

# **INVOLVE**

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

The NHS logo consists of the letters 'NHS' in a bold, white, sans-serif font, set against a blue rectangular background.

*National Institute for  
Health Research*

# **Information Pack for INVOLVE Members**

# **2011**

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Email: [admin@invo.org.uk](mailto:admin@invo.org.uk)**

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# INVOLVE

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**National Institute for  
Health Research**

August 2011

Dear member of INVOLVE

Many congratulations on your successful application to become a member of INVOLVE. A very warm welcome on behalf of your fellow members, the INVOLVE team and our colleagues at the National Institute for Health Research (NIHR).

I hope that this Information Pack will help you in getting to know us as an organisation and in understanding your role as a member. It is a resource that you can dip in and out of when you need it.

However our experience is that it is the network of people you are joining rather than pieces of paper from whom you will draw most support as you settle into your role. As a new member of INVOLVE you will have a named member of the Coordinating Centre team who will be available to you throughout the duration of your membership. You will also have the opportunity to ask one of the existing Working Group members to be your mentor, if you would find this helpful. As a Group we actively encourage people to ask questions, seek clarification, make suggestions and challenge our practices.

We are looking forward to working with you in promoting and advancing public involvement in research and hope that you enjoy your time as a member.

Warm regards,



Simon Denegri  
**INVOLVE Chair**

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Wessex House, Upper Market Street, Eastleigh, Hampshire SO50 9FD  
Tel: 02380 651088 E-mail: [admin@invo.org.uk](mailto:admin@invo.org.uk) Web: [www.invo.org.uk](http://www.invo.org.uk)

# Section 1: About INVOLVE

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## 1.1 Background

INVOLVE is a national advisory Group established in 1996. It was established to support public involvement in research\* in England, to improve the way that research is prioritised, commissioned, undertaken, communicated and used.

INVOLVE is funded by, and is part of the National Institute for Health Research (NIHR). It reports to the Director of Research and Development, Department of Health, England. We are one of the programmes of the National Institute for Health Research (NIHR). If you would like to find out more about the NIHR please visit their website: [www.nihr.ac.uk](http://www.nihr.ac.uk)

In 1999, a Coordinating Centre was established to support the work of the Group and to provide information, advice and support on involvement to the public, researchers, research funders and those working within the NHS.

The Group was originally called 'Consumers in NHS Research' and was set up as a standing advisory group on consumer involvement in NHS research. In 2001 the remit of the Group was widened to cover public health and social care research commissioned by the Policy Research Programme of the Department of Health. In 2003 the Group was renamed 'INVOLVE' with the strap line 'supporting public involvement in NHS, public health and social care research' to better reflect its extended remit.

We believe that the active involvement of the public in research can improve the way that research is prioritised, commissioned, undertaken, communicated and 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. At INVOLVE we seek to maximise the opportunities for public involvement in research and ensure support and guidance is available to researchers, research commissioners, research funders and the public who either wish to get involved or who are supporting others to become involved.

### \* Public involvement in research

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

- patients and potential patients
- people who provide care or support on an informal (i.e. unpaid) basis
- parents/ guardians
- people who use health and social care services
- disabled people
- members of the public and communities who are potential recipients of health promotion and public health programmes, and social care interventions

- groups asking for research because they believe they have been exposed to potentially harmful substances or products
- organisations that represent people who use health and social care services.

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 professionals in the research process, rather than the involvement 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.

## **1.2 INVOLVE's Strategic and Operational Plans**

We are currently in the process of developing our new Strategic Plan for 2012 – 2015. Our Strategic Plan will provide the overall direction for our work over the next three years. Our current Strategic Plan (2007 – 2011) can be viewed on our website (<http://invo.org.uk/pdfs/INVOLVEStrategicPlan2007081107.pdf>).

We also agree an annual Operational Plan which outlines activities and projects for each year to take forward our strategic objectives. Our Operational Plan for 2011 – 2012 can be viewed on our website (<http://www.invo.org.uk/pdfs/OperationalPlan2011-2012.pdf>).

## **1.3 Organisation and structure**

INVOLVE has a Main Group and three Working Groups. The Main Group reports and makes recommendations to the Director of Research and Development, Department of Health, England (see Figure 1 below).

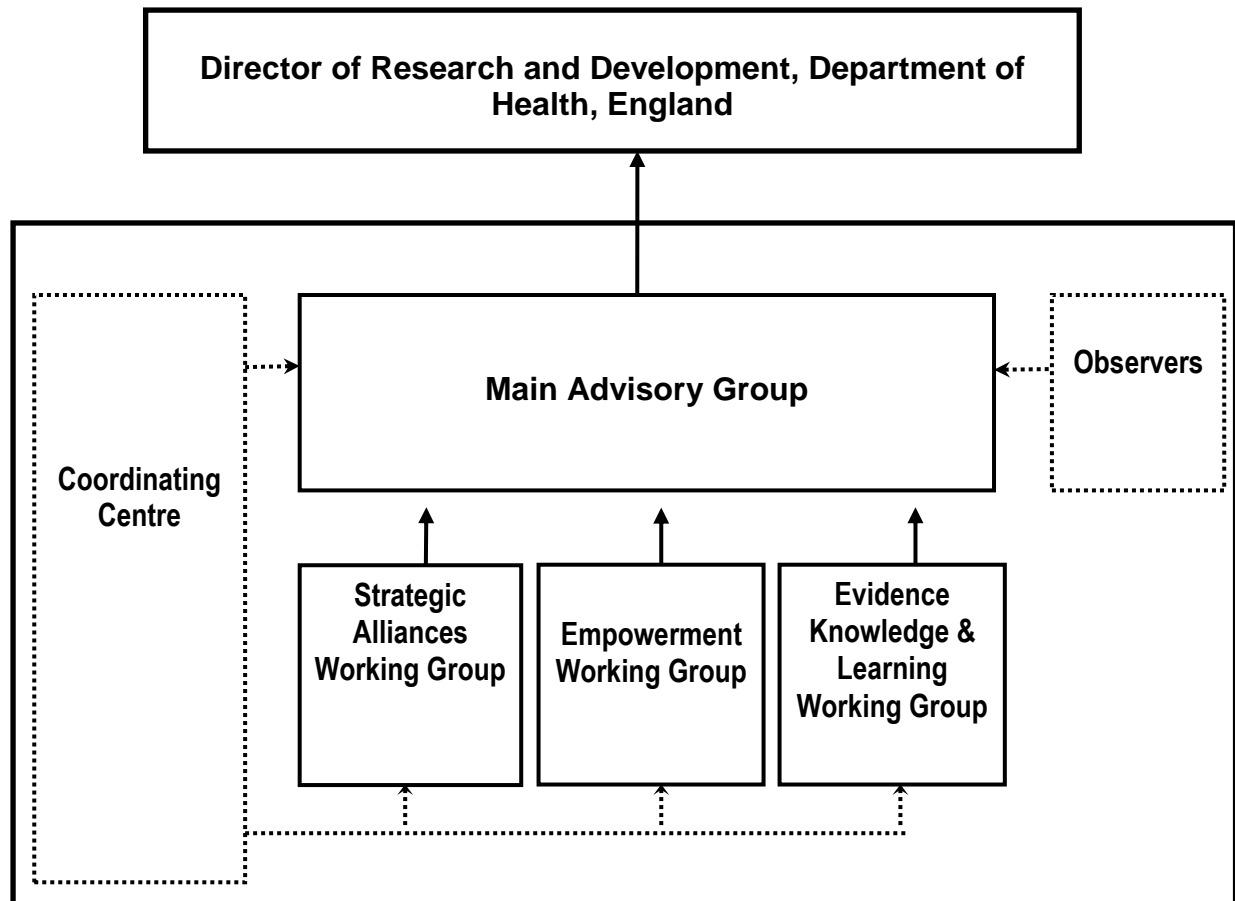
The Main Group addresses the broad issues of public involvement in research, receives reports from each of its Working Groups and makes recommendations to National Institute for Health Research organisations.

