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**Notes of the Fifty Third meeting of INVOLVE  
held at  
The Kings Fund, London  
Wednesday 09 December 2009**

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**Present:** Nick Partridge (Chair)  
Stuart Eglin  
Anne-Louise Caress  
Sophie Staniszewska  
Poonam Jain  
Patsy Staddon  
Rosemary Barber  
Diana Rose  
Ade Adebajo  
David Evans  
Richard Baker  
Sue Banton  
Peter Beresford  
Maria Palmer  
Laura Serrant-Green  
Ray Fitzpatrick  
Jim Elliott

**In attendance:** Tony Williams – Department of Health (DH)  
Roger Steel – NIHR Clinical Research Network  
Coordinating Centre (NIHR CRN CC)  
Melanie Knetsch – Economic and Social Research  
Council (ESRC)  
Sarah Buckland – Support Unit  
Sarah Bayliss – Support Unit  
Helen Hayes – Support Unit  
Maryrose Tarpey – Support Unit  
Lucy Simons – Support Unit

**Guests:** Ellie Keen, Training Officer, British Institute for Human  
Rights

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

**Declarations of conflicts of interest**

No conflicts of interest were declared.

## **Introductions and welcome**

Nick welcomed Ellie Keen, Training Officer, British Institute for Human Rights who would be giving a presentation to the group.

## **Apologies**

Apologies had been received from:

- Kay Pattison
- Karen Collins
- Susie Parr
- Alison Faulkner
- Simon Denegri
- Louca-Mai Brady
- Tracey Williamson
- Vanessa Pinfold
- Mark Petticrew
- Sarah Carr
- Hugh McLaughlin
- Kathy Mann
- John Sitzia
- Angela Barnard
- Mary Nettle

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## **2. Notes of the meeting and awayday report 9<sup>th</sup> and 10<sup>th</sup> September 2009 and any actions arising**

No corrections to be made

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## **3. Ellie Keen, Training Officer, British Institute for Human Rights**

Nick welcomed Ellie to the group meeting and reported that she had been invited to talk about how Human Rights applies to the work of INVOLVE.

She stated the aims of her talk were to:

- Make explicit how she thought INVOLVE is a human rights orientated organisation
- Suggest how we might extend into other human rights areas
- Set out the Human Rights Act to clarify/correct myth and misleading media reports

A presentation covering the main points of Ellie's talk is attached with the meeting notes.

Ellie set out the history and development of human rights. This included explaining how:

- Human Rights are a set of core values, encompassing dignity and equality
- They have developed over centuries and are now enshrined in law.
- Human Rights are a way of limiting and auditing the power the State has over individuals.
- They are highly relevant to health and social care as it is not only about refraining from some kinds of treatment but also taking positive action to provide services in a particular way.

She explained that the UK 1998 Human Rights Act brought in the key change that human rights cases can now go to British courts and the important development that there is now an obligation on public bodies (e.g. NHS Trusts, Social Services, Education Authorities) to respect human rights.

She illustrated how human rights applied to health and social care, by giving a number of example cases where human rights have been contravened and information about the relevant article in each case.

She reported that a human rights based approach is being endorsed by the Department of Health. This is where human rights are a starting point so everything in an organisation stems from this. The approach has emerged from overseas development work. In this context a human rights based approach covers five issues, of which the last two are most relevant to the work of INVOLVE:

1. Human rights are uppermost
2. Non-discriminatory policies and practices
3. Accountability - human rights concerns are followed up and there is feedback and discussion
4. Participation - every individual has a genuine right to participate
5. Empowerment - only if people feel able, competent and have the opportunities to participate will they be able to.

She spoke about the relevance of human rights to the work of INVOLVE as two-fold:

- Research in the context of public bodies is subject to the Human Rights Act, for example, any research activity in an NHS Trust has to be compliant with the Act, although she noted the likelihood of research activity being non-compliant was small
- Making sure our methods for involvement are fully Human Rights compliant and anti-discriminatory. This includes making sure there are no obstacles to involvement and also conscious attempts to empower others who may not be already involved.

