

# **INVOLVE**

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

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## **OPERATIONAL PLAN 2007/2008**

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**April 2007**

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### 1. Strategic Objectives

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

- 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.
- 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.
- 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.

To take forward these strategic objectives and to further the principles and direction of INVOLVE we have 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 and understanding about the work of INVOLVE and the value of public involvement in research
  - 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.
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## **2. Plans for 2007 / 2008**

The following sections outline the proposed operational plan for 2007 / 2008, for approval at the March 2007 Group meeting. This plan was produced following discussions by the INVOLVE working groups (October and December 2006) and a meeting of the sub-group chairs (March 2007). At the chair's meeting a programme of activities were agreed to take forward as part of the Operational Plan for 2007 / 2008.

This is an ambitious programme of work, with three workshops planned as well as various commissioned projects and considerable Support Unit input. However, it is also an opportunity for facilitating greater cohesion across the working groups with many potential links and overlaps as well as providing scope for developmental work which will enable us to build alliances and focus the direction of our work over the next few years.

The total estimated cost is £160,000. This is higher than our anticipated funding of approximately £125,000. However, inevitably some plans will get delayed or altered during the financial year and thus we anticipate that expenditure will be within the £125,000 budget.

Sections 2.1 to 2.5 summarise the proposed activities for 2007 / 2008. Details of proposed budgets are included in Appendix 1. More detailed information about the activities are included in Appendix 2.

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

- through undertaking or commissioning research
- encouraging others to undertake or commission research
- monitoring public involvement in research

#### We will:

- Research and study examples of research demonstrating the impact of public involvement in research
- Explore options for monitoring the extent of public involvement within projects funded by the National Institute for Health Research
- Organise a third invoNET event early in 2008
- Continue to add references to our invoNET database of resources

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

### We will:

- Develop a 'statement' to explain what INVOLVE does and its approach
- Develop plans to improve communication of the value of public involvement
- Continue our strategy for the publication and dissemination of INVOLVE publications
- Continue to develop the INVOLVE website, including a section on research commissioning and funding
- Publish regular Current Awareness Bulletins for INVOLVE members
- Make up to 20 presentations at conferences and workshops
- Identify a venue, and initiate plans for the INVOLVE national conference 2008
- Evaluate use of our guidelines for public involvement in commissioning research

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

### We will:

- Promote and support public involvement in research through the new structures outlined in the R&D Strategy and the Cooksey Review
- Further develop our support to the National Institute for Health Research programmes
- Continue to explore opportunities to promote and support public involvement in research within the UK Clinical Research Collaboration and UK Clinical Research Network
- Continue to undertake development work to support greater public involvement in social care research
- Explore ways of promoting and supporting greater involvement in public health research
- Continue to work with the James Lind Alliance and others to promote public involvement in agenda setting in research
- Continue to develop partnerships with other relevant organisations
- Respond to relevant consultation documents

## **2.4 Providing advice and support for the public, researchers, research funders and commissioners**

- **Providing links to share knowledge and experiences**

### We will:

- Explore ways of encouraging greater use of our discussion forum
- Revise the design of our quarterly Newsletter
- Revise our web based database of research projects
- Develop a database of key articles on public involvement in research
- Undertake development work with relevant organisations to support the involvement of people from black and ethnic minorities in research

- **Providing guidance to facilitate greater understanding about public involvement in research**

### We will:

- Work with the National Research Ethics Service (formerly Central Office for Research Ethics Committees) to evaluate and develop public involvement in research ethics review
- Promote and disseminate the INVOLVE leaflet on good practice for public involvement in research
- Promote and disseminate our new Public Information Pack for the public on getting involved in research
- Respond to enquiries to the Support Unit
- Present at conferences and workshops (see 2.2)
- Identify the support and empowerment needs of researchers in respect of involving people who use services
- Collect and disseminate examples of user controlled research
- Collect and disseminate examples of public involvement in social care research
- Work with the NHS R&D Forum to provide advice and support on the legal liabilities and responsibilities for the public involved in NHS research

