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**Notes of the Fifty Seventh meeting of INVOLVE  
held at  
The King's Fund, Cavendish Square, London  
Wednesday 26 January 2011**

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**Present:**  
Richard Baker  
Rosemary Barber  
Peter Beresford  
Louca-Mai Brady  
Ann-Louise Caress  
Simon Denegri  
Stuart Eglin  
David Evans  
Jim Elliott  
Alison Faulkner  
John Hughes  
Poonam Jain  
Hugh McLaughlin  
Mary Nettle  
Maria Palmer  
Nick Partridge (Chair)  
Tony Sargeant  
Sophie Staniszewska  
Patsy Staddon  
Christine Vial  
Tracey Williamson

**In attendance:**

Roger Steel	NIHR Clinical Research Network Coordinating Centre (CRN CC)
Tony Williams	Department of Health
Sarah Buckland	INVOLVE Coordinating Centre
Barbara Dawkins	INVOLVE Coordinating Centre
Helen Hayes	INVOLVE Coordinating Centre
Sarah Howlett	INVOLVE Coordinating Centre
Lucy Simons	INVOLVE Coordinating Centre
Maryrose Tarpey	INVOLVE Coordinating Centre

## **1. Introductions, welcome and apologies, declarations of conflicts of interest:**

Nick reported that since the last meeting of the Group, Angela Barnard had decided to step down as a member of INVOLVE. Nick thanked Angela in her absence for all the work she had undertaken for INVOLVE and in particular, as chair of the Conference Planning Group.

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

No conflicts of interest were declared.

### **Apologies**

Apologies had been received from:

Ade Adebajo (am only)

Sue Banton

Sarah Bayliss

Diana Rose

Ray Fitzpatrick

Kay Pattison

Mark Petticrew

Vanessa Pinfold (am only)

Laura Serrant-Green

Angela Sweeney

Philippa Yeeles

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## **2. Notes of the meeting and awayday report 21 and 22 September 2010 and any actions taken since the meeting**

The meeting notes were agreed as correct. It was noted to correct the mis-spelling of Andrew Lansley's surname.

There were no actions.

Nick explained there would be a slight change in the order to the agenda: item 4 (reports from observers) would follow item 7 (INVOLVE conference feedback).

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## **3. Directors Report and budget update – paper 1**

Sarah Buckland announced that Alison Faulkner would be finishing as a member of the Coordinating Centre team at the end of January and returning to being a Group member. Sarah thanked Alison for the valuable contribution she had made to the team.

Sarah explained that from the beginning of February the Coordinating Centre would be on their new contract and would need to make savings in their budgets.

The website is being revised for the end of March. The Coordinating Centre team, led by Helen Hayes, are also working on the new resource for researchers which is an update on the Briefing Notes for Researchers (2004). Helen explained that the new resource will be web-based, and will have a core unit alongside supplements that are being developed by different people. The emphasis will be on providing a practical resource that will include examples of projects as well as templates with examples of job descriptions, terms of reference and ground rules etc.

### **Academy of Medical Sciences – Review of regulation and governance**

Simon Denegri from the Academy of Medical Research Charities (AMRC) talked through the history to this review and the report of which was published on the 11<sup>th</sup> January 2011. 'A new pathway for the regulation of governance of health research'. As part of the consultation process, the AMRC held a joint workshop with INVOLVE to get the views of members of the public about the governance of research.

The AMS report encouragingly includes numerous references to the joint workshop and the views expressed around the importance of public involvement and engagement. Amongst the recommendations is that there should be a greater push to raise public awareness about the role of research in the NHS – a potential role for AMRC and INVOLVE. Simon also reported that the Academy of Medical Sciences were keen to explore how they might increase public involvement within their own structures and processes.

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## **5. Membership recruitment 2011 – paper 2**

Nick introduced the need to begin the process of recruiting new members to INVOLVE, to replace members who would be leaving over the next year or so. Nick introduced paper 2, which describes a proposal to help improve the recruitment process and recruit the best people we can to INVOLVE within the resources available.

