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**Notes of the forty first meeting of INVOLVE  
held at the  
The Kings Fund, Cavendish Square, London W1  
Thursday 12 October 2006**

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**Present:**

Nick Partridge (Chair)  
Kate Sainsbury (Vice Chair)  
Sue Banton  
Peter Beresford (part of meeting)  
Sarah Carr  
Stuart Eglin  
Alison Faulkner  
Mary Nettle  
Maria Palmer  
Susie Parr  
Vanessa Pinfold  
Rachel Purtell  
Bob Revell  
John Sitzia  
Deborah Tallis  
Tracey Williamson

**In attendance:**

Carol Lupton (Department of Health)  
Marianne Miles (UK Clinical Research Network UKCRN)  
Susanne MacGregor (Professor of Social Policy, London  
School of Hygiene and Tropical Medicine)  
Maria Payne (PA to Rachel Purtell)

Sarah Buckland (Support Unit)  
Sarah Bayliss (Support Unit)  
Barbara Dawkins (Support Unit)  
Sofie De Broe (Support Unit)  
Helen Hayes (Support Unit)  
Jane Royle (Support Unit)  
Roger Steel (Support Unit)  
Maryrose Tarpey (Support Unit)

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## **Introductions, welcome and apologies, declarations of conflicts of interest**

### **Declarations of conflicts of interest**

No new conflicts of interest were reported.

### **Introductions and welcome**

Nick Partridge welcomed Rachel Purtell from Folk.us, Exeter. He reported that Rachel had joined the Empowerment sub-group as a temporary member in June, but this was her first time attending the main Group meeting.

Nick also welcomed Sofie De Broe to her first meeting (Public Involvement Advisor, Support Unit).

### **Apologies**

Apologies had been received from:

- Karen Collins
- Chris Caswill
- Kay Pattison
- Morton Philipps
- Lester Firkins
- Sophie Staniszewska

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## **Reflections from the conference Annex A**

A draft report of the Conference is being produced, focusing on the themed sessions. Kate Sainsbury introduced this item by highlighting some of the common issues reported from the themed sessions. These covered:

- Payment
- Dissemination of results of research
- Training about involvement
- Encouraging people to share their experiences of involvement
- Role of the UK Clinical Research Collaboration (UKCRC) and the UK Clinical Research Network (UKCRN)
- The need for transparency in research
- Collaboration between researchers and members of the public

After small group discussions the following points were highlighted:

- Tensions - important to recognise some of the tensions expressed at the conference between different stakeholders. For example, tensions around the role of INVOLVE, as well as tensions between service users and carers, and researchers. It is important to clarify to people the role and nature of INVOLVE and address some of the misconceptions.
- Capacity - INVOLVE can't do everything. It needs to prioritise and draw on the Group's skills as well as those of the Support Unit. It also needs to clarify alliances and links with others.
- Dissemination – important to continue work to encourage the accessibility of research findings and documenting the value and experiences of public involvement.
- Social care and public health - the lack of reference to social care and public health amongst the common issues highlighted in the conference report.
- Electronic patient records - should we be getting involved in contributing to this issue?
- Payments - this was acknowledged as continuing to be a difficult area. Should we be saying or doing more about this?

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## **Review of Progress against Strategic Plan 2003 - 2006 Annexes B and C**

Nick Partridge explained the purpose of the session was to reflect on what INVOLVE had been aiming to do and what had been achieved. He asked Group members to work in small groups to reflect on the main achievements of INVOLVE over the last three years and to highlight / prioritise the most important activities.

Summary of feedback from the Group discussion:

- User involvement in NHS policy has become more visible for example in commissioning research and research governance, and has been influenced by INVOLVE. There are also now many more people involved in promoting public involvement.
- INVOLVE had prospered and flourished and had also protected and expanded its place at high level tables.
- However, the wider acceptance of user involvement also brings its' own tensions. There is the risk of involvement becoming diluted and being more

about engagement and consultation rather than partnership. The extent that we have influence at the tables we sit around and the risk of tokenism.

- Some of the positive aspects of the work of INVOLVE were highlighted, including the use and accessibility of the website, the approach of openly recruiting new members, the range and quality of information and guidance produced by INVOLVE, and the strength and commitment of the Support Unit staff.