The three Working Groups each have a responsibility for leading on one of the strategic objectives of the Main Group. They are:

- Empowerment
- Evidence, Knowledge and Learning
- Strategic Alliances

(Appendix 1 lists the specific terms of reference for each of these groups).

The annual budget for the INVOLVE Group in 2011 / 2012 is approximately £130,000.

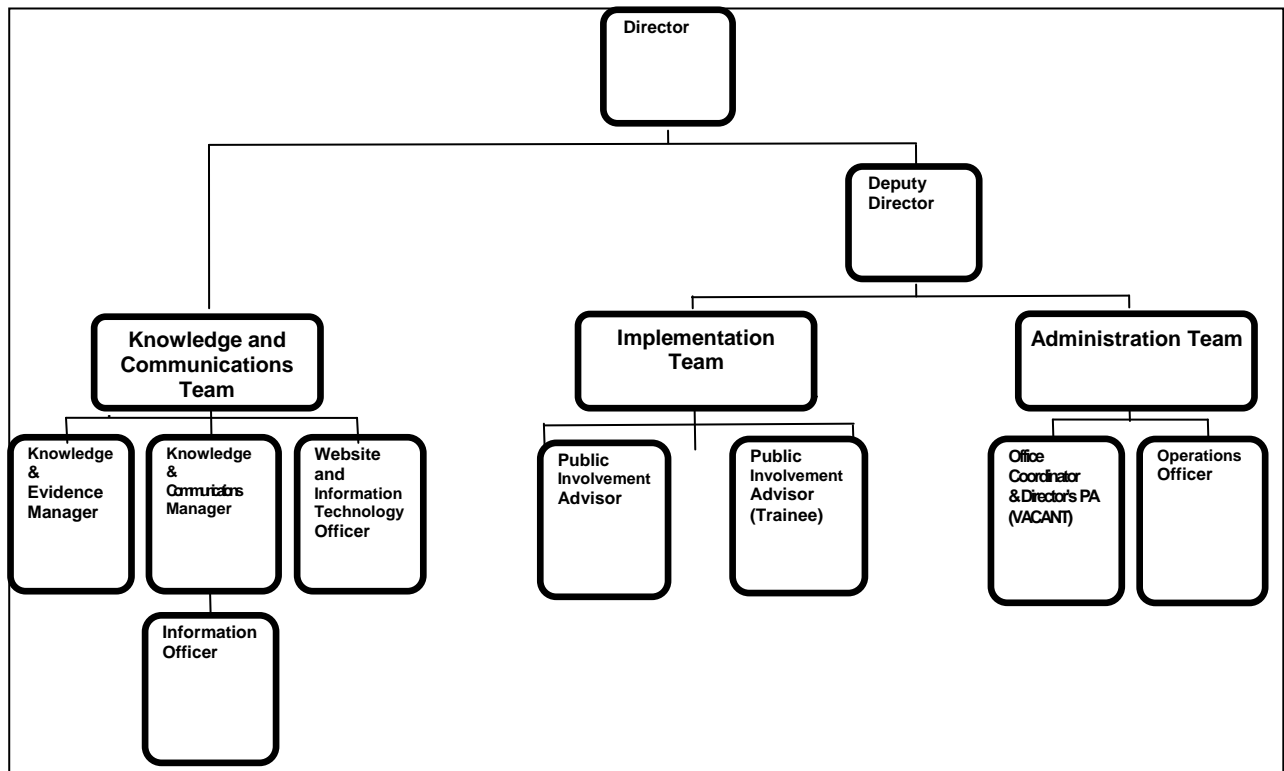


**Figure 1 – INVOLVE organisational structure**

## 1.4 INVOLVE's Coordinating Centre

INVOLVE has a Coordinating Centre to support the work of INVOLVE and to provide information, advice and support to the public, researchers and research funders. The Coordinating Centre is based in Eastleigh, Hampshire and is managed through the Faculty of Medicine at the University of Leeds. There are currently nine members of staff (five of whom work part time) to carry out and support the work of INVOLVE.

Figure 2 shows how the team at the Coordinating Centre is structured.



**Figure 2: Structure of Coordinating Centre team**

As well as supporting and taking forward the work programme of INVOLVE, the Coordinating Centre works to support and share learning on public involvement in research by:

- Encouraging and supporting public involvement within the Programmes and organisations of the National Institute for Health Research.
- Providing resources (e.g. publications, databases, web-based materials, guidance and advice on good practice) for researchers, research organisations and the public on how to involve members of the public in research.

- Publishing information to support members of the public who are thinking about getting involved in research.
- Managing the INVOLVE ([www.invo.org.uk](http://www.invo.org.uk)) and People in Research ([www.peopleinresearch.org](http://www.peopleinresearch.org)) websites.
- Building knowledge and understanding of the impact of public involvement in research and facilitating invoNET, a network of people interested in this area.
- Sharing information on public involvement in research through website databases, publications and a quarterly newsletter.
- Speaking about public involvement in research with researchers, research organisations and members of the public.
- Organising a biennial conference on public involvement in research.
- Working with others within the research community to raise awareness of public involvement in research.

The budget for the work of the Coordinating Centre, including staff salaries, is separate to the INVOLVE Group budget and is managed by the University of Leeds. The annual Coordinating Centre budget is approximately £620,000.

### **Working with others**

INVOLVE has developed links with a broad range of relevant academic, statutory, voluntary and private sector organisations and individuals and we continue to expand this network. These links provide a vital part of INVOLVE's intelligence and information, and underpin our ability to positively influence research and development in relation to public involvement.

# Section 2: Members of INVOLVE

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## 2.1 Membership

### Who are INVOLVE members?

INVOLVE currently has 25 members. Our members include a broad mix of people who use health and social care services, carers, people from voluntary organisations, health service and social care practitioners, managers and researchers.

Through their direct experience and knowledge of public involvement in research, our members help to identify issues that need to be addressed by INVOLVE and they can also help disseminate new ideas on policy and practice. By striving to maintain diversity in our membership, discussions reflect a wide range of perspectives. Members are recruited on the basis of their individual knowledge and experience, not as representatives of a particular constituency or group of people. However, we do expect members to have links with different groups or constituencies.

### How are INVOLVE members recruited?

New members are recruited through public advertisements and interviews to one of three Working Groups. Members are invited to join one of INVOLVE's three Working Groups on the basis of their ability to provide personal and/or professional expertise that will be valuable in moving INVOLVE's work forward.

Members of INVOLVE's Main Group are drawn from the three Working Groups. Main Group members are appointed by the Director of Research and Development, Department of Health, England, often following a recommendation from the Chair of INVOLVE.

In addition to Group members there are four observers on the Main Group. In 2011 these are from the Department of Health, the Social Care Institute for Excellence and the National Institute for Health Research Clinical Research Network Coordinating Centre. INVOLVE Coordinating Centre staff (see section 4.3) are also present in the Group.

### What qualities do INVOLVE members have?

Members have a wide range of backgrounds and experiences, but there are some key attributes that are common to all. These are:

- a commitment to public involvement in research
- knowledge or experience in health, social care and/or public health services or research
- an ability to demonstrate commitment to diversity and equality of opportunity

- a willingness to give time to the Group
- a willingness to engage constructively with other members of the Group to take forward our values and approach
- a willingness to promote the work of INVOLVE to others.