Finally, Ellie noted that research is required to explore compliance (or non-compliance) with the Human Rights Act and the extent to which Human Rights are embedded within NHS practice.

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

Sarah Buckland was delighted to report that Philippa Yeeles who was currently working at the UKCRC would be joining Involve from March as the new Deputy Director.

Helen Hayes reported on the INVOLVE Impact study. She advised the group that the review of the literature on the impact of public involvement in research had been very well received and considered timely. She reported that we had already received large numbers of requests for the publication.

She went on to say that a full report of 116 pages and a summary of 16 pages had been produced and work was ongoing on a series of two page summaries for specific audiences, initially they would be for service users, researchers and research funders and commissioners.

Helen Hayes advised the group that she had met with Robin Banerji to discuss the best approach to disseminating the INVOLVE Exploring Impact Study. The full report had been sent to key individuals within health and social care research with a personalised covering letter, and details of the report had been widely disseminated. Helen asked the group for ideas on further dissemination which are listed below:-

- Data pens with a downloaded version of the Impact Project
- Send hard copies to Service User organizations
- Copies to Mark Wolpott, OSCHAR board, UKCRC Board, NIHR satellites, NIHR advisory groups, PPI and Health Services (NIHR)

Maryrose reported that along with the JLA, INVOLVE is working with the UKCRC and the Association for Medical Research Charities to run a joint 'think tank' event titled 'Building on success - opportunities to progress public and patient involvement in research prioritisation and commissioning'. It is planned for the morning of Tuesday 09 February 2010 and will be chaired by Russell Hamilton (NIHR) and Simon Denegri (AMRC).

**Action: Maryrose to circulate information regarding this event to group members.**

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#### **5. Verbal feedback on Boards attended by INVOLVE Group members:**

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## **6. Reports from observers**

### **National Institute for Health Research (NIHR)**

Tony Williams reported that:

- INVOLVE's Impact Report was currently profiled on the NIHR's website home page.
- Sally Davies had reconfirmed the ring-fencing arrangements for NIHR funding
- The closing date for tendering for the INVOLVE Coordinating Centre was Monday 14th December 2009. The selection panel were due to meet on 14th January 2010 to assess the applications.
- The UKCRC had produced a booklet (2009) titled the changing regulatory and governance environment for health research across the UK. It provided an overview of initiatives that have been put in place to streamline the regulatory governance environment and can be downloaded from the UKCRC website ([www.ukcrc.org](http://www.ukcrc.org)).
- The NIHR website now listed all the programmes' calls for research proposals

### **Economic and Social Research Council**

Melanie Knetsch gave a brief update on her work around Science and Society. She also explained that they were planning to run a workshop in January 2010 called embedding public engagement. This would focus on developing a strategy to progress public engagement internally, within the ESRC's decision making structures. The INVOLVE Coordinating Centre, Joseph Rowntree Foundation, Carnegie Trust and Research Council UK have been invited to attend.

### **NIHR Clinical Research Network Coordinating Centre**

Roger Steel gave a detailed presentation on the background and future plans of the patient and public involvement workstream within the NIHR Clinical Research Coordinating Centre and the Topic Specific and Comprehensive Research Networks. This was followed by a broad discussion covering the relationship between active public involvement and strengthening research design / recruitment to trials, the potential use of the Impact Report to illustrate public involvement in the various stages of the research pathway (slide 10) and the potential to take an action learning set approach to public involvement within the networks.

Copies of Roger's powerpoint slides were circulated at the meeting.

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## **7. Feedback on discussions from working groups**

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

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

Please see separate minutes for each working group.

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

None.

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## **9. Dates of future meetings**

- 11 March 2010
  - 15 June 2010
  - 21/22 September 2010
  - Involve Conference 16/17 November 2010
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