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## **Development of Strategic Plan - Annex D**

Discussion took place around identifying the key changes in the research environment and the implications for INVOLVE.

The meeting divided into small groups to explore these issues and to identify if our aims and the Strategic Plan 2003 – 2006 'The Expert Resource' was still appropriate.

Following discussion the following issues were raised:

- Concern that public involvement in research was not sufficiently embedded in the new research networks and structures. How does INVOLVE influence organisations to move beyond the 'tick box' stage?
- It was suggested that more progress had been made within the NHS and that there were not as many champions for public involvement in research in social care and public health.
- Service user organisations and user controlled research are in a precarious situation as a result of underfunding, and limited infrastructure. How will INVOLVE offer support to them?
- There was a need for clarification of the role INVOLVE might play in industry research – should we produce guidelines for service users working within this context?
- Public involvement in clinical research is a challenge but at the same time an opportunity.
- How do we build and disseminate evidence around public involvement in research?

- A need for INVOLVE to create an environment for involvement. It was important to be realistic and aspirational in encouraging achievable steps when working with others.
  - INVOLVE has an important role as a conduit of expertise for others to draw on, through communicating and sharing learning.
  - It is important that INVOLVE does not get too drawn into the complexities of the changing environment and new systems.
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### **Afternoon Meeting**

#### **1. Notes of the meeting held on 8<sup>th</sup> June 2006 – annex H**

There were no corrections to the minutes of 8<sup>th</sup> June 2006.

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#### **2. Notes of actions taken since the meeting and any other matters arising – annex I**

Nick reported that INVOLVE had responded to the Cooksey Review, and the UK Clinical Research Collaboration (UKCRC) Health Research Analysis Report had been circulated to members.

He also advised the Group that work on the following was ongoing:

- Legal obligations and liabilities of public involvement
  - Joint working with the UKCRC re public involvement
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#### **3. Susanne MacGregor – Professor of Social Policy, London School of Hygiene and Tropical Medicine – Public involvement in social policy / social care research**

A presentation was given by Susanne where she outlined the history of social policy and social science disciplines as well as exploring some of the issues around public involvement in this area. She was puzzled as to why there was a perception of barriers to user involvement in Social Policy and Social Work research, but felt that this could be something to do with the nature of research in social care and social sciences.

Susanne outlined a couple of potential barriers:

- Social work and social policy research are considered to be of lower status than other social sciences and this can result in a tendency to defend them as a science, which may be a barrier for user involvement
- Social work research is often carried out at a local level, and so it may be harder to find out about ongoing work where there is public involvement
- There may be fears by some researchers that the project will be skewed if service users have more power

However, Susanne reflected that although there may be different disciplinary paradigms among social sciences, this kind of research founded user involvement. She suggested that a way forward in influencing for more public involvement was to highlight good practice, particularly at a local level.

Susanne suggested that although the Research Assessment Exercise (RAE) is often identified as conflicting with the public involvement agenda, she felt there are important indicators in the Social Research RAE that affect the public.

There was a brief discussion following the presentation.

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#### **4. What's new in the Department of Health – Carol Lupton**

Carol Lupton provided an update.

- There is no news on the Cooksey Review of UK Health Research – due to be reported in the Chancellor's Autumn statement.
- Research for Patient Benefit Programme (RfPB)
  - The deadline for the first call is 20 October 2006
  - There will be 10 Regional Funding Committees; the first meetings of the committees will be in January 2007.
- The Central Commissioning Facility has taken over the management of the Policy Research Programme. It is hoped that this will lead to consistent practice in public involvement across the programme.
- NHS Service Delivery and Organisation R&D programme (SDO) has just announced a Public Health, limited open call scheme around the following themes:
  - Patient and carer centred services
  - Workforce issues
  - Evaluating models of health service delivery
  - Change management

- Studying health care organisation
  - Research methods.
- Social care
  - The National Research Register for Social Care (NRRSC) has been relaunched. All records on social care research will be found in one place. It includes a field on 'what extent the research has public involvement over and above as participants in research'.
  - The Department of Health are consulting on the new Social Care strategy. This is a cross government national strategy. 351 responses have been received, including one from INVOLVE.