### **Duration of membership**

Successful applicants are offered membership of INVOLVE Working Groups for three years initially. This can then be renewed for a further three years subject to agreement between the member and the Chair of INVOLVE. During this period of time Working Group members are usually invited to become a member of the Main Group. Very occasionally, members are asked to stay on longer, but for most members the maximum term of office is six years.

### **Time commitments**

There are four Working Group meetings each year. Members are expected to attend at least three of these meetings, as well as giving additional time for the tasks outlined below.

The Working Group meetings are held mid-week. Three meetings are in London, with the fourth one held as part of an Awayday spread across two days, usually requiring an overnight stay outside London.

The Working Group meetings usually take place in the morning, with the Main Group meetings on the same day in the afternoon. For each meeting, members are also expected to set aside sufficient time to read the meeting papers beforehand.

Members of the Working Groups are encouraged to attend the Main Group meetings as well as their Working Group meetings (which always occur on the same day) and to contribute fully to the Group discussions. However they are not part of the decision making process of the Main Group and so are not able to vote.

In addition, members are expected to provide feedback on documents written by Coordinating Centre staff, attend events organised by the Group and review project proposals. They may also undertake other activities as a representative of INVOLVE. Occasionally members may take forward specific tasks arising from the Group discussions or volunteer to become a member of an advisory group for a project.

## **2.2 Supporting new members**

### **Induction and support**

All new INVOLVE Working Group members will be invited to an induction day before attending their first Working Group meeting. This induction day will help to prepare new members for their role and provide practical information about getting involved in INVOLVE activities (for example, style of meetings, format of Working Group papers, how to participate effectively, claiming expenses and payment of fees).

In addition to the induction day, all new members will be offered a mentor - an existing Group member - who will offer individual support on an ongoing basis for as long as it is found to be useful. New members are also linked to a named member of staff at the INVOLVE Coordinating Centre who will act as their main point of contact and support. Members will only be expected to take on additional tasks when they feel ready to do so.

### **The INVOLVE Coordinating Centre**

The Coordinating Centre team is available to support new members, both during and between meetings and will be pleased to provide any further information or assistance that you may need. Please do not hesitate to contact them (see section 4.3 for names and contact details).

The contact details for the Coordinating Centre are:

INVOLVE Coordinating Centre  
Wessex House  
Upper Market Street  
Eastleigh  
Hampshire  
SO50 9FD

Telephone: 023 8065 1088

Textphone: 023 8062 6239

E-mail: [admin@invo.org.uk](mailto:admin@invo.org.uk)

### **Individual requirements**

If you have any particular needs, for example, with respect to accessibility, diet or religious and spiritual beliefs, please let Sarah Bayliss at the Coordinating Centre know, so that suitable arrangements can be made. This may include sending out meeting papers in a different format or assisting with particular travel requirements. Sarah's contact details are:

Telephone: 023 8065 1088

Email: [sbayliss@invo.org.uk](mailto:sbayliss@invo.org.uk)

## 2.3 Expenses and payment for involvement

When getting involved with the work of INVOLVE we will cover your out of pocket expenses and, where appropriate, give you payment for your time, skills and expertise.

Full details of how we cover expenses and make payments are explained in the **'INVOLVE policy on payments and expenses for members of the public including INVOLVE Group members'** which is available from our website (<http://www.invo.org.uk/pdfs/INVOLVEinternalpaymentpolicyFeb2010.pdf>).

### Expenses

Expenses we will cover include:

- travel costs
- overnight accommodation (when required)
- food and non alcoholic drink – usually called subsistence (when necessary)
- alternative carer or child care costs
- costs of an accompanying carer, personal assistant or support worker.

The amount we can assist with some of these costs is limited. These rates are detailed in our policy. If you expect to incur any other out of pocket expenses during your involvement with INVOLVE, these must be discussed with a member of staff especially before you spend any of your own money. If not, you may not be able to have these costs covered.

Expenses can be covered in two ways.

- Paid for directly by INVOLVE in advance. This is our preferred option for expenses such as travel and accommodation.
- You can pay the costs yourself and be reimbursed afterwards. This is for claiming expenses such as food and drink. It is important that you provide a full itemised receipt (a credit or debit card bill alone is not sufficient).

In both cases you should tell a member of staff of your preferred option and give details of the expenses that will need to be covered. This is especially important if you prefer to be reimbursed and before you pay out any money yourself.

For further details of how to claim your expenses, please refer to section 2.3 of the INVOLVE policy on payments.

### Payment for involvement

If you are not receiving a full-time salary from public funds you could be offered payment for your involvement. You must also meet **both** of the following criteria:

- You are a **member of the public** (according to our definition in section 1.1)

- You are being asked to provide a public perspective on the work you do for INVOLVE.

If you are offered payment, the amount will depend upon the involvement activity and will always be agreed in advance. If you prefer not to receive payment you can choose not to. Examples of the types of activity that we offer payment for include:

- Attending INVOLVE Group meetings and other meetings such as project steering groups, consultations or seminars where views are specifically sought to benefit our knowledge base
- Commenting on the content and design of INVOLVE publications
- Presenting talks and workshops with INVOLVE Coordinating Centre staff.

Payment is subject to Income Tax and National Insurance liability; this is not deducted at source but should be declared to HM Revenue and Customs when appropriate.

For further details of how to claim payment, please refer to section 3.4 of the INVOLVE policy.  
(<http://www.invo.org.uk/pdfs/INVOLVEinternalpaymentpolicyFeb2010.pdf>).

## **2.4 Additional Information**

When you join INVOLVE as a new member, you will receive the following information in addition to this Information Pack:

- a form requesting your contact details
- INVOLVE's current Strategic Plan
- INVOLVE's current Operational Plan
- copies of the minutes of the most recent meeting of your working Group and the Main Group
- a list of agreed dates of members' meetings and any other INVOLVE events that have been scheduled
- a Declaration of Interests form
- INVOLVE policy on payments and expenses for members of the public including INVOLVE Group members.

If you require any further information or if you find that any information is missing, please contact the Coordinating Centre (see section 2.2 for contact details).

# Section 3: Group meetings

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## 3.1 Group and Working Group meetings

The Main Group and three Working Groups meet three times a year to review progress and agree future actions. In addition to these regular meetings, there is also a two day awayday each year for all INVOLVE members.

### Autumn awayday

Once a year, we have a two day 'awayday' for all INVOLVE members and observers which also incorporates a Working Group meeting. During these 'awaydays' the members:

- review current action plans at the mid-way point of the financial year
- identify possible areas of work for the next financial year
- discuss broader issues relevant to INVOLVE and public involvement in research.

The outcomes of the awaydays are to inform the operational planning for the following year and to identify Working Group priorities.

### Winter meeting

Priorities for work are discussed at the winter Group meeting, in preparation for the year ahead. The Main Group discusses and agrees these priorities in principle.

### Spring meeting

At the spring meeting the Operational Plan for the forthcoming year is discussed and agreed. It is then formally agreed by the Department of Health. As the Group endeavours to respond to issues as they arise, some of the plans for action may change or develop as the year progresses.

### Summer meeting

This meeting reviews the progress of INVOLVE projects and activities so far that year.

