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**Notes of the fortieth meeting of INVOLVE  
held at the  
The Kings Fund, Cavendish Square, London W1  
Thursday 08 June 2006**

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**Present:** Nick Partridge (Chair)  
Kate Sainsbury (Vice Chair)  
Sue Banton  
Peter Beresford  
Sarah Carr  
Karen Collins  
Stuart Eglin  
Alison Faulkner  
Lester Firkins  
Vinod Kumar  
Maria Palmer  
Susie Parr  
Bob Revell  
John Sitzia  
Sophie Staniszewska  
Tracey Williamson

**In attendance:** Dawn Duncan (Medical Research Council)  
Marianne Miles (UK Clinical Research Network UKCRN)  
Kay Pattison (Department of Health)

Sarah Buckland (Support Unit)  
Sarah Bayliss (Support Unit)  
Barbara Dawkins (Support Unit)  
Helen Hayes (Support Unit)  
Jane Royle (Support Unit)  
Roger Steel (Support Unit)  
Maryrose Tarpey (Support Unit)  
Philippa Yeeles (Support Unit)

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## **1. 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 thanked the Group for the messages of support at his announcement that he will be staying on as chair of INVOLVE for a further eighteen months.

Nick welcomed Dawn Duncan from the MRC to the meeting. He reported that in future either Simon Wilde or Dawn Duncan would attend as observers to the Group replacing Elizabeth Mitchell and Joan Box.

Nick also welcomed Rachel Purtell from Folk.Us in Exeter. Rachel would be joining the Empowerment sub-group as a temporary member. (Rachel was unable to stay for the main Group meeting).

### **Apologies**

Apologies had been received from:

- Vanessa Pinfold
- Mary Nettle
- Morton Phillips
- Chris Caswill
- Carol Lupton
- Deborah Tallis
- Rachel Purtell

### **Farewells**

Nick said goodbye to Vinod Kumar and thanked him for his excellent contribution during his time on the Group.

Nick also bid farewell to Philippa Yeeles, who was leaving to join the UKCRC as a Programme Manager where she would be taking the lead on patient and public involvement.

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## **2. Notes of the meeting held on 15<sup>th</sup> March 2006**

It was noted that Susie Parr was not included on the attendance list for the March meeting.

**Action: Admin to amend the minutes accordingly.**

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

Sarah apologised for the error that had come to light in the budget at the last meeting.

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## **4. Public involvement and the Medical Research Council (MRC) Dawn Duncan, MRC**

Dawn reported that her post at the MRC was part of the MRC Corporate Affairs Department. Her role was to support public involvement and consultation.

The main points of her talk were as follows:

- The MRC have always had a degree of public involvement, although this has moved on. The 16 member MRC Advisory Group on Public Involvement (AGPI) has gone through transition and more recently the group has been chaired by Colin Blakemore (Chief Executive of the MRC).
- The new Health Research Fund means more collaboration with the UKCRC. This has meant that there are new drivers to make public involvement in the MRC much broader.
- There was now involvement in specific projects, such as in being members of steering groups. The MRC now require that all trial protocols should be developed in discussion with the relevant patient groups.
- The MRC is proposing to introduce a new Public College of Experts in order to capture lay expertise from various backgrounds. This would mean for example that for the peer review of research applications, a very large and broad group of lay experts could be called upon. It also meant there could be a matching service, linking public experts with research projects.
- The MRC has decided to commission research on public views on the use of secondary personal medical data following the Academy of Medical

Sciences (AMS) report. This will be both qualitative and quantitative to draw out majority versus minority public views on the use of medical data.

The following questions were asked by Group members:

- What influence do service users have in the running of the MRC?
- What resources were available to cover the costs of public involvement?
- What are the comparative budgets for the Public College of Experts as opposed to that for professionals / researchers?
- How do you define 'experts' in respect of the Public College of Experts and how will people be recruited?

Nick Partridge raised concerns over the brief for commissioning the work on the use of patient data, where he felt the wording seemed to be biased towards the belief that the use of patient data without consent was a good thing and the public needed to be persuaded.

