MRC), UK Clinical Research Collaboration (UKCRC) and the UK Clinical Research Network (UKCRN). Our Research Programmes Liaison Manager also meets individually with the public involvement leads of the National R&D Programmes of the National Institute for Health Research.

Table 1 summarises the number of meetings attended by Support Unit staff between 2004 and 2007.

**Table 1 – Meetings attended 2004 – 2007**

|                               | <b>April 2004 –<br/>March 2005</b> | <b>April 2005 –<br/>March 2006</b> | <b>April 2006 -<br/>March 2007</b> |
|-------------------------------|------------------------------------|------------------------------------|------------------------------------|
| <b>Meetings – one<br/>off</b> | 76                                 | 68                                 | 51                                 |
| <b>Meetings -<br/>regular</b> | 88                                 | 90                                 | 123                                |

**INVOLVE representation on committees / regular meetings**

INVOLVE membership of national committees and organisations has doubled since 2002, reflecting both our wider influence in promoting public involvement as well as increased recognition of the value of public involvement. Below is a list of INVOLVE membership 2007:

- UKCRC Board
- UKCRC Regulatory and Governance workstream Working Group
- UKCRC Patient Public Involvement Project Group and Strategy Development Group
- UKCRC Use of Patient Data Coordination Group
- UKCRN Patient Public Involvement Group
- UKCRN Diabetes Research Network Operational Steering Group and Advocacy Group
- National Cancer Research Institute, Consumer Liaison Group (observer)
- NHS R&D National Programme Managers
- James Lind Alliance Steering Group
- Research Governance Framework in Social Care reference group
- Association of Directors of Adult Social Services (ADASS) Research Group
- Folk.us Management Committee
- Planning Group for the Race Equality Foundation (REF) Conference
- Care Record Development Board, Secondary Uses Working Group
- NHS R&D Forum Representatives Group (observer)
- NHS R&D Forum Users and carers group (observer)
- Royal College of Nursing (RCN) Research Strategy Research Policy for Nursing Task and Finish Group
- Research Assessment Exercise 2008, sub panel C, Nursing and Midwifery

**Consultations**

We regularly respond to consultations where appropriate. Between 2004 and 2006 we responded to the following consultations:

- Ad Hoc advisory group on NHS Research Ethics Committees.

- Department of Health's consultation on Ethics Review in Social Care Research
- Healthcare Commission Consultation 'Assessment for Improvement – Our Approach'
- Choosing Health?
- National Institute for Health and Clinical Excellence
  - Operational Model for the Centre for Public Health Excellence
  - The role of regional teams in the new organisations
- Department of Health, Best Research for Best Health consultation
- Review of UK Health Research (Cooksey Review)
- Implementing the recommendations of the report of the ad hoc advisory group on ethical review

### **Other work to promote alliances**

- Regularly review articles for journals
- Writing articles for local and national newsletters
- Many organisations now have website links to the INVOLVE website

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## **3.4 Providing advice and support**

One of our main activities is providing advice and support for the public, researchers, research funders and commissioners to encourage public involvement in research. We promote public involvement in research and share knowledge and experience through a combination of different activities. These have included producing guidance documents, running workshops and events, giving presentations and organising a two yearly conference. In March 2007, we published our Public Information Pack - a guide for the public on getting involved in research. We have also worked collaboratively with the UK Clinical Research Collaboration to develop a new website 'People in Research' which aims to help members of the public make contact with organisations that want to actively involve people in clinical research.

### **Publications**

All of our current publications can be downloaded from the INVOLVE website in pdf format, but people can also request to receive hard copies. The following is a list of publications we have produced between 2003 and 2007.

- Involving the public in NHS, public health and social care research: briefing notes for researchers - second edition (Hanley et al, 2004)
- A guide to actively involving young people in research: for researchers, research commissioners, and managers (Kirby, 2004)

- Getting started with involving the public in public health research: an information sheet for researchers (INVOLVE, 2004)
- Involving vulnerable and marginalised people in research: A consultation document (Steel, 2004)
- A guide to reimbursing and paying members of the public who are actively involved in research (Steel, revised 2006)
- Guidance documents for research commissioners, researchers and the public. Involvement in grant applications, peer review and advisory groups. (INVOLVE, written by Royle and Tarpey, 2006)
- Why people get involved in health and social care research: a working paper (Tarpey, 2006)
- INVOLVE leaflet for members of the public on getting involved in research (INVOLVE, 2006)
- What user controlled research means and what it can do. An easy read summary of a report by Turner and Beresford on user controlled research (INVOLVE, 2006)
- National Institute for Health Research: payment rates for public involvement (INVOLVE, 2006)
- Summary of INVOLVE activities (INVOLVE, 2006)
- Public Information Pack – Getting involved in NHS, public health and social care research (Buckland et al 2007)
- Good practice guidance leaflet for researchers (2007)
- Report of INVOLVE Conference 2006
- Report of invoNET event, February 2007

