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**Notes of the Fiftieth meeting of INVOLVE  
held at  
The Kings Fund, London  
Tuesday 20<sup>th</sup> January 2009**

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**Present:** Nick Partridge (Chair)  
Peter Beresford  
Stuart Eglin  
Mary Nettle  
Jim Elliott  
Ray Fitzpatrick  
Anne-Louise Caress  
Sophie Staniszewska  
Poonam Jain  
Louca-Mai Brady  
Tracey Williamson  
Patsy Staddon  
Simon Denegri  
Rosemary Barber  
Maria Palmer  
Diana Rose  
Vanessa Pinfold  
Ade Adebajo  
Mark Petticrew  
Hugh McLaughlin  
Sarah Carr

**In attendance:** Tony Williams (DH)  
Roger Steel (NIHR CRN CC)  
Melanie Knetsch (ESRC)  
Kate Sainsbury (Chair of Conference Planning)  
Sarah Buckland (Support Unit)  
Sarah Bayliss (Support Unit)  
Barbara Dawkins (Support Unit)  
Helen Hayes (Support Unit)  
Maryrose Tarpey (Support Unit)

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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 Melanie Knetsch from the Economic and Social Research Council who had joined the Group as an observer. Nick thanked Group members for the congratulations he had received on his knighthood and was delighted that the work of INVOLVE had played a part in this.

Nick also welcomed Kate Sainsbury who would be giving feedback on the conference.

## **Apologies**

Apologies had been received from:

- Chris Caswill
- Hala Patel
- Kay Pattison
- Angela Barnard
- David Evans
- Karen Collins
- Richard Baker
- Laura Serrant-Green
- Susie Parr
- Alison Faulkner
- Sue Banton

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## **2. Notes of the meeting and awayday report 10<sup>th</sup> and 11<sup>th</sup> September 2008**

No corrections to be made.

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## **3. Notes of actions taken since the meeting and any other matters arising**

Nick reported that no one had requested a transfer between working groups but the offer remained open.

Nick advised that slides from Jonathan Nichols talk at the awayday had been circulated.

Nick reported that INVOLVE had submitted a response to the National Institute of Health Research (NIHR) and Medical Research Council (MRC) 'Setting the National Ambitions for Health Research'.

**Action: Nick to circulate response to all Group members**

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#### **4. Mark Petticrew – Public Health Research and public involvement**

Mark Petticrew gave a powerpoint presentation on his reflections about public involvement in public health research. He outlined his approach to public health research and focused on 'social determinants' – that is research on the main influences on health and health inequalities, and the means of improving health.

He gave two examples of large scale community based public health trials (Well London RCT and GOWELL in Glasgow) that he has been involved with. Both trials were designed to improve quality of life measures through health promotion and disease prevention for people living in those communities. They actively sought involvement of all interested stakeholders both in the trials themselves and the evaluation studies assessing the public health outcomes of the trials. Mark ended his presentation by discussing some of the challenges for public involvement in these types of public health research studies such as:

- 'public disengagement' – where there is no particular interest in the public health issues – which, for example, can have a seriously negative effect on survey response rates from residents, as well as on engaging stakeholder groups more actively in the design and completion of the research;
- the difficulty of agreeing outcome measures for the trials amongst the various partners involved in the research - where there are likely to be differing and conflicting expectations and interests.

Mark's presentation was followed by questions from Group members and included comments on the following:

- the evidence base used for public health interventions and its reliance on observational studies, surveys (e.g. of housing conditions) or evaluations rather than randomised controlled trials;
- more detail on how public health outcomes are developed for complex interventions that take account of communities' broader interests in social improvements in an area as well as measuring individual health outcomes;
- tend to avoid the term 'participatory' research when describing public involvement in public health research to avoid it being badged as less 'objective' in its evaluation of the impact of an intervention.

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#### **5. What's new in the National Institute for Health Research (NIHR) and Policy Research Programme (PRP)**

Tony Williams congratulated Nick on his knighthood and INVOLVE on its impressive conference. He gave an update to the Group as follows:-

### **Integrated Research Application System (IRAS) updated to Version 2.0**

The Integrated Research Application System for applying for permissions and approvals for health and social care research in the UK has been updated. The main enhancement in Version 2.0 is a system of electronic authorisation as an alternative to ink signature for most declarations required in IRAS. A number of other changes have also been made to improve functionality and guidance for users.

