



*National Institute for  
Health Research*

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# **INVOLVE**

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

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**OPERATIONAL PLAN  
2010/2011**

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**April 2010**

## **1. Background**

This is the INVOLVE Operational Plan for 2010 / 2011. This plan was produced following discussions by the INVOLVE Group, the working group and main Group chairs, and Coordinating Centre staff.

In 2007 we published our Strategic Plan for 2007 – 2011 which has seven strategic priorities. Below is a summary of our plans to take forward these priorities in 2010 / 2011. Many of the activities fulfil more than one of our strategic priorities, however we have listed each activity under the priority that best matches the activity.

### **1. Influencing policy and practice**

- Responding to consultation documents
- Representation on committees
- Developing partnerships and alliances
- Working with journal editors

### **2. Creating an environment that encourages involvement**

- Promoting and supporting public involvement in the National Institute for Health Research (NIHR)
- Supporting public involvement in strategic roles
- Empowering and supporting researchers and service users
- Including the views of groups and people who are often ignored or overlooked in mainstream society

### **3. Improving understanding of the extent, nature and effects of involvement**

- Developing the knowledge base on public involvement in research
- Producing accessible resources to support examples of user controlled research
- Mapping public involvement in research in the NIHR
- Reporting of public involvement in NIHR funded research
- invoNET forum

### **4. Encouraging further understanding of the value of genuine involvement**

- Presentations at conferences and workshops

### **5. Increasing understanding of the practicalities and opportunities for public involvement**

- Responding to enquiries to the INVOLVE Coordinating Centre
- Revising Briefing Notes for Researchers
- Producing advice on payment
- Training and support for public involvement

**6. Developing our role as a conduit of expertise identifying and sharing good practice and increasing awareness of the remit of INVOLVE**

- INVOLVE Conference 2010
- Disseminating INVOLVE publications
- Developing INVOLVE website
- Developing INVOLVE databases
- Publishing INVOLVE Newsletter
- Publishing current awareness bulletins
- Communications

**7. Regularly reviewing our processes to improve the work of INVOLVE**

- Improving accessibility of INVOLVE materials, processes and events

Sections 2 and 3 provide further detail of the proposed nature of the activities to be undertaken by the Group and the Coordinating Centre, as well as the estimated costs. Inevitably some unforeseen opportunities and activities will emerge during the course of the year however the Operational Plan outlines the main activities and associated costs. Many of the activities identified for 2010 / 2011 are either a continuation of, or building from, the activities of 2009 / 2010.

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## **2. INVOLVE working group plans for 2010 / 2011**

The work of INVOLVE is driven through the working groups and the Coordinating Centre. The main Group provides the opportunity for broader discussion, including developing policy as well as the opportunity for discussion on some of the activities of the working groups. The main Group of INVOLVE signs off the plans for the working groups which are then carried out by the INVOLVE Coordinating Centre.

### **2.1 Empowerment working group**

**A) Improving accessibility of INVOLVE materials, processes and events (£5,000)**

This is an ongoing remit of the Empowerment working group which has produced a strategy which aims to ensure that the work and activities of INVOLVE are accessible to as wide a range of people as possible. Funds might be used, for example, to produce large print, audio or easy read versions of documents.

**B) Accessible resources to support examples of user controlled research (£11,000)**

The second part of the User Controlled Examples project is being undertaken by Alison Faulkner with the support of an advisory group drawn from the Empowerment working group. Summaries of up to seven user controlled research projects will be presented in a written report. We expect the report to be available in early summer 2010.

An important addition to this project is the production of a selection of accessible resources in different formats to ensure the information can be widely available to a broad audience. This is particularly important as a number of the example projects involve people who have different communication needs, for example, people with learning difficulties or hearing impairments.

We plan to work with some of the user controlled projects and others, for example, filmmakers, graphic designers and communication consultants where appropriate, to devise and produce:

- a short stand-alone film about user controlled research
- additional film clips about the case studies to be featured on the INVOLVE website

We aim to launch these at the INVOLVE Conference in November 2010.