### Budgets

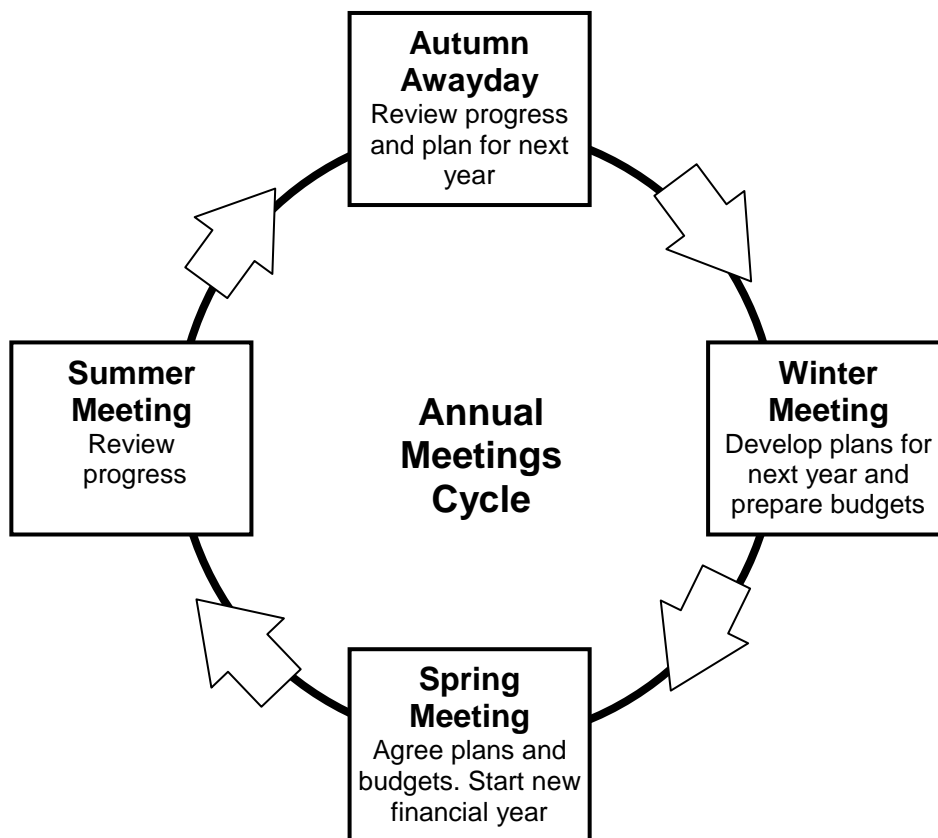
The annual budget for the INVOLVE Group is approximately £130,000. This budget is for all activities and work projects conducted through the Group. Anticipated underspends can be diverted to other projects prior to the end of March, but any underspent money will be reabsorbed by the Department of Health after that time.

## Decision making process

The proposed activities in the Operational Plan are developed through discussion in the Working Groups. Chairs of the Working Groups make recommendations about which activities should be included in the Operational Plan for each year. The draft Operational Plan is discussed and agreed collectively by the Working Group Chairs. The Chair of INVOLVE and the Department of Health make the final decisions on the Operational Plan. The Working Group Chairs, Chair of the Main Group and Department of Health observer meet with Coordinating Centre staff twice a year to discuss the work of INVOLVE and the Operational Plan.

## Planning cycle

Figure 3 shows the usual calendar of meetings for each financial year:



**Figure 3 – Annual cycle of meetings**

## 3.2 How the meetings are run

Usually, the three Working Groups meet in the morning and the Main Group meets in the afternoon of the same day. The Chair of each Working Group is a member of the Main Group and reports back on the activities of their Working Group to the Main Group meeting.

In between meetings, much of the work is carried out and/or managed by the Coordinating Centre team, although Group members may take on certain tasks. Each Working Group has a designated member of the Coordinating Centre team to support them, as follows:

Main Group:	Sarah Buckland
Empowerment:	Lucy Simons
Evidence Knowledge and Learning:	Maryrose Tarpey
Strategic Alliances:	Sarah Howlett

### Agendas and papers

Each meeting has an agenda which lists the items that are going to be discussed at the Working Groups and Main Group meetings. The Chairs set the agenda ahead of the meetings with assistance from the relevant Coordinating Centre team member. If you wish to add items to the Main Group agenda, or have suggestions for agenda items, please speak to the Chair or Director of the Coordinating Centre four to eight weeks before a meeting. Alternatively, you can raise any additional issues at the meeting itself. The last item of the agenda, termed 'Any Other Business', is designed for this purpose.

The agenda will be sent to you with relevant papers on the topics that are going to be discussed. All papers are 'open' and can be discussed with others unless they are marked 'confidential'. They will be sent by email one to two weeks before each meeting to give you time to read them. If you have any queries about the content of the papers please do not hesitate to contact the Coordinating Centre link for your Working Group. They will be happy to give you any additional information. Please also let the Coordinating Centre know if you would prefer to be sent a printed copy of meeting papers.

### The procedure at meetings

The Chair of each Working Group is responsible for running the meetings. It is the Chair's job to:

- start the meeting
- introduce each item on the agenda, putting it into context and explaining the purpose of the discussion
- keep the meeting to time and monitor the pace so that there is time for all the items on the agenda to be discussed
- ensure everyone can contribute and no one dominates the discussion
- keep the discussion to the point

- conclude each topic by summarising what has been agreed or decided
- identify individuals to take forward specific pieces of work
- close the meeting.

The meeting always begins by introducing any new members to the Working Group, receiving apologies from those unable to attend, reminding members of the ground rules (Appendix 4) and giving people the opportunity to declare any potential conflict of interests.

Then the minutes from the last meeting are reviewed to check for accuracy, as well as to ensure that everyone is aware of the decisions that have been recorded, and to follow up on any actions since the last meeting. After this, discussion of the main items on the agenda begins.

The members of the Coordinating Centre team who provide secretariat support will take minutes at the Working Groups meetings. The minutes summarise the conclusions of discussions and the agreed actions. Each action identifies a discrete task to be carried out by a particular individual or group of people. Once agreed by Working Group members at the subsequent meeting, the minutes are also made available on the INVOLVE website ([http://www.invo.org.uk/INVOLVE\\_Minutes.asp](http://www.invo.org.uk/INVOLVE_Minutes.asp)).

### **The ‘culture’**

The ethos of INVOLVE is to value, encourage and support all members’ contributions.

- If you are unclear about what anyone is saying, do ask them to explain it. It is likely that others in the group will also be unclear, and by asking you will be helping them as well.
- If there is anything more generally you do not understand then do ask for it to be explained to you either at the time or later by Coordinating Centre staff. INVOLVE produces a jargon buster that may help you to understand some of the many acronyms used in this field.
- If you think that something being said or done is wrong, makes questionable assumptions, or needs to be qualified, then please do raise it at the meeting or later if you prefer with the Chair of the Group, your mentor or your Coordinating Centre team link.
- Please do offer any comments or ideas which you think may contribute to the discussion. What you want to say may be very important to others in the group and very relevant to the issues under discussion.
- If you would like additional information, training or support to help you to participate more fully, please ask a member of the Coordinating Centre.
- Do try to be clear about the views you are offering. Are they your personal views, or are they what you think is representative of a particular group of people, or what you think to be the views of people in general? Each has its value, so think

about which is the most helpful contribution to the issue being discussed at any time.

- One of our working principles is a belief in the values of inclusion, diversity and equity to challenge assumptions regarding the potential of the public to contribute to research and development. We are committed to supporting and promoting the involvement of groups and communities who have often been excluded from the research process, for example, people with learning difficulties, older people and those from minority ethnic communities. We are also committed to improving our own knowledge and understanding of the barriers faced by such groups and communities. If you think that we are not working in a way that genuinely reflects this commitment then please challenge us. We are an organisation that wants to learn.