### **Reports of work externally commissioned by INVOLVE 2003 – 2006**

- Training for service user involvement in health and social care research - a study of training provision and participants' experiences (Lockey, et al 2004)
- Effectiveness and Quality in User Involvement Projects (EQUIP) Final Report (Hovard, et al 2004)
- Capturing the experiences of those involved in the TRUE Project: a story of colliding worlds (Faulkner, 2004)
- User controlled research – its meanings and potential (Turner and Beresford, 2005)
- Summary of PC11 Report. Evaluation of consumer involvement in London Primary Care studies programme (Barnard et al, 2005)

### **Website**

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](http://www.invo.org.uk)). In 2004, we redeveloped our website to make it more accessible and to improve the nature and range of information available.

Prior to this the average number of visits a month was 4,500. Since 2004 the number of visits to the website have continued to increase, with an average of 22,000 a month in 2006 / 2007.

**Table 3: Visits to INVOLVE website 2004 – 2007**

|                    | <b>2004 / 2005</b> | <b>2005 / 2006</b> | <b>2006 / 2007</b> |
|--------------------|--------------------|--------------------|--------------------|
| April - June       | 13,500             | 45,985             | 68,495             |
| July - September   | 13,500             | 44,474             | 54,747             |
| October - December | 25,910             | 46,661             | 60,032             |
| January – March    | 43,481             | 70,183             | 81,002             |
| Total for year     | 96,931             | 207,303            | 264,276            |

## **Databases**

### **Database of research projects**

We continue to update our database of research projects where the public are actively involved in research. Since November 2002, the database has been available via the INVOLVE website. There are currently 222 entries in the database.

### **Database of trainers**

In 2004 we launched a new section on our website providing information about current training initiatives as well as a database of training providers and information about training and relevant reports.

## **Newsletters**

We produce a quarterly newsletter which in 2002 was distributed to just over 2,000 people on our mailing list and was 4 pages long. We now have a regular circulation of over 3,500 people and the newsletter is 8 pages long. The newsletter includes articles on public involvement in social care, public health and NHS research and gives up to date news and links on relevant events, publications and activities. The newsletter is available electronically for those who do not wish to receive a hard copy of the document.

## **Enquiries**

We take routine enquiries and requests for advice through email, telephone and by post. The INVOLVE mailing list can be joined by an individual requesting via email, phone, a written form or online.

## **Discussion Forum**

In 2006, we launched a new online discussion forum on our website. This forum provides the opportunity for people to share experiences and ideas around public involvement in research.

## **People in Research**

We have been working with the UKCRC to develop a website for members of the public to find out what opportunities are available to get actively involved in clinical research. At the heart of the website is a searchable database of information about organisations or groups that sometimes look for members of the public to get actively involved in their work. The website became publicly available in February 2007. The website address is: [www.peopleinresearch.org](http://www.peopleinresearch.org).

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### **3.5 Ensuring INVOLVE continues to develop as an effective organisation**

INVOLVE regularly invites speakers to INVOLVE Group meetings, to help widen our knowledge and understanding. We also draw on the expertise of our diverse membership. Since 2004, we have introduced regular open advertising for new working group members.

#### **Membership**

In 2004, we advertised and recruited 9 new working group members. In April 2007, we again advertised for new members to join the working groups, and recruited 17 new members.

We regularly invite external speakers to our INVOLVE Group meetings, in order to widen our understanding of issues related to public involvement in NHS, social care and public health research. Below are some of the external speakers who have given presentations to the Group in the last 2 years:

Rosemary Barber, University of Sheffield

Noreen Caine, Department of Health

Dawn Duncan, Medical Research Council

Amanda Edwards, Social Care Institute for Excellence

Joan Higgins, Patient Information Advisory Group

Sandy Oliver, Institute of Education

Peter Selby, UK Clinical Research Network

Kristina Staley and Marianne Miles, The Multiple Sclerosis Society Research Network

Jonathan Tritter, National Centre for Involvement

Michael Turner and Peter Beresford, Shaping Our Lives

We have also had many interesting and stimulating presentations from present and past Group members who have a wealth of experience to share.

## **Accessibility of information**

All our core publications and newsletters are available in alternative formats. In 2004, we also produced an easy to read version of our leaflet explaining about the work of INVOLVE. In 2003, we established a Readers' Panel of service users and informal carers to assist us in improving the format, readability and presentation of our documents. We have a text phone for callers to the Support Unit.

In 2006, the Central Office for Information was commissioned to carry out an accessibility audit of INVOLVE publications and the 2006 INVOLVE conference. In 2005, the Empowerment working group established an accessibility working group to develop an accessibility strategy for INVOLVE. The strategy is being developed.

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