### **NIHR Coordinated System for gaining NHS Permission (CSP) goes live**

The NIHR CSP will standardise and streamline the process for gaining NHS permission for clinical research studies. The NIHR CSP has a single entry point, via the Integrated Research Application System (IRAS), so that researchers can apply for permission from all NHS sites in England through a single gateway. NHS Research and Development offices and researchers should use the NIHR CSP as a matter of routine for NIHR Clinical Research Network Portfolio studies.

If you have any questions about CSP or IRAS please contact [csp@ukcrn.org.uk](mailto:csp@ukcrn.org.uk)

### **Publication of the UK Clinical Research Collaboration (UKCRC) Progress Report 2006-2008**

The UKCRC Progress Report can be downloaded from the UKCRC website. Pages 51 to 55 cover the UKCRC's patient and public involvement agenda.

### **Chair of Social Care Research Ethics Committee announced**

Professor David Stanley has been appointed chair designate of the new national Social Care Research Ethics Committee (SCREC). Professor Stanley holds Northumbria University's research Chair in Social Care and is a co-Director of the Centre for Collaborative Gerontology in the School of Health, Community and Education Studies. Professor Stanley has served as an appointed member of a Research Ethics Committee (REC) within the National Research Ethics Service (NRES) and was part of the Department of Health planning group on research ethics review in social care.

### **NIHR Service Delivery Organisation (SDO) Panel/Commissioning Board recruitment – professional and service user advisors**

The NIHR SDO programme is recruiting professional and service user advisors for their advisory panels and Commissioning Board to provide expertise to the SDO programme.

New developments in the SDO programme have seen a review of commissioning structures and processes with a new model being adopted from 1<sup>st</sup> April 2009. As part of these changes there will be the creation of three advisory panels whose focus will be primarily on assessing NHS needs; and a Commissioning Board which will make funding recommendations.

For details see: <http://www.sdo.nihr.ac.uk/recruithomepage.html>

## 6. Verbal feedback on Boards attended by INVOLVE Group Members

INVOLVE members sit on various boards linked to implementation of the NIHR strategy. Members were asked to describe their roles on these boards and highlight some of the issues associated with their membership.

**UKCRC** – Nick Partridge sits on the UKCRC Board representing INVOLVE. Simon Denegri also sits on the Board representing the Association of Medical Research Charities (AMRC). Sarah Buckland Director INVOLVE Support Unit chairs the UKCRC Patient and Public Involvement (PPI) Subgroup to the Board.

Nick gave a brief update on the UKCRC. It was intended that UKCRC would provide the opportunity to create greater transparency and collaborative working between the key partners which have included medical charities, NIHR and pharma. It was always envisaged that the workstreams would in time be picked up by a lead partner organisation rather than continue to rely on UKCRC secretariat input.

This handover is currently underway and due to be completed by December 2009. Liam O'Toole has already left his part-time post as Chief Executive of the UKCRC. Other members of the UKCRC secretariat are leaving as workstreams are completed or handed over to lead partners. The UKCRC Board is due to meet in February 2009 to discuss future arrangements for next year including the workstream on public involvement.

**NIHR Board** – Peter Beresford and Angela Barnard represent INVOLVE and Simon Denegri (AMRC) also sits on the Board.

Peter discussed his experience of the last meeting and how helpful it is when Angela and Simon are also there (they were absent this time). The meetings cover a range of topics and can be challenging, particularly when you have a different perspective or opinion to the other members – on sharing of patient records for example.

**Office for Strategic Coordination of Health Research (OSCHR)** – Jim Elliott sits on the Translational Medicines Board of OSCHR which was set up two years ago to strategically facilitate research. For its tenth meeting in November 2008 it invited two lay members on to the Board. However it is unclear in what capacity they have been invited other than as 'honest broker'. The meeting provided an update from each of the OSCHR partners (MRC, NIHR, Wales and Scotland), this was followed by a detailed discussion on 'human capital' and how to create more opportunities to develop research capacity. The key purpose of these Board meetings is to encourage the partners to work together.

Jim and the other lay member had a debrief meeting with Liam O'Toole, in his role as Chief Executive of OSCHR in December 2008. They challenged the lack of public involvement currently within OSCHR. The conclusion was that

public involvement needed to be championed at future meetings to raise the issue and to push to get it introduced more systematically.