# Section 4: Who's Who at INVOLVE

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## 4.1 Summary table: Group Members and Observers




Chair: Simon Denegri




<b>Strategic Alliances</b>	<b>Empowerment</b>	<b>Evidence Knowledge &amp; Learning</b>
<p><b>Chair:</b> <b>Stuart Eglin</b></p> <p>Richard Baker Sue Banton Poonam Jain Maria Palmer Mark Petticrew Laura Serrant-Green Christine Vial</p>	<p><b>Chair:</b> <b>David Evans</b></p> <p>Ade Adebajo Rosemary Barber Ann-Louise Caress John Hughes Hugh McLaughlin Patsy Staddon</p>	<p><b>Chair:</b> <b>Sophie Staniszewska</b></p> <p>Louca-Mai Brady Jim Elliott Alison Faulkner Ray Fitzpatrick Vanessa Pinfold Diana Rose Tony Sargeant Tracey Williamson</p>




**Observers:**




Kay Pattison, Department of Health  
 Peter Fleischmann, Social Care Institute for Excellence  
 Roger Steel, Clinical Research Network Coordinating Centre  
 Tony Williams, Department of Health




## 4.2 Directory of Members and Observers

<p>Ade Adebajo</p> 	<p>I am a clinician involved with research at Barnsley Hospital and I lead a South Yorkshire Musculoskeletal Research Network. I also have a wider research role across Barnsley Hospital including membership of Barnsley Hospital Research Governance Committee. I am an Honorary Senior Lecturer and an Associate Director of Teaching for the University of Sheffield Medical School. I am Chair of the South Yorkshire Patient and Public Involvement Strategy Group. I am Clinical patient and public involvement lead for both the South Yorkshire Comprehensive Local Research Network and the South Yorkshire Collaboration for Leadership in Applied Health Research and Care. I am also a member of the Health Services Research National Specialty Group for the NIHR Comprehensive Research Network and of the Yorkshire and Humber Research Design Service Patient and Public Involvement Forum. I have a particular interest in helping hard to reach groups to participate in all aspects of research.</p>
<p>Richard Baker</p> 	<p>I work for the University of Leicester in the Department of Health Sciences. I am a GP by profession, but have been interested for a long time in ways to improve the quality of health care, and in consequence have spent a fair amount of time investigating patients' experiences of care. I have been involved in studies that have included patients as co-applicants, as part of the research team, and as advisors. My present role is as Director of the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Leicestershire, Northamptonshire and Rutland. This is a large research programme planned to improve the use of research evidence by NHS organisations.</p>
<p>Sue Banton</p> 	<p>I am founder and Director of STEPS, a national charity for people with lower limb conditions. I became involved with research projects through STEPS and have worked with parents, carers and young people in quantitative and qualitative research projects; both as a member of focus groups and on steering committees. I have a strategic role in promoting public involvement in research as a member of the Medicines for Children Research Network and the British Paediatric Surveillance Unit.</p>




<p>Rosemary Barber</p> 	<p>I am an Honorary Senior Research Fellow at the University of Sheffield, School of Health and Related Research (SchARR), Public Health, where I jointly lead a research theme on public involvement in health and social care research. I became interested in public involvement through my work as a clinical psychologist and researcher in adult mental health. Current research interests include investigating ways of evaluating the impact of public involvement, and working with service user co-investigators to explore acceptable and unacceptable aspects of psychological interventions, and ways of improving services for people with long-term depression. I teach undergraduates and postgraduates about public involvement and am also a member of the Medical Research Council's Public Panel.</p>
<p>Louca-Mai Brady</p> 	<p>I am a freelance researcher with a particular interest in the involvement of children and young people in research. Until recently I was a Senior Research Officer at the National Children's Bureau Research Centre, where I recruited, trained and supported young people's involvement as young researchers and advisors, including supporting young people-led research and involvement in public health and clinical research. Recent projects include training paediatric researchers in public involvement, managing a young people's reference group on public health research and training and supporting a group of young disabled researchers. My background is in social care and disability research, with a particular interest in user involvement and participative methods.</p>
<p>Ann-Louise Caress</p> 	<p>I am a Senior Lecturer in Nursing at the University of Manchester and Head of the Long Term Conditions and Self Management Research Team. I have been actively involved in research since 1988 and my research focuses on living with, and clinical management of, long-term health problems. I have research expertise in service user participation. My particular areas of clinical interest are respiratory and renal disease. I was a contributor to the National Health Service Executive/Asthma UK National Clinical Asthma Research Strategy and Chair of the Working Group which developed the Royal College of Nursing Position Statement on promoting nursing research in healthcare organisations. I have strong research collaborations nationally and internationally.</p>




<p>Simon Denegri</p> 	<p>In June 2011 I joined the Ovarian Cancer Action as their Chief Executive. Before that I was Chief Executive of the Association of Medical Research Charities (AMRC) from 2006-2011. My background is in campaigning and communications and has included roles such as Assistant Chief Executive and Head of Public Affairs at the Alzheimer's Society in 2002-2003 and 1992-1997 respectively. The latter coincided with the formation of the Society's Quality Research in Dementia (QRD) public involvement programme. Since my arrival at AMRC the Association has actively promoted the merits of public involvement to its members including our 'Natural Ground' report in 2009 and recent route-map to public involvement co-produced with TwoCan Associates. I am a member of the UKCRC Board, NIHR Advisory Board and also on the patient sub-group of the Royal College of Physicians 'Medicines Forum.'</p>
<p>Stuart Eglin</p> 	<p>I am the Director of Research &amp; Development for the North West Strategic Health Authority where I manage a team who work on building research activity in the region, supporting public involvement and strategic leadership. Since 1997 I have worked to support public involvement in research. I established the North West Users in Research Advisory Group. Recently I have been leading work to establish a new region-wide forum to share good practice, support training and provide support to people in this field. I have had an active interest in public involvement and empowerment issues since I began my career in the charitable sector. I am an Honorary Senior Research Fellow at Manchester Business School. I have also held honorary posts at Lancaster University and Liverpool John Moores University and have been an external advisor to Macmillan Cancer Support and NHS Institute for Innovation and Improvement.</p>
<p>Jim Elliott</p> 	<p>In 2010 I started working as a freelance research management consultant in health and social care. Prior to that I managed and developed research at the UK-based cancer care charity Macmillan Cancer Support and for the Department of Health and NHS in the East of England. In my current work I look for opportunities with my clients to promote public involvement in their research. At Macmillan I developed a research funding scheme with public involvement at its heart, as well as promoting involvement widely with researchers and funders. I have experience as a cancer carer and have lost a number of close family and friends to cancer. This was one of the main motivations for working for Macmillan and for my interest in the involvement of patients and the public in research and in the development and management of health services.</p>




<p>David Evans</p> 	<p>I am a Reader in Applied Health Policy Research at the University of the West of England, Bristol. I undertake research on partnership, participation and involvement in health, including involvement in research. I am also the Programme Leader for the Masters in Public Health. I became interested in promoting involvement in health in the 1980s when I was a nurse but also discovered I had a long term condition that required frequent interactions as a patient. My experience was that in those days, health professionals generally did not welcome shared decision making. As I became involved in research, my commitment to involvement naturally led me to support involvement in research.</p>
<p>Alison Faulkner</p> 	<p>I am a mental health service user, and work as a freelance researcher, writer and trainer. I have worked in the mental health field for over 20 years and for most of the national mental health charities. Much of my work has involved training and supporting service users to become involved in research and I have a particular interest in user-controlled research. I have written and presented on public involvement in research as well as on various aspects of mental health policy, service delivery and personal experience.</p>
<p>Ray Fitzpatrick</p> 	<p>I am Professor and Head of the Department of Public Health, University of Oxford. Much of my research over thirty years has focused on patients' and users' perspectives on health and their views about care and outcomes received from services. My first formal role in supporting user involvement was when, as a member of council for the Medical Research Council, I set up and chaired a Consumer Liaison Group to provide public and user feedback on the work of MRC. I am National Programme Director for the National Institute for Health Research, Health Services Research and have been working with colleagues in INVOLVE to launch and fund a research programme in patient and public involvement in health research.</p>