**C) Web-based directory of examples of training and support (£10,000)**

On 19 January 2010, we held a workshop entitled Sharing Innovative Practice for training and support for public involvement in research. The workshop aimed to provide an opportunity to discuss a range of training and support examples across different contexts and consider how a more strategic approach to addressing training and support needs could be developed. A key part of the workshop was the production of initial action plans for how this more strategic approach could be developed. A report from this workshop will be published in spring 2010.

During 2010 / 2011, in consultation with the workshop participants and identified key contacts in each strategic health authority area, we propose to undertake a project to create a web-based directory of examples of training and support for public involvement in research. This will enable people to access from one location, information about different approaches which have been taken and suggested models to adopt within their own practice.

**D) Including the views of people and groups who are often ignored or overlooked by mainstream society (£10,000)**

INVOLVE has a wide remit and needs to, wherever possible, develop support, advice and guidance that is broadly generic.

In March 2010, the Empowerment working group held a workshop with Shaping Our Lives, focusing on service user perspectives on the inclusion of the views of people and groups who are often ignored or overlooked by mainstream society.

In 2010 / 2011, we plan to build on this work further. This will include work to explore researcher views and experiences of including the views of people and groups who are often ignored or overlooked by mainstream society. It is anticipated that the service users who contribute to the March 2010 workshop will be invited to be involved in this further work. The approach we will take is to be agreed through discussions with the Empowerment advisory group for this project and the whole Empowerment working group, and may include a further workshop or session at the INVOLVE conference.

Subsequent to this, we will undertake to produce guidelines for helping others to ensure the views of people and groups who are often ignored or overlooked by mainstream society are included more widely in research. This work will continue into 2011 / 2012.

#### **E) Guide on payments for members of the public**

The work undertaken by the INVOLVE Coordinating Centre on payments in 2009 / 2010 has focused on updating and revising existing resources about payments for involvement. However, the need for two new information resources has been identified. These are:

1. a short booklet for members of the public to help them to think about the relevant information they need when considering accepting payment for involvement in research
2. a series of examples of when payments may affect state benefits (these may be drawn from real life but will be anonymised). Advice would then be sought from the Department of Work and Pensions (DWP) about the implications for benefit entitlement if payments are received.

The Empowerment working group will support this work through a reporting line to the quarterly meetings.

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## **2.2 Strategic Alliances working group**

#### **F) INVOLVE Conference 2010 (£35,000 plus additional £10,000)**

Every two years INVOLVE holds a national conference which aims to provide a forum for people who are interested in promoting and supporting public involvement in research to learn, reflect and network. Our seventh conference will take place in Nottingham on 16 and 17 November 2010.

### **G) Journal editors scoping study (£15,000)**

This will be a small piece of work to gather intelligence on a cross section of journal editors on their view of reporting public involvement in research. This work is also supported by the Evidence, Knowledge and Learning working group. The purpose of this study will be to help inform INVOLVE's long term aim of influencing journal reporting of public involvement in research studies.

### **H) Developing alliances**

As part of the working group's ongoing commitment to identify, map and develop INVOLVE's key strategic alliances in 2010 / 2011 we will:

- continue to look at ways to develop public involvement research champions within and across the NIHR to advocate and cascade knowledge about public involvement as well as mentor and influence new researchers e.g. work with NIHR funded Senior Investigators
- continue to encourage and strengthen working alliances with NIHR programmes and infrastructure
- continue the work initiated by the UK Clinical Research Collaboration (UKCRC) to support public involvement in strategic decision making.

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## **2.3 Evidence, Knowledge and Learning (EKL) working group**

### **I) invoNET forum (£10,000)**

invoNET is a forum for people with an interest in researching and building an evidence base on active public involvement in research. Consideration will be given to a sixth annual event as well as taking forward some of the issues raised at previous invoNET events such as working with journal editors, librarians, database developers and the NIHR research programmes on how best to ensure that public involvement in research is more visible. This work will be complemented by the work that Strategic Alliances plan to commission to gather intelligence on a cross section of journal editors on their views of reporting public involvement in research. (See also reporting of public involvement in NIHR funded research).