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

### We will:

- Advertise and recruit new members to the INVOLVE working groups
- Continue to explore opportunities to enable the public to influence the work of INVOLVE

- Continue to explore accessibility and disability awareness issues within INVOLVE
  - Continue to monitor the work of the Support Unit
  - Support Group members, in engaging with the work of INVOLVE and monitor their activities in promoting public involvement through their networks
  - Undertake a survey of Group members to elicit their views on the operation of INVOLVE
  - Complete our accessibility strategy and continue to improve the accessibility of INVOLVE materials, processes and events.
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### **3. Areas of work not prioritised for 2007 / 2008**

Various potential additional areas of work were discussed by INVOLVE members in the process of prioritising activities for 2007 / 2008. Some of these were areas that needed further development and may be explored and developed throughout the year as future activities. Below is a list of these activities highlighted by the working groups:

- The development of a core curriculum for the training of public involvement
- Work to support the involvement of young people in research
- Influencing industry to develop public involvement
- Supporting and promoting public involvement in public health research
- Exploring pathways for seldom heard groups in making a difference to the services they receive through involvement in research
- Special journal edition to promote public involvement in research

## Appendix 1: Operational Plan Budget for 2007 / 2008

### Main Group budget Chair: Nick Partridge

ACTIVITY	Areas of work	NHS Social Care Public Health	Estimated Cost
A. Support Group members / Group meetings	2.5	All	£20,000
B. UK Clinical Research Collaboration	2.2 2.4	Health	No budget
<b>TOTAL</b>			<b>£20,000</b>

### Empowerment working group Chair: Kate Sainsbury

ACTIVITY	Areas of work	NHS Social Care Public Health	Estimated Cost
C. Improve accessibility of INVOLVE materials, processes and events	2.2 2.5	All	£7,000
D. Development work black and ethnic minority communities	2.4	All	£4,000
E. Dissemination of Public Information Pack – guide for the public	2.2 2.4	All	£1,500
F. Statement and working paper about INVOLVE	2.1 2.2	All	£1,500
G. Empowerment issues for researchers (survey and workshop)	2.4	All	£15,000
H. Examples – user controlled research	2.4	All	£15,000
<b>TOTAL</b>			<b>£44,000</b>

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

<b>ACTIVITY</b>	<b>Areas of work</b>	<b>NHS / Social Care / Public Health</b>	<b>Estimated Cost</b>
I. INVOLVE conference 2008	2.2	All	£10,000
J. Evaluating commissioning guidelines	2.2	Health	-
K. Involving service users in research ethics review service	2.4	NHS	£10,000
L. Communication (raising profile of INVOLVE and public involvement)	2.2	All	£10,000
M. Social care (workshop, examples)	2.4	Social care	£20,000
N. James Lind Alliance	2.3	Health	No budget
<b>TOTAL</b>			<b>£50,000</b>

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

<b>ACTIVITY</b>	<b>Areas of work</b>	<b>NHS Social Care Public Health</b>	<b>Estimated Cost</b>
O. invoNET forum	2.1	All	£6,000
P. Dissemination of INVOLVE publications	2.2	All	£5,000
Q. Study of impact of public involvement in research	2.1	All	£35,000
R. Mapping information collected by research funders	2.1	Health	No budget
<b>TOTAL</b>			<b>£46,000</b>

**TOTAL ESTIMATED COST**

**£160,000**

**Support Unit**  
**Director: Sarah Buckland**

<b>ACTIVITY</b>	<b>Areas of work</b>	<b>NHS Social Care Public Health</b>
Develop INVOLVE website	2.2	All
Publish current awareness bulletin	2.2	All
Respond to consultation documents	2.3	All
Representation on committees	2.3	All
Publish INVOLVE Newsletter	2.4	All
Develop databases - research projects	2.4	All
Respond to enquiries to Support Unit	2.4	All
Presentations at conferences and workshops	2.2 2.4	All
Developing partnerships	2.3	All
Promoting and supporting public involvement in the NIHR	2.3 2.4	Health
Legal liabilities and responsibilities of public involvement	2.4	NHS
Conduct a survey of Group members	2.5	

## **Appendix 2:**

### **MAIN GROUP**

#### **A) Support group members / group meetings (£20,000)**

Ongoing work, 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.