<p>Peter Fleischmann</p> 	<p>I work for the Social Care Institute for Excellence (SCIE) as Head of Participation. My job is to make sure that everything SCIE does involves users and carers. My job also involves producing reports, leaflets, films and websites about involvement. I became involved in public involvement in research because of my experiences of using mental health services. Public involvement in research is important to me because I think that people who have direct experience of using health and social care services have a perspective that can be absent from traditional research. At SCIE we often work with user-led groups, carer groups and user researchers. If we commission work from universities we ask them to tell us how they are going to involve service users and carers. Before SCIE I worked at the Service User Research Enterprise (SURE) on several user-led pieces of research.</p>
<p>John Hughes</p> 	<p>Following a career in the Probation Service, I was appointed as a member of the UK Clinical Research Collaboration (UKCRC) PPI subgroup in 2008. The group's task was to support the development of PPI within the UKCRC and with its partners. My experience there included steering group membership of PPI related research projects and the development of strategy. A record of the development of PPI and lessons learned were subsequently published by UKCRC in 2009. I remain a PPI member of the UKCRC Board and contribute a PPI perspective to the Senior Investigators programme. This year I contributed to the User Controlled research report and film and the service users' "Count us In" workshop and report. I also acted as one of the PPI representatives on the Health Service Research and Involve Commissioning Board.</p> <p>Throughout my career I have had a particular interest in promoting user and public involvement in the governance of public services and research, in the belief that such involvement helps ensure both their relevance and their transparency.</p>
<p>Poonam Jain</p> 	<p>I am a carer and also a counsellor for Relate. I also work part-time in a local authority in a research, planning and service commissioning capacity, which involves encouraging a user voice in the development of services which affect them. As a lay member I serve on the London regional funding committee for Research for Patient Benefit, and on the steering group for evaluating polyclinics.</p>

<p>Hugh McLaughlin</p> 	<p>I am currently a Professor in Social Work based at Manchester Metropolitan University. Prior to moving to academia I was a social worker, team manager, service manager and assistant director of social services. I have always been interested in service user involvement and in recent years my research has focused on meaningful involvement, epistemological underpinnings, strengths and limitations and keeping service user involvement in research honest.</p>
<p>Maria Palmer</p> 	<p>I have been Director of Research and Clinical Effectiveness for the United Bristol Healthcare NHS Trust (a medium-sized teaching hospital associated with the University of Bristol) for five years. I am a pharmacist by profession and have been personally involved in healthcare research, ranging from laboratory studies to patient-focussed clinical research, over the past 25 years. As I have been involved in implementing major changes in the management and strategic direction of research in my organisation, it has become clear that most healthcare researchers find it very difficult to develop strategies to meaningfully involve the public and service users in their research. Part of my role is to help them achieve this.</p>
<p>Kay Pattison</p> 	<p>I manage the contract for the INVOLVE Coordinating Centre. I have a very genuine interest in the work undertaken by INVOLVE and am particularly keen to ensure that it continues to have an impact on NIHR National Programmes.</p>

<p>Mark Petticrew</p> 	<p>I am a public health researcher based at the Public and Environmental Health Research Unit at the London School of Hygiene and Tropical Medicine, where I have a Chair in Public Health Evaluation. My work involves carrying out studies into the links between government policies and health (and health inequalities). For example, we are currently investigating whether investing in public housing improves the health of tenants, and I also carry out research into the effects of transport, employment and other policies on health. All of these studies have involved substantial links with non-academic colleagues, such as policymakers. Where possible we also endeavour to involve local communities in the research, and in disseminating the subsequent findings</p>
<p>Vanessa Pinfold</p> 	<p>I am the Deputy Director of Knowledge and Learning for the mental health charity Rethink. My role is to oversee our research team, learning and young people's team and the Rethink Advice and Information Service (RAIS). In all our work we involve people affected by mental health problems in different ways and we are committed to following and establishing best practice. I first became interested in consumer involvement in research while I was working at the Institute of Psychiatry on studies addressing stigma and discrimination. Current research projects include lay review work within the Cochrane Schizophrenia Partnership, methodological development on studies that adopt a co-production approach with service user researchers and a research panel of service user and carer volunteers.</p>
<p>Diana Rose</p> 	<p>I am a social scientist and mental health service user. I started to work in the field of user-led research in mental health in a London charity where I developed the model of User Focused Monitoring (UFM). In 2001 I went to the Institute of Psychiatry, King's College London where I am now co-director of the Service User Research Enterprise (SURE). I have developed models of patient-centred systematic reviews and participatory research in a mental health context. My journey back from the blight of 'community care' started with my involvement in the UK user/survivor movement and I remain determined to maintain those roots.</p>

<p>Tony Sargeant</p> 	<p>I am a long term user of heart failure services and have participated as a subject in related clinical trials. Through this I became interested in the contribution of health research to improve health outcomes. I have been a public patient member of health research programmes at national and regional level with a particular interest in the impact of research on clinical practice. I am an active member of my Local Involvement Network where I work to improve patient and public involvement in forthcoming health service reforms and service changes.</p>
<p>Laura Serrant-Green</p> 	<p>I am a director of research and enterprise in the School of Health and Wellbeing at the University of Wolverhampton where I manage a team of researchers who carry out studies into health and social care improvement. A key focus of this work involves projects which aim to reduce health inequalities and improve health and social care services to benefit the diverse communities and workforce within society. Additionally I have been an advisor to government departments nationally and internationally around ethnicity and health, sexual health and nursing professional development. Part of my role is to encourage researchers to meaningfully involve marginalised groups and communities in their research and I have a particular interest in developing capacity and capability in user-led research.</p>
<p>Patsy Staddon</p> 	<p>I am a survivor of the alcohol services and a user of the mental and neurological health services. I am a researcher and a Visiting Fellow at the University of Plymouth, with a special interest in alternative approaches to the alcohol use of disadvantaged groups, particularly lesbian women. I want to find ways to change public thinking about the use of substances, and the kind of treatment and support currently on offer. I belong to a variety of service user organisations such as Shaping Our Lives, the national service user organisation, and Women's Independent Alcohol Support. This group developed out of my service user led research, and ran for several years.</p>

<p>Sophie Staniszewska</p> 	<p>I Chair the Evidence, Knowledge and Learning group of INVOLVE. I lead the patient experiences and involvement programme at the RCN Research Institute, based in the School of Health and Social Studies at the University of Warwick. Until recently I was Director of Research at the NHS Centre for Involvement seconded from the RCN Research Institute. I also work closely with the Royal College of Nursing to take forward the PPI agenda for nursing. I have also carried out a range of externally funded studies looking at different aspects of users' experiences of healthcare and patient and public involvement, supervise PhD students and conduct reviews for a range of journals and funding bodies.</p>
<p>Roger Steel</p> 	<p>I am Patient and Public Involvement Manager at the NIHR Clinical Research Network Coordinating Centre. My role is broad but essentially concerns supporting and developing patient and public involvement across the Clinical Research Networks. To this end I liaise with the PPI Leads in the Topic Clinical Research Networks and I am also involved with development of PPI in the Comprehensive Clinical Research Network and contribute to the Primary Care Research Network. There are also strategic elements to my work and during 2010 I have had a Project Coordinating role in a review of PPI in the Clinical Research Networks called 'The Way Forward'. My involvement in this work continues into the implementation of the recommendations stage of the project through 2011.</p>
<p>Christine Vial</p> 	<p>My background is in education, working with adults returning to education and I am a qualified counsellor. After health problems (including M.E.), and being a carer for my elderly parents, I became a member of the Royal College of Physicians' Patient and Carers Network. Later, having become interested in user- engagement in clinical research, I joined the UK Clinical Research Collaboration public and patient involvement pilot group. I became a member of INVOLVE in January 2010.</p> <p>I also sit on National Institute for Health Research sub-panels for award of programme grants and am a member of the Enfield Local Involvement Network.</p>

Tony Williams



I work in the Research and Development Directorate of the Department of Health (DH) and represent the National Institute for Health Research (NIHR) as an observer at meetings of the main INVOLVE Group. I am responsible for the day to day management of the contract for the INVOLVE Coordinating Centre, which provides support to INVOLVE, working with Dr Kay Pattison the DH contract lead.