The library and the invoNET area of the website will continue to be developed with a view to producing a 3<sup>rd</sup> edition of the invoNET Bibliography.

### **J) Dissemination of INVOLVE publications (£5,000)**

During 2010 / 2011 there will be ongoing dissemination of reports published in 2010 / 2011 as well as new publications.

### **K) Mapping public involvement in NIHR funded research (£15,000)**

There is currently little baseline data available on the extent or nature of public involvement in research in England. During 2010 / 2011 we will work with the NIHR research programmes and the National Research Ethics Service (NRES) to undertake a piece of work to draw together available information that is routinely collected on public involvement in NIHR funded research. A report will be produced summarising current knowledge as well as the value and feasibility of future monitoring of data on public involvement as well as possible scope for future work.

### **L) Reporting of public involvement in NIHR funded research**

Work will continue with the Programme Managers of the National Institute for Health Research (NIHR) and researchers to identify ways to encourage reporting of public involvement by researchers throughout the research process. This will also link with the work with Journal editors (see G).

### **M) Developing the knowledge base on public involvement in research (separately funded by the Department of Health)**

A joint funding call on public involvement in research funded by the National Institute for Health Research (NIHR) through INVOLVE, and delivered by the NIHR Health Services Research (HSR) programme managed by the NIHR Evaluations, Trials and Studies Coordinating Centre (NETSCC) was announced in February 2010. The deadline for outline proposals is the 06 May 2010. Final decisions on funding will be made at the February 2011 Health Services Research Board meeting.

The three key aims of the call are to collect evidence on:

- **Impact:** to increase knowledge and understanding of the impact of public involvement in research
- **Evaluation:** to identify methods of evaluating public involvement in research
- **Implementation:** to identify effective ways of involving the public in research

The INVOLVE Coordinating Centre will be supporting this programme during 2010 / 2011.

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## **2.4 Main Advisory Group**

### **N) Support Group members / Group meetings (£35,000)**

We will continue arranging and providing secretariat support for both main Group and working group meetings and recruitment of new members. This

includes arranging payments of members travel expenses and attendance allowances, as well as any training required.

## **O) INVOLVE Strategic Plan**

Our current INVOLVE Strategic Plan runs from 2007 – 2011. In 2010 / 2011 we will be producing a new Strategic Plan.

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The following are additional potential areas raised by INVOLVE working group members which will be discussed during 2010 / 2011 for possible future development:

- Production of a short leaflet for the public on getting involved in research to complement the Public Information Pack (Empowerment)
  - Evaluating the experience of service user involvement in the NIHR (EKL and Empowerment)
  - Clarifying for others the distinction between active public involvement in research and engagement, highlighting what INVOLVE can offer e.g. by working with the NIHR Communications team (Strategic Alliances)
  - Special journal supplement on public involvement in research (Strategic Alliances)
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## **3. INVOLVE Coordinating Centre plans for 2010 / 2011**

The work of the INVOLVE Coordinating Centre complements and supports the INVOLVE working group plans for 2010 / 2011. The plans for the INVOLVE Coordinating Centre in 2010 / 2011 include delivering on core activities as well as responding to new initiatives relevant to our overall strategic priorities.

### **Areas of ongoing and developing work:**

- **Developing and maintaining partnerships with organisations**
- **Promoting and supporting public involvement in the NIHR**
- **Representation on committees**
- **Publishing the INVOLVE newsletter**
- **Publishing current awareness bulletins**
- **Responding to consultations**
- **Responding to enquiries to the Coordinating Centre**
- **Presentations at conferences and workshops**
- **Maintaining and developing the INVOLVE website**
- **Maintaining and developing INVOLVE databases (including People in Research website)**
- **Updating and revising Briefing Notes for researchers**

- **Project managing work commissioned by INVOLVE**
  - **Servicing the INVOLVE Advisory Group and working groups**
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## Appendix 1: Operational Plan Budget for 2010 / 2011

The total estimated cost for the activities outlined is £151,000, plus an additional £10,000 for the INVOLVE Conference. This is higher than our anticipated funding of approximately £129,500 (plus £10,000). However inevitably, some plans will get delayed or altered during the financial year and thus we anticipate that expenditure for this programme of work will be within budget.