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## **5. What's new in the Department of Health (NHS R&D and PRP)**

Kay Pattison thanked Nick Partridge for agreeing to stay on as chair of INVOLVE.

Kay reported on the following:

- Cooksey Review of UK Health Research

Kay reported that the Department of Health are delighted that the research and development budget is going to be ring fenced. INVOLVE will be responding to the consultation.

### **Action: INVOLVE responding to the Cooksey review of UK Health Research**

- National Institute for Health Research (NIHR)

The NIHR website has been launched and the Central Commissioning Facility (CCF) website is up and running. The Laboratory of the Government Chemist (LGC) were successful in gaining the contract. The Research for Patient Benefit (RfPB) programme will mean there will be a lot of funding opportunities. The role of INVOLVE and the Support Unit is very important in ensuring public involvement is at the core of the commissioning process and ensuring other work is learned and shared. The Programme Director for RfPB, Celia Davies, is very enthusiastic about public involvement. It was suggested that the Group might invite her to a future INVOLVE meeting.

- UK Clinical Research Collaboration (UKCRC)

The UKCRC has produced a report entitled 'UK Health Research Analysis'. The report gives a good picture of R&D funding in the country and where the imbalances are.

**Action: Support Unit to circulate the email address ([www.ukcrc.org](http://www.ukcrc.org)) and request copies for those who would like hard copies.**

**Note: Please inform the Support Unit if you would like to be sent a hard copy.**

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## 6. Director's Report

Sarah Buckland thanked Philippa Yeeles and wished her good luck in her new job. She reported that she hoped to advertise her post in a couple of weeks and that the new person would start in September.

Sarah also advised the Group that she was pleased that Jane Royle had now become a member of the Involve Support Unit and employee of University of Leeds, and was no longer seconded from the University of Southampton.

Sarah reported that the University of Leeds had recently introduced a new system for reporting of finances which had caused some difficulties. She advised that there might be some minor discrepancies in the budget figures once the final accounts were received from the University.

Sarah reported that overall, the budget was underspent by approximately £5,000 in the last financial year. She advised this was largely due to the delay in INVOLVE being able to commission some of the work planned by the Empowerment sub-group, as a result of the restriction on expenditure by the Department of Health at the beginning of 2006.

Sarah referred the Group to the annual activity statistics of the Support Unit and advised that the most popular downloads were:

- True report
- Briefing Notes for Researchers
- Conference 2004 abstracts

## **7. Legal obligations and liabilities of public involvement in research – annex F**

Sarah Buckland explained that INVOLVE had been working on this issue with the NHS R&D Forum and Department of Health. A brief powerpoint presentation by Sarah highlighted the need to address five specific questions related to plans to develop guidance (see below). Sarah invited suggestions for additional questions or issues to address.

- When do members of the public require an honorary contract?
- When do members of the public require occupational health interviews?
- When are members of the public not covered by NHS indemnity arrangements?
- What are the personal liabilities of members of the public
- Can members of the public be named as researchers or co-applicants on research proposals?

### **Discussion by the Group:**

The following points were raised:

- When and how often do members of the public require Criminal Records Bureau (CRB) checks?
- The need to think about different levels of legal obligations and liabilities for different types of involvement.
- There was general agreement on the importance of working with Human Resources (HR) departments within NHS Trusts particularly on their use of occupational health interviews.
- Important to draw on known examples of the difficulties encountered by Group members and others in relation to occupational health checks
- How best to link this work to the Research Passport Scheme which is currently being considered by NHS lawyers, but plans to establish a comprehensive passport system with common principles.
- Reference to the rolling out of a single R&D management structure which should help progress these issues.

In conclusion the Group supported the joint working approach on this and agreed that it was an important area of work. Sarah asked for volunteers from Group members to help her take this work forward.

**Action: Sarah Buckland to continue to work with the NHS R&D Forum to take this work forward.**

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## **8. UK Clinical Research Collaboration and Public Involvement - update**

Maryrose Tarpey gave a presentation to the Group.

She advised the Group that the UKCRC Public Involvement Project Group is chaired by Roger Wilson (Chair of the National Cancer Research Institute Consumer Liaison Group). She reported that the role of the Group was to bring together partner organisations who have an interest in promoting public involvement in clinical research.