Tracey Williamson






I currently work as a Research Fellow in the field of Public Engagement/User Involvement in Research at Salford University. My background is as a nurse in the NHS most recently as a Nurse Consultant and I worked mostly in rehabilitation and care of older people settings. Most of the public I work with tend to be older adults but not exclusively and they tend to be involved in roles such as study advisers or co-researchers. My research is generally participative and concerns improvement of patient experience and evaluation or development of health and social care services, but I am also working a lot with 'assistive technology' researchers (e.g. electronic walking aids, technology integrated in clothing for older people etc.) and so I am interested in public involvement in design. I sit on the INVOLVE Evidence, Knowledge and Learning working group and the main Group. I am also a public involvement adviser of the North West Research Design Service which supports applicants seeking research funding. I believe the public have a right to be involved in research and that they add value to it.




### 4.3 The Coordinating Centre Team




Below is an alphabetical list of members of the Coordinating Centre, along with their job titles and contact details.

<b>Name</b>	<b>Job Title</b>	<b>Contact Details</b>
Sarah Bayliss	Operations Officer	sbayliss@invo.org.uk 023 8062 6236
Sarah Buckland	Director	sbuckland@invo.org.uk 023 8062 6232
Paula Davis	Information Officer	pdavis@invo.org.uk 023 8065 1088
Helen Hayes	Knowledge and Communication Manager	hhayes@invo.org.uk 023 8062 6235
Sarah Howlett	Public Involvement Advisor (Trainee)	showlett@invo.org.uk 023 8062 6231
Lucy Simons	Public Involvement Advisor	lsimons@invo.org.uk 023 8062 6237
Maryrose Tarpey	Knowledge and Evidence Manager	mtarpey@invo.org.uk 023 80 626234
Gill Wren	Website and Information Technology Officer	gwren@invo.org.uk 02380 626238
Philippa Yeeles	Deputy Director	pyeeles@invo.org.uk 02380 626233

## Introductory statements from the Coordinating Centre team

<p>Sarah Bayliss</p> 	<p>I joined the INVOLVE Coordinating Centre in 2002 and work as part of the administration team. I have day to day operational responsibility for key aspects of the functioning of the INVOLVE Coordinating Centre office, including policies and procedures, premises, developing financial management systems and health and safety. My other duties include arranging travel and accommodation for staff and INVOLVE Group members, purchasing of all goods and services and producing financial budgetary reports.</p>
<p>Sarah Buckland</p> 	<p>I am the Director of the INVOLVE Coordinating Centre where I have worked since 1999. I have overall responsibility for the work of the Coordinating Centre and work closely with the Chair of INVOLVE. Prior to becoming Director, I managed the Research Section of the Help for Health Trust, a health information charity based in Winchester. During this time I became increasingly committed to the importance of public involvement in research, working with service users and carers on several projects. My background is in the social sciences and I carried out mainly qualitative, policy related research in the areas of health and social care over a period of approximately 20 years. During this time I worked for several universities, the Department of Health, the Health Education Authority and West Sussex Social Services.</p>
<p>Paula Davis</p> 	<p>I was appointed as INVOLVE's Information Officer in July 2011. As part of the Knowledge and Communications Team, I am responsible for ensuring the INVOLVE website content is accurate and regularly updated, and for liaising with organisations and individuals to generate and disseminate knowledge about public involvement in research. Before coming to INVOLVE, I worked at the University of Southampton for one of the Higher Education Academy Subject Centres. My role there included researching, commissioning, writing and editing content for a variety of reports, publications and websites, servicing advisory group meetings, and managing European funded projects and networks.</p>

<p>Helen Hayes</p> 	<p>I am the Knowledge and Communications Manager at the INVOLVE Coordinating Centre. I am responsible for ensuring that the knowledge and evidence we have on public involvement in research is reflected in practical information for research commissioners and funders, researchers and members of the public. I manage the INVOLVE website, databases and publications and facilitate the sharing of knowledge and good practice. My interest in public involvement in research has developed from my background in health information and health promotion.</p>
<p>Sarah Howlett</p> 	<p>I joined INVOLVE in September 2010 as a Trainee Public Involvement Advisor where I support work which is identified in the operational plan. This can include assisting at INVOLVE events and supporting the development of public involvement activities in NIHR programmes. I also provide secretariat support to the Strategic Alliances working group. I work alongside INVOLVE Coordinating Centre team members to increase my knowledge and skills in developing and supporting public involvement in research. I have previously worked in health promotion and public health research.</p>
<p>Lucy Simons</p> 	<p>I joined the INVOLVE Coordinating Centre in September 2008 as a Public Involvement Advisor. I work with the Empowerment working group supporting a range of projects. Recently this has included developing information about user-controlled research (including some short films), payments for involvement, training and support for public involvement in research and seldom heard groups and people. I also coordinate the shared learning group for the public involvement leads in the Research Design Services.</p> <p>I have over ten years experience of mental health services research including evaluating service user involvement in health professional education and support for self-care in mental health services.</p>

<p>Maryrose Tarpey</p> 	<p>I work full-time for the INVOLVE Coordinating Centre and have the lead responsibility for the identification and generation of knowledge and evidence of public involvement in research.</p> <p>My other responsibilities include:</p> <ul style="list-style-type: none"> <li>• supporting the development of public involvement in clinical research which includes working with the UK Clinical Research Networks</li> <li>• providing secretariat and project management support to INVOLVE's Evidence, Knowledge and Learning working group</li> <li>• working on a variety of projects related to INVOLVE's core activities including planning the biennial national conference.</li> </ul>
<p>Gill Wren</p> 	<p>As Website and Information Technology Officer I am responsible for providing IT support to the Coordinating Centre and updating and developing the INVOLVE website and databases.</p> <p>Key areas of activity include:</p> <ul style="list-style-type: none"> <li>• Maintenance of IT within the Coordinating Centre</li> <li>• Providing IT support to Coordinating Centre staff</li> <li>• Providing IT support to external users</li> <li>• Updating the INVOLVE website and databases</li> <li>• Monitoring website usage and Coordinating Centre staff activity</li> </ul>
<p>Philippa Yeeles</p> 	<p>I joined the INVOLVE team as Deputy Director in 2010. I lead on providing support to the National Institute for Health Research programmes and the Policy Research Programme on public involvement in research commissioning and am also responsible for overseeing the operation of the Coordinating Centre.</p> <p>My interest in public involvement in research developed from my experience as a social worker supporting mental health service users to challenge, influence and re-organise the provision of local services. I have an 'eclectic' work history that includes some years working in catering, festival management, film and video production - before I discovered the world of public involvement in research.</p>

## Appendix 1: Terms of references of INVOLVE

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### Main Group

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 of Research and Development at the National Institute for Health Research on progress, and make recommendations to the NIHR about the development of public involvement in research.

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### Evidence, Knowledge and Learning

1. To promote active use of the evidence/ knowledge base.
2. To facilitate communication and debate among those building this evidence/ knowledge base.
3. To promote understanding of the diverse sources of this evidence/ knowledge base.
4. To network actively with, and undertake collaborative work with, other organisations, groups and individuals whose work is complementary and relevant to our objective.
5. Within INVOLVE to foster a culture of organisational learning with regards to this evidence/knowledge base.
6. On an ongoing basis, to identify the education, training and development needs of INVOLVE members required to meet INVOLVE's objectives, and pursue strategies to meet these needs.
7. To promote evaluation on the impact/effectiveness of public involvement in research.