INVOLVE strategic priorities:

1. Influencing policy and practice
2. Creating an environment that encourages involvement
3. Improving understanding of the extent, nature and effects of involvement
4. Encouraging further understanding of the value of genuine involvement
5. Increasing understanding of the practicalities and opportunities for public involvement
6. Developing our role as a conduit of expertise identifying and sharing good practice and increasing awareness of the remit of INVOLVE
7. Regularly reviewing our processes to improve the work of INVOLVE

(N.B. Numbers highlighted in bold in the summary tables are the main focus of the activity).

### Empowerment working group Chair: David Evans

ACTIVITY	Relevance to strategic priorities	Areas covered: NHS Social Care Public Health	Estimated cost
A. Improving accessibility of INVOLVE materials, processes and events	<b>7</b>	All	£5,000
B. Accessible resources to support examples of user controlled research	<b>2,3,4</b>	All	£11,000
C. Web based directory of examples of training and support	<b>5,6</b>	All	£10,000
D. Including the views of groups and people who are often ignored or overlooked in mainstream society	<b>2</b>	All	£10,000
E. Guide on payments for members of the public	<b>2, 5, 6</b>	All	-
<b>TOTAL</b>			<b>£36,000</b>

**Strategic Alliances working group**  
**Chair: Stuart Eglin**

<b>ACTIVITY</b>	<b>Relevance to strategic priorities</b>	<b>Areas covered :NHS Social Care Public Health</b>	<b>Estimated Cost</b>
F. INVOLVE conference 2010	1, 2, 3, 4, 5, 6	All	£35,000*
G. Journal Editors Scoping study (joint work with Evidence, Knowledge and Learning)	1, 2, 3	All	£15,000
H. Developing partnerships and alliances	1, 2, 6	All	-
<b>TOTAL</b>			<b>£50,000</b>

\* plus additional £10,000 for conference

**Evidence, Knowledge and Learning working group**  
**Chair: Sophie Staniszewska**

<b>ACTIVITY</b>	<b>Relevance to strategic priorities</b>	<b>Areas covered: NHS Social Care Public Health</b>	<b>Estimated Cost</b>
I. invoNET forum	3,4,6	All	£10,000
J. Dissemination of INVOLVE publications	3,5,6	All	£5,000
K. Mapping public involvement in NIHR funded research	3,4	All	£15,000
L. Reporting of public involvement in NIHR funded research	3,4,6	All	-
M. Developing the knowledge base on public involvement in research	3	All	-
<b>TOTAL</b>			<b>£30,000</b>

**Main Advisory Group budget**  
**Chair: Nick Partridge**

<b>ACTIVITY</b>	<b>Relevance to strategic priorities</b>	<b>Areas covered: NHS Social Care Public Health</b>	<b>Estimated Cost</b>
N. Support Group members / Group meetings		All	£35,000
O. INVOLVE Strategic Plan		All	-
<b>TOTAL</b>			<b>£35,000</b>

<b>TOTAL ESTIMATED COST:</b> <b>( + additional £10,000 for conference)</b>	<b>£151,000</b>
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**Appendix 2: INVOLVE Coordinating Centre  
Director: Sarah Buckland**

<b>ACTIVITY</b>	<b>Relevance to strategic priorities</b>	<b>Areas covered: NHS Social Care Public Health</b>
Developing and maintaining partnerships	1,2,5,6	All
Promoting and supporting public involvement in the NIHR	1,2,4,5,6	All
Representation on committees	1,2,5,6	All
Publishing INVOLVE Newsletter	5,6	All
Publishing current awareness bulletin	3,6	All
Responding to consultations	1	All
Responding to enquiries to Coordinating Centre	2,4,5,6	All
Presentations at conferences and workshops	1,2,4,5,6	All
Maintaining and developing the INVOLVE website	2,3,4,5,6	All
Maintaining and developing INVOLVE databases	3,4,5,6	All
Updating and revising Briefing Notes for Researchers	4,5,6	All
Project managing work commissioned by INVOLVE		
Servicing the INVOLVE Group and working groups		