The presentation outlined the four proposed joint projects of the Group, some of which are pieces of work that will complement the work of INVOLVE.

1. Development of criteria for patient and public involvement in research for adoption by funders when assessing research applications.  
(There is some cross over between this work and the commissioning guidelines developed by INVOLVE).
2. Training for new Clinical Fellows in patient and public involvement in research. Exploring opportunities to embed patient and public involvement in new job roles within the NIHR Faculty.
3. Building an evidence base. The gathering of evidence from different research sectors to illustrate where involving patients and the public was a) ignored and would have added value; b) included and clearly added value to the process and outcomes of research.  
(There is a crossover between this work and that of two Evidence, Knowledge and Learning Projects: invoNET and the scoping study of the evidence of the impact of public involvement in research).
4. Consumers in Clinical Research Exchange / Clearing House.

This clearing house would be web-based and aim to i) promote patient and public involvement in clinical research; and ii) allow those interested to quickly and simply express that interest to one or more of the participating organisations.

Discussions covered:

- Need to consider maintenance of the clearing house to ensure information was current
- Need to provide support and guidance to help people through the process

- Ensuring a good ‘quality’ experience for those expressing an interest in being actively involved
- Need to inform people of the stage at which patients and service users can be involved in the research
- Concern that in the future the exchange might be used to recruit participants to trials
- The importance of the location of the website / clearing house
- Possibility of ‘kitemarking’ websites where actively involving the public
- Clinical trials being provided with a ‘kitemark’ to identify those who have actively involved people who use services in the development of the trial.

**Action: Maryrose Tarpey and Sarah Buckland to continue to work with the UKCRC in the further development of the plans for joint working on public involvement.**

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## 9. James Lind Alliance (JLA) – update

Lester Firkins updated the Group on the work of the James Lind Alliance and invited their comments on the initiative either at the meeting or by email. A diagram outlining the role of the Database of Uncertainties about the effects of treatments (DUET’s) and the James Lind Alliance was tabled along with information on the organisations affiliated to the James Lind Alliance.

The current objectives of the JLA are to:

- Conclude the priority setting cycle of the JLA Asthma Working Partnership
- Establish two further JLA Working Partnerships
- Adopt lessons learnt from the piloted working partnerships and other models
- Work with the UK Clinical Research Network (UKCRN)
- Collaborate with other organisations.

Lester updated the Group on the progress of the following JLA Partnerships and areas that they are developing relationships with:

- Asthma
- Epilepsy
- Schizophrenia
- Rheumatoid Arthritis

Further information on their work is available on the James Lind Alliance website <http://www.lindalliance.org/>

Discussions took place on:

- The importance of finding out what research priorities are important for patients
- Funding decisions based on service user priorities
- Researchers prioritising ideas alongside service users
- The challenge of ensuring that the broadest selection of people contribute their views
- How service users can get involved in the prioritising process.

The Group thanked Lester for his commitment and the hard work he contributes on behalf of INVOLVE. It was recognised that the JLA was an important piece of work which will take time to develop.

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## **10. INVOLVE Conference - update**

Kate Sainsbury reminded everyone to complete a booking form for the INVOLVE Conference if they wished to attend. Kate advised the Group that the next conference planning meeting would take place on the 20<sup>th</sup> July. She reported that the conference report would focus on the themed sessions.

She thanked volunteers for chairing themed sessions and advised that requests for more help would follow.

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## **11. Reports from sub-groups**

Verbal reports were received from the following:

Empowerment	Kate Sainsbury
Strategic Alliances	Stuart Eglin
Evidence, Knowledge and Learning	Sophie Staniszewska

Please see the individual minutes for notes of these meetings.

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## **12. Any other urgent business**

None reported

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**13. Dates of future meetings**

11<sup>th</sup> / 12<sup>th</sup> October 2006 (dinner only on the 11<sup>th</sup>)  
Thursday 14<sup>th</sup> December 2006

**INVOLVE Conference 6<sup>th</sup> – 7<sup>th</sup> September 2006**

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