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## **Empowerment**

1. To identify, develop, and promote opportunities for the public to become actively involved in health, social care and public health research.
2. To identify, develop and promote ways to overcome barriers to the public in becoming actively involved in research.
3. To identify, develop, and promote ways to enable traditionally marginalised and seldom heard groups affected by research to play an equal and active role in research.
4. To establish and monitor the performance of a comprehensive accessibility strategy for INVOLVE.
5. To identify, develop, promote and uphold the values of good practice in public involvement in research.
6. To produce and disseminate relevant, easily used and accessible guidance, information and communication to support 1 – 5.
7. To ensure that the Empowerment working group's values and objectives are understood and supported by the work of INVOLVE as a whole.
8. To network actively, and to undertake collaborative work with other organisations, groups, and individuals whose work and aspirations are complementary to the work of Empowerment.

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## **Strategic Alliances**

1. To build links with research commissioners and funders of NHS, public health and social care research, such as the Department of Health and the Research Councils, to ensure that they actively promote public involvement in research.
2. To develop alliances with the NHS, public health and social care bodies to ensure that they actively promote public involvement in research.
3. To work with regulators of research, such as the National Research Ethics Service (NRES) to ensure that the regulatory process supports the active involvement of the public in research.

4. To form alliances with other organisations that support or promote NHS, public health and social care research, such as the academic sector and educational institutions, the James Lind Alliance, United Kingdom Clinical Research Collaboration (UKCRC) and Social Services Research Group (SSRG), to ensure that they actively promote public involvement in research.
  5. To support the development of resources which facilitate strategic alliances e.g. the conference, discussion forum, workshops etc.
  6. To support the development of guidelines and publications which facilitate greater public involvement in research.
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## Appendix 2: Role description and person specification

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This section details the key tasks and essential criteria for members of INVOLVE working groups.

### Role description

The key tasks required of a Working Group member are as follows.

- To prepare for, and participate in Working Group / Main Group meetings. This will include reading meeting papers that may be lengthy and/or complex.
- To advise the Chair of the Working Group / Main Group in identifying and prioritising INVOLVE work.
- To provide advice and comment on the work being carried out by or on behalf of INVOLVE.
- To provide ideas and suggestions, contributing new areas of experience and knowledge to the work of INVOLVE.
- To assist the Working Group / Main Group Chair in ensuring that the work identified and carried out is within the remit of INVOLVE.
- To respect any requests for confidentiality and to declare any conflicts of interest if these arise.
- To undertake activities for the Group between meetings. This is likely to include some or all of the following:
  - membership of a project advisory group
  - attending events organised by INVOLVE (for example, our national conference or a particular seminar or workshop)
  - attending meetings or events on behalf of INVOLVE
  - giving talks or running workshops
  - other relevant activities as appropriate.
- To promote the work of INVOLVE to others.
- When appropriate, provide support to new members of the Working Groups.

## Person specification

All members are required to have the following experience, skills and attributes:

### Experience and links

- Experience of and a commitment to **public involvement** in NHS, public health and/or social care research and development.
- Knowledge or experience of NHS, social care and/or public health **services or research**.
- Experience of membership of **committees** or **working groups**.
- Current **links** with **relevant groups** or **organisations**.

### Skills

- Ability to **listen** and to **express own views** about relevant issues in a way that respects the contributions of others and avoids jargon as far as possible.
- Ability to work as **part of a group** with people from a wide range of different backgrounds.
- Ability to focus on **tasks** and **achieving outcomes**.
- Ability to bring **relevant knowledge** from the perspective of service users/carers, user researchers, researchers/research managers, research funders, commissioners, practitioners, policy makers, or other relevant groups to the work of INVOLVE.
- Ability to **generalise from personal experiences/interests** of patients, service users, carers, user researchers, researchers/research managers, research funders, commissioners, practitioners, policy makers or other relevant groups.

### Attributes

- An understanding of and commitment to the **terms of reference and broad objectives** of INVOLVE.
- A commitment to **diversity and equality of opportunity**.
- A commitment to **respecting the perspectives and views** of a range of stakeholders.
- A commitment to **prepare fully** for meetings.

## **Appendix 3: A selection of INVOLVE's publications**

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All of our publications are available for downloading from our website  
[www.invo.org.uk](http://www.invo.org.uk)

**Turning the pyramid upside down: examples of public involvement in social care research** (Blackburn H, Hanley B and Staley K INVOLVE 2010)

**Changing our Worlds: examples of user controlled research**  
(Faulkner A INVOLVE 2010)

**invonet Bibliography 3** (INVOLVE 2010)

**Payment for involvement: a guide for making payments to members of the public actively involved in NHS, public health and social care research**  
(INVOLVE 2010)

**Examples of training and support for public involvement in research: Sharing innovative practice workshop** (INVOLVE 2010)

**Senior Investigators and public involvement** (INVOLVE 2009)

**Exploring Impact: Public involvement in NHS, public health and social care research. Full report 116 pages** (INVOLVE 2009)

**Patient and public involvement in research ethics committee review Guidance developed by the National Research Ethics Service and INVOLVE** (2009)

**Public Information Pack (PIP): How to get actively involved in NHS, public health and social care research** (INVOLVE 2007)

**Good practice in active public involvement in research A5 leaflet** (INVOLVE 2007)

**Involving the public in NHS, public health, and social care research: Briefing notes for researchers** (INVOLVE 2004)

**A guide to actively involving young people in research: for researchers, research commissioners and managers** (Perpetua Kirby 2004)

**Visit our website [www.invo.org.uk](http://www.invo.org.uk) for further information including:**

- signing up to our mailing list to receive our quarterly newsletter
- signing up for email alerts for new items added to the website
- a database of research projects that have actively involved the public
- a training database which includes details of trainers who have experience of training in public involvement in research
- invoNET, a network of people working to build evidence, knowledge and learning about public involvement in NHS, public health and social care research.

## **Appendix 4: Ground rules for INVOLVE meetings**

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### **It is the responsibility of INVOLVE members to:**

- Inform the Coordinating Centre in advance if you would like papers in hard copy, or in other formats.
  - Contact the Coordinating Centre in advance if you would like an item discussed at the working group meeting.
  - Read all relevant papers prior to the meeting. (Please call the Coordinating Centre if you would like to talk through any of the papers).
  - Become familiar with the relevant Working Group briefing notes in advance of the meeting. These are designed to help bring members up to date with progress since the previous meeting, so that less time during the meeting is spent updating members verbally.
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### **Management of meetings**

- It is the responsibility of the Chair to ensure that everyone has an equal opportunity to access and contribute to the discussion. It is the responsibility of Working Group members to support the Chair in this role.
  - Meetings will start promptly and aim to finish on time.
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### **Ethos**

- Respect and value that everyone is different and will think differently about things
- Only one person to speak at a time (do not interrupt person speaking)
- Be aware that covering your mouth when speaking might make it difficult for someone to read your lips or hear what you say
- Use plain and simple English, avoiding jargon and abbreviations
- If you don't understand what someone is saying – ask them to explain or repeat it
- Switch off mobile phones

# INVOLVE

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



***National Institute for  
Health Research***

**INVOLVE is a national advisory body that is funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research and development.**

**If you would like to know more about what we do, please contact us:**

**INVOLVE  
Wessex House  
Upper Market Street  
Eastleigh  
Hampshire  
SO50 9FD**

**Web: [www.invo.org.uk](http://www.invo.org.uk)  
Email: [admin@invo.org.uk](mailto:admin@invo.org.uk)  
Telephone: 02380 651088  
Textphone: 02380 626239**