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## 5. Update on INVOLVE accessibility audit – Susie Parr

Susie has volunteered to chair the accessibility working group, and she reported on progress so far with accessibility. Susie raised the following points:

- We need to be clear about what we mean by accessibility. It means the widest possible range of people being able to benefit from INVOLVE activities, products and communications. This is important because INVOLVE aims to benefit all people who are affected by research.
- But there are dilemmas. Different groups may have very different specific requirements, and sometimes these requirements can conflict or compete for priority.
- At present INVOLVE have lots of good work and ideas, but there is a need for an overall strategy. We also need to use our resources wisely.
- The first step has been to commission independent accessibility audits of INVOLVE written communications (internal and external) and of the conference. The audits were carried out by the Central Office of Information (COI). Generally the two audit reports show that we have done well and are generally positive. The reports are available from the Support Unit if you would like to read them. Some recommendations are already being implemented by the Support Unit.

Roger Steel and Susie Parr will develop a draft accessibility strategy. They will consult with the Accessibility Group, and the Empowerment sub-group. They hope to get the draft strategy finalised in the new year.

There are members of the Accessibility Working Group from all sub-groups as this issue cuts across all aspects of INVOLVE's work. The Accessibility Working Group is comprised of:

Susie Parr (Chair)  
Rachel Purtell (Empowerment)  
Stuart Eglin (Strategic Alliances)  
Alison Faulkner (Evidence Knowledge and Learning)  
Roger Steel (Support Unit)

**Action: Roger Steel and Susie Parr to develop the draft accessibility strategy in consultation with the Accessibility Group and Empowerment sub-group**

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## **6. Director's report – annex J , K, L**

Sarah Buckland reported the following:

### **Conference**

The total estimated expenditure for the conference was approximately £79,000 and it has been estimated that there will be an income from the conference of £44,000. Thus the overall expected cost would be around £35,000.

### **Statistics**

There was a brief discussion about the statistics produced by the Support Unit. In particular, a query was raised as to why there were so many hits on the INVOLVE website from North America, and whether this was a true reflection of the interest from this area.

A question was also raised about how the Support Unit decided which meetings and events to attend. Sarah replied that this was a combination of reflecting on previous experiences and interest at events, as well as judgements as to the likely value of contributing. A large proportion of the work was as a result of invitations either to speak at events or attend meetings etc.

**Action: Helen to investigate use of the website from North America and report back to the Group**

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## **7. Strategic direction / Operational Plan**

Sub-group chairs reported back on discussions about their views on the strategic direction and operational plan for the Group.

## **Empowerment sub-group**

Kate Sainsbury reported back on discussions in the Empowerment sub-group. The following issues were highlighted:

- The need to ensure we implement our accessibility policy once agreed.
- The need to ensure that attention is also given to social care and public health research, in light of much current emphasis on NHS clinical research.
- The importance of reiterating our core principles as outlined in INVOLVE's Strategic Plan 2003 / 2006. This includes a commitment to ensure that people from excluded groups are included in the research process.
- The value of compiling good practice examples of involvement in research.

## **Strategic Alliances**

Stuart Eglin reported on discussions in the Strategic Alliances sub-group. He said that four themes were highlighted by the discussions:

- Children and young people
- Industry
- Generic influencers including Research Councils, medical schools and Royal Colleges
- The need to raise INVOLVE's profile with members of the public

## **Evidence Knowledge and Learning**

John Sitzia reported on discussions in the Evidence, Knowledge and Learning sub-group. John reported that the sub-group planned to continue to develop the evidence base on public involvement in research by:

- Producing a position paper on evaluating the impact of public involvement in research and further development of invoNET
- The proposed scoping study should focus on documenting good practice examples with future implications for training, or a core curriculum
- To revisit the original monitoring role of the sub-group, by looking at funders who ask researchers to specify their inclusion of public involvement in research grant applications
- Promotion of INVOLVE - possible through sponsorship of an award for good practice

**8. Any other urgent business not included on the agenda**

No items were discussed

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**9. Dates of future meetings:**

Thursday 14 December at the British Library

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