#### **B) UK Clinical Research Collaboration (UKCRC)**

Ongoing work to promote and support active public involvement within the UKCRC across the different workstreams, and within the UK Clinical Research Networks.

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### **EMPOWERMENT WORKING GROUP**

#### **C) Improving accessibility of INVOLVE materials, processes and events (£7,000)**

A part of this will go towards the implementation of the INVOLVE Accessibility Strategy. It will also be used for producing accessible materials, within reason, on request and to support inclusion of individuals in the work of INVOLVE.

#### **D) Development work on Black and Ethnic Minority (BEM) issues in research (£4,000)**

Links have already been established with the Race Equality Foundation and the Social Services Research Group, and INVOLVE supported the Inclusion and Exclusion 2007 conference.

The aim this year will be to bring in more organisations working in this area to form a BEM research 'forum' or working group, to agree and co-ordinate work to improve the way that research addresses BEM issues, so that BEM communities both nationally and locally benefit. Such organisations would include those affected by, or working in health as well as social care research.

Financial support will be needed to establish such a forum, which is likely to need to include people from organisations with very few resources.

**E) Dissemination of Public Information Pack (PIP) – a guide for the public on getting involved in research (£1,500)**

Design, printing and postage of publicity to promote awareness of the new Public Information Pack - a guide for the public on getting involved in research.

**F) Development of a ‘statement’ about what INVOLVE is and who is involved in it, the influences, and the role of the Group in a changing research environment over the last 10 years (£1,500)**

Small budget for printing costs. Support Unit time is needed in developing the statement. The statement needs to address questions from an individual, grassroots point of view about INVOLVE. ‘Who are you? What right have you to be saying what you are saying?’. A historical context is needed to help answer this question as well as information about what INVOLVE is trying to do and the way it is doing it. An information sheet would be produced and made readily available.

**Fi) Working paper on how INVOLVE can increase opportunities for the public to influence its work (no budget)**

There are now many people working in the field of public involvement in research. The paper will explore ways that the wider community can feed into the work of INVOLVE.

**G) Identifying ‘empowerment’ issues for researchers (£15,000)**

There is a need to find out what sort of support is needed for researchers to involve people who use services in their work. Some initial survey and scoping work needs to be done to see if research has already been undertaken in this area. This would be followed by a workshop/seminar for researchers. Commissioning a report of the event might be necessary.

Gathering this information would help INVOLVE identify what further ‘tools’, communications, and support is needed. The question needs to focus on researchers ‘empowerment’ and ‘enablement’ rather than simply identifying barriers and drivers for researchers in respect of user involvement.

**H) Examples of User Controlled research (£15,000)**

Collect and publish examples of user controlled research. The work would emphasise the value of user controlled research in improving services. The work would explore ways to make the examples useful and relevant for two different audiences:

funders/commissioners

and service users.

Those examples which demonstrated impact and the difference that public involvement had made to the research could contribute to the work that Evidence, Knowledge and Learning is developing on building an evidence base.

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## **STRATEGIC ALLIANCES WORKING GROUP**

### **I) INVOLVE Conference 2008 (£10,000)**

INVOLVE's sixth national conference. Every two years the conference has provided a forum for people who are interested in promoting and supporting public involvement in research to learn, reflect and network. A budget is needed in 2007/2008 to cover deposits for the venue and other preparatory costs.

### **J) Evaluating guidelines for Public Involvement in Commissioning Research (no budget)**

Monitoring and evaluating use of the INVOLVE Commissioning guidelines, and encouraging and supporting the implementation of the guidelines in practice. Monitoring to include, downloads from the website, numbers of printed copies used, and references to the guidelines by commissioning briefs. Evaluation to include interviews with National Institute for Health Research programmes, questionnaires via the INVOLVE website, and other follow up with users of the guidelines.

### **K) Involving Service Users in the National Research Ethics Service (£10,000)**

There are two possible projects to be developed in collaboration with the National Research Ethics Service (formerly Central Office for Research Ethics Committees) during this financial year.