Nick also informed the Group that after being Chair of INVOLVE for over 10 years, he felt this was a good time to step down and make room for someone else. The time was right because a further five year contract with the National Institute of Health Research (NIHR) had been secured for the Coordinating Centre and the new Chair would be able to shape the new strategic plan (see agenda item 6) and play a key role in the appointment of new members. Nick has informed Professor Dame Sally Davies of his intention to step down, with an expected handover to take place at the next Advisory Group meeting in May 2011.

Tony Williams reported that the appointment of a new Chair would be managed by the Department of Health. He was drawing up an advert and job description which would be approved by Sally Davies. Advertising would be through the NIHR website and other relevant networks. No press adverts would be possible due to resources.

The Group then discussed paper 2 – INVOLVE membership recruitment 2011. The suggestion to hold open regional events for interested people to find out more about

what being an INVOLVE member entails, was supported by Group members. Other suggestions included linking with public involvement leads in other organisations to help run and publicise any regional events. Group members offered to help in this process.

In discussion the members raised a number of issues for the recruitment process:

- Important to target recruitment in areas where we need to build our work e.g. social care, public health.
- A critical look at the current membership was suggested, e.g. carrying out a skills and experience audit, which could be taken from the current Member's Information Pack, and take positive steps to fill any gaps.
- The range of perspectives in membership needs to match the tasks that need to be achieved by INVOLVE – we need the right people who can drive through the right changes.
- Ensure voluntary and other sectors are represented especially with the shifting landscape for health services.
- As there has been a vast increase in the number of service users involved in research studies and we are in contact with a wide range of networks, we can target these people.
- Advertising suggestions included: SOLNET, survivor networks and disability studies departments at some universities, information in other organisations newsletters.
- Thought is required into the feasibility of professional and academic members becoming members – many external activities are expected to bring funds into departments, therefore we may need to be clear what advantages there will be for people to be members e.g. demonstrating impact for the Research Excellence Framework etc. It was suggested we ensure people have the support of their department before committing to INVOLVE.
- It is important to think about the role of observers e.g. the Economic Social Research Council (ESRC) and the Social Care Institute for Excellence (SCIE).

Some additional ideas for recruitment material were made:

- Vignettes / examples / testimonies – what's it like being a member of INVOLVE?
  - Ensure photos of current members are available so people can see what we look like – may have positive impact for recruiting new people. It was confirmed that photos of current members would be going up on the refreshed website.
  - It may be difficult to explain the difference between working group membership and main Group membership to applicants. This may be an opportunity to explore whether decisions on membership could be devolved to the Chair.
  - In the previous application, people applying were asked to provide detail of referees. Some people may not know what this means or find it difficult to meet in the traditional way – we should therefore think about alternatives.
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## 6. Strategic Framework consultation plans – paper 3

Nick introduced discussions on the strategic framework consultation plan explaining that it had been developed from discussions at the away day in September and the Chairs meeting in December. He outlined that we wanted ideas about the process that we are proposing, as well as any views on the value, mission and strategic objectives.

The following suggestions were made:

- the introductory statement should be expanded to include a biography of INVOLVE which outlines its specific achievements with an explanation that we are now in a different environment with limited resources;
- there could be a supplementary document that provides background information about INVOLVE;
- consider omitting the vision and mission statements and instead provide background information about INVOLVE and seek views as to what people feel INVOLVE should do in the future;
- need to highlight what is unique to INVOLVE and to clarify the position of INVOLVE within the current climate where there are a greater number of organisations providing advice and support on public involvement
- greater emphasis on the role of INVOLVE in developing critical thinking on issues
- the vision needs to positively frame what INVOLVE is doing. For example, using “we will” rather than “we seek to”;
- some of the statements are too general, they need to be developed.

### Consultation process

In discussion, the members raised a number of suggestions about who to consult during the consultation process. Members also discussed the importance of being clear about what will happen to the results of the consultation and to stress the opportunity to influence the strategic plan.

Other suggestions or views about the consultation document and process:

- it has to be credible
- change the format of the document by integrating the information into the questionnaire rather than providing the information and then asking the questions.
- the term ‘appropriate for INVOLVE’ in the consultation form was discussed as not being meaningful to people who were not aware of us.