The Public Health Board (OSCHR) is chaired by Ray Fitzpatrick. Angela Barnard has been invited to be a member of this board.

This Board held its first meeting in late 2008 with the purpose of facilitating and encouraging public health research including infection and microbiology as well as health promotion. As above the four main partners (MRC, NIHR, Wales and Scotland) attended.

EHealth Records Board / Research Capacity Board – Nick Partridge is a member of this Board, and there are also another two members of the public who are supported by the UKCRC patient and public involvement secretariat.

This Board is linked to Connecting for Health and both are tasked with oversight of the programme to deliver secondary uses of patient data. Nick reported that the scale of paperwork and technical information is very difficult as are the ethical issues involved.

In conclusion:

- Finding people to be prepared to shoulder these types of meetings is challenging. Sarah Buckland reported that this echoed a recent discussion at the last UKCRC PPI sub group meeting, where a UKCRC patient and public involvement member outlined his experiences and concerns of sitting on one of these Boards.
- We need greater clarity on what mandate members of the public have in this role.
- We need to consider what arrangements can be made to communicate and support members across the various boards.

The UKCRC PPI sub group was planning a workshop in March, to bring together people in these roles to further discuss these issues.

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## **7. INVOLVE NHS Alliance DVD: Public involvement at the heart of research**

The DVD was played at the end of the meeting for anyone wishing to watch it.

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## **8. INVOLVE Conference 2008 – feedback by Kate Sainsbury**

Kate Sainsbury, the out going chair of the Conference Planning Group gave a brief report back on INVOLVE's November 2008 National Conference.

All members had been circulated with the feedback comments from delegates and she reported that the Conference report would be available in February 2009. Kate made the following summary points:

- it was agreed that it had been a good, enjoyable conference with nearly 390 delegates;
- we should use the same venue for the next conference;
- the conference has a budget deficit of approximately £10,000 (2008/2009) which is due to additional venue / IT costs and the higher number of bursaries and community based delegates that attended;
- Kate gave special thanks to existing Conference Planning Group members for the two year commitment into the planning process as well as the long hours spent reading and commenting on the presentations submitted.
- Strategic Alliances will take forward the appointment of a new chair for the next Conference Planning Group (2009/2010). Kate offered to provide a mentoring role to the incoming chair.

Group members were asked for feedback. One suggestion was that the conference had been too hectic and should be more streamlined in future. However it was agreed that it had been made clear that delegates had the choice to attend sessions or take time out if they wished to.

Nick thanked Kate for her role as Chair of the Conference Planning Group and for the huge amount of work that had been involved in making it such a success. Maryrose Tarpey was also thanked for her role within the Support Unit.

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## **9. Reports from working groups and plans for 2009/2010**

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	- Rosemary Barber

Please see separate minutes for each working group.

The chairs then outlined their proposed plans for 2009 / 2010.

### **Evidence, Knowledge and Learning (EKL)**

- invoNET
- Dissemination of publications
- Dissemination of the findings of the Impact Study – to include a set of publications targeted at different groups and a possible event

- Development of a short set of case studies to illustrate how people have evaluated public involvement in their research – different approaches in a diverse range of projects
- Work generated as a result of the findings of the Impact Study
- How do we put evidence into practice? – developing thinking around implementation of evidence

### **Strategic Alliances (SA)**

- Conference – disseminate 2008 materials
- Conference – oversee plan for 2010
- Continue work on social care examples
- Communications / awards
- Continue to develop work on mapping INVOLVE’s strategic alliances
- The work on the social care examples was discussed in detail. It was agreed to work in parallel with the user controlled examples project in the planning of phase 2 for both pieces of work. The senior investigators examples were also identified as a third important strand and members recommended that all three pieces of work should be connected together.

### **Empowerment**

- Research Design Services – mapping / others / training
- Examples work (user controlled and social care) – to include seldom heard groups
- Empowering social care researchers
- Intelligence gathering – support needed
- Monitoring of public involvement in grant applications to funders (recommendation to EKL)

### **10. Directors report**

Sarah reported that final expenditure for 2008 / 2009 would be higher than originally budgeted due to the conference costs (see above).

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

None reported

### **13. Dates of future meetings**

Tuesday 21 April 2009

09 and 10 September 2009 (awayday)

Wednesday 09 December 2009

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