1. Survey among lay members of NHS research ethics committees
2. Guidance / training for involving service users in research ethics review bodies.

### **L) Communications / Promoting public involvement (£10,000)**

There is considerable scope for raising awareness amongst a wider audience about public involvement in research. In addition, patient and public involvement in research is often confounded with 'participation' of the public (as in, the public being the subjects of research) or 'engagement' with the public and there is need to help clarify understanding about public involvement.

We need to consider different ways of influencing people and raising the profile of INVOLVE and public involvement.

Other possible areas to explore are the development of an award scheme for public involvement in research, or a beacon scheme to recognise examples of good practice. These could be planned in collaboration with other organisations such as the Economic and Social Research Council. Separate awards could be developed, or INVOLVE could link to existing awards such as the Health and Social Care awards. Awards or beacons could either concentrate on public involvement in social care research or include all types of public involvement in research.

Development work is needed to identify effective methods to adopt, and audiences to target. INVOLVE will commission consultants to explore options and provide advice on improving our communication about public involvement as well as assist in writing articles and generating wider interest in public involvement.

#### **M) Social care (£20,000)**

Several strategies are suggested for building and developing links within social care research. The following are proposed as projects for 2007/08.

##### Seminar for social care research – to include the sharing of good practice examples within social care (£10,000)

There is potential interest by others to work with us on an event, for example the Economic and Social Research Council (ESRC), and the National Centre for Research Methods which is ESRC funded.

The seminar could request papers/presentations on examples of good practice in public involvement in research in social care, and projects that demonstrate the impact and difference public involvement has made to the research. Funds could be set aside for a report of the seminar. This could be widely disseminated throughout the social care research community.

##### Identification of good practice examples of social care research projects, highlighting strengths within social care (£10,000)

A piece of work which would identify examples of good practice of active public involvement in social care research. This could be the precursor to an event, or could follow from / run alongside the above event.

Those examples which demonstrated impact and the difference that public involvement had made to the research could contribute to the work that Evidence, Knowledge and Learning is developing on building an evidence base.

**N) James Lind Alliance (JLA)**

The James Lind Alliance is a coalition of organisations representing patients and clinicians collaborating to confront important uncertainties about the effects of treatments. Nick Partridge is a member of the Steering Group. The Support Unit is in discussion with the JLA to develop further collaboration.

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**EVIDENCE, KNOWLEDGE AND LEARNING WORKING GROUP**

**O) invoNET forum (£6,000)**

A forum for researchers with an interest in researching active public involvement in research. A third event is planned in 2007/08 as well as additional work on the invoNET website and library content.

**P) Dissemination of INVOLVE publications (£5,000)**

During 2007/08 there will be ongoing dissemination of reports published in 2006/07 and of reports produced during 2007/08 (for example the Public Information Pack, and good practice leaflet).

**Q) Researching and studying examples of research demonstrating the impact of public involvement in research (£35,000 pa for two years)**

This work will develop and build on the bibliographic work being carried out in 2006/2007 to develop an evidence base for public involvement in research, as well as the position paper produced by the working-group. It will include analysing the findings from work identified through the current bibliographic work as well as identifying new research, to explore what has worked well /made a difference. This piece of work could then be developed to identify common themes and lessons learnt which could lead to practical good practice guidelines or have implications for training. This learning could also feed in to the next INVOLVE conference in 2008. The Support Unit will employ a new member of staff for 15 months to specifically carry out this piece of work. The work will span over the next two financial years, starting in September 2007.

Some of the examples identified by the Strategic Alliance and Empowerment working groups which demonstrated impact and the difference that public involvement had made, could contribute to this project.

## **R) Mapping information collected by research funders**

Information provided by applicants to the Central Commissioning Facility for the Research for Patient Benefit Programme, provide a rich source of information on the nature and extent of proposed involvement of the public in research projects. This information could be used to highlight misunderstandings around public involvement as well as examples of good practice, which could both assist in the assessment of applications, as well as be used to improve guidance to applicants. INVOLVE is exploring the options for monitoring and analysing this information in an anonymised form.

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