**Action: Group members to send any further comments to Sarah Buckland.**

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## **7. INVOLVE Conference: feedback and future plans – papers 4a and 4b**

Stuart Eglin gave a brief report on INVOLVE's November 2010 National Conference. He reminded members that the planning and resourcing of the conference has been an ongoing area of work for the Strategic Alliances working group.

He referred Group members to Discussion paper 4a which provided a brief outline of the role of the conference, the resources required and a summary of some key considerations for future conference planning, including whether or not Group members thought INVOLVE should plan to hold a conference in 2012.

Tony Williams explained that currently the Department of Health (DH) were no longer allowing conferences although shared learning events are still being supported. However if INVOLVE can make a sufficiently strong business case, the DH may be able to make an exception.

There was then a wide ranging discussion on the unique role the conference plays in providing at a national level, the opportunity to bring together the huge variety of people in patient and public involvement in research. Members agreed that it was a core part of INVOLVE's identity and is its flagship event. If discontinued it would undo years of hard work. It would be impossible to create a different format and achieve the same benefits and impact that the conference has.

In conclusion, Group members agreed that the INVOLVE Coordinating Centre should submit a business case to put to the DH proposing the continuation of the biennial INVOLVE Conference (next one due to be held in 2012).

Nick Partridge thanked the Conference Planning Group and the conference organisers, Professional Briefings, for the huge amount of work that had been involved in making the 2010 Conference such a success. Maryrose Tarpey was also thanked for her role within the INVOLVE Coordinating Centre.

**Action: INVOLVE Coordinating Centre to write a business case presenting the reasons why the INVOLVE 2012 national Conference should be allowed to go ahead.**

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## **4. Reports from observers**

### **Tony Williams – Department of Health**

Tony and Kay Pattison extended their thanks to Nick for his commitment to INVOLVE during his time as Chair. Tony noted Nick was a well respected figure in the National Institute of Health Research (NIHR) and Department of Health (DH).

Tony reported on the patient and public involvement developments in the two research commissioning centres (NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) and the NIHR Central Commissioning Facility (CCF)).

Tony was asked if the NIHR has begun to assess the impact of the NHS White paper re-organisation on health research and how current research contracts/obligations can be fulfilled. One potential impact highlighted was the request by some Primary Care Trusts to withdraw their funding contribution to Collaborations for Leadership in Applied Health Research and Care (CLAHRC). There was some discussion from members as to their own experiences of the situation. Stuart Eglin reported that the North West Strategic Health Authority is doing some work on this issue. Tony Williams offered to find out more.

### **Roger Steel – NIHR Clinical Research Network Coordinating Centre (CRN CC)**

Roger reported that Jonathan Sheffield has been appointed Chief Executive of the Clinical Research Network. His role is to move the clinical research networks towards operating as one big network, to develop high level objectives for the network and to introduce a performance management framework. Part of this will be to ensure patient and public involvement fits strategically across the clinical research networks – locally and nationally.

This was helping the continuation of the Way Forward process. The report from the consultation stage of this process was now available. They were now in the implementation stage, devising a framework for involvement across the network, which will provide tighter parameters for involvement activity. The framework will include work to:

- communicate and link patient and public involvement (PPI) to core business of the network (that is, to support research and ensure studies recruit participants to target and on time)
- develop cross-network and cross NIHR collaboration
- routinely collect and record information on PPI and related outcomes
- integrate learning and development opportunities

**Action: Tony to send a copy of the notes about the research programmes to the Coordinating Centre for circulation to Group members.**

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## **8. Changing Our Worlds: Examples of user-controlled research in action**

A screening of the INVOLVE film produced to accompany the report written by Alison Faulkner was well received and the Group congratulated Alison on the success of her work.

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## **9. Feedback on discussions from working groups and INVOLVE Operational Plan 2011 / 2012**

The following chairs of each working group gave a post card report from their group:

Strategic Alliances	- Stuart Eglin
Evidence, Knowledge and Learning	- Sophie Staniszewska

Empowerment

- David Evans

Please see separate meeting notes for each working group.

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

There was no further business.

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**11. Dates of future meetings**

- 19 May 2011 – INVOLVE Group meeting
  - Dates for meetings in September and December would be circulated shortly.
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