

**Notes of the 69th meeting of INVOLVE  
held at the  
Kings Fund, 11 - 13 Cavendish Square,  
London W1G 0AN**

**Wednesday 10 September 2014**

---

**Present:**

Simon Denegri (Chair am)  
David Evans (Chair pm)  
Ade Adebajo  
Jonathan Boote  
Louca-Mai Brady  
Ann-Louise Caress  
Tina Coldham  
Lynne Corner  
Rosemary Davies  
Jo Ellins  
Linda Laurie

Tara Mistry  
Carol Rhodes  
Diana Rose  
Tony Sargeant  
Patsy Staddon  
Veronica Swallow  
Lizzie Thomas  
Christine Vial  
Amander Wellings  
Patricia Wilson

**In attendance:**

Roger Steel  
Katalin Torok  
Tony Williams  
Sarah Buckland  
Sarah Bayliss  
Paula Davis  
Erica Ferry  
Helen Hayes  
Martin Lodemore  
Maryrose Tarpey

Clinical Research Network  
Central Commissioning Facility  
Department of Health  
INVOLVE Coordinating Centre

“  
“  
“  
“  
“  
“

**Apologies**

Pam Carter  
John Hughes  
Marisha Palm

Kay Pattison  
Una Rennard  
Lesley Roberts

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

Simon welcomed Katalin Torok from the Central Commissioning Facility to the meeting. He thanked Jonathan Boote for preparing a presentation for the afternoon session, which would be chaired by David Evans as Simon had to attend a meeting at the Department of Health.

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

No conflicts of interest were declared.

---

## **2. Notes of meeting held on 7 - 8 May 2014 and any actions arising**

Apart from the NHS England item (see below) it was agreed that the notes were a fair and accurate record of the last meeting.

### **Matters arising**

#### **NHS England (item 5, page 7)**

The description in the meeting notes of the collaborative work underway in the West of England with the Health Integration Teams is inaccurate.

**Action: Rosie Davies to send suggested amended wording to Sarah Buckland for correction of the description of Health Integration Teams.**

### **Business meeting**

#### **Care.data**

Simon updated on progress around Care.data and reported that he is now on the programme board, which will be meeting in November 2014 to agree its mission and vision. Tony Sargeant provided some reflection on the Health and Social Care Information Centre meeting he attended in July when Care.data was discussed.

---

## **3. Chair's hot topics**

### **National Institute for Health Research (NIHR) Public involvement review findings**

Simon reported that the review panel had reflected on the evidence and that they would be meeting on 11 September and 17 October to distil the findings into a report and recommendations, which are due to be published before the INVOLVE conference. Tina Coldham and Tara Mistry are on the panel and Sarah Buckland is an observer. Simon gave a presentation on the review.

Simon invited feedback from Group members. Comments included:

- Recognising capacity and capability and support needs - acknowledging in the report that some groups were unable to respond to the review.
- Confusion that exists about the different parts of the NIHR.
- What success looks like and the importance of metrics reporting on patient and public involvement.
- The risk that when public involvement becomes embedded it also becomes invisible.
- Diversity and inclusion – existing models of patient and public involvement attract particular types of people to get involved. There is a need to look at who we are excluding unintentionally.
- There is a risk that the absence of evidence is seen as a problem. There is a distinction between evidence used to prove and evidence used to learn. There is a need to be more creative about how evidence is presented and framed.
- Having a NIHR-wide definition of language is important but it is equally important to look at charity and university sectors, who are increasingly using ‘engagement’. Researchers are getting mixed messages.
- Accountability has not come through as strongly as expected in the evidence but this may be due to the questions asked.

**Action: Simon to provide a preview of the Breaking Boundaries report to INVOLVE Group members prior to publication.**

---

#### **4. Director’s report**

Sarah Buckland explained that this session was to provide more detail on some of the projects that the Coordinating Centre is currently working on and to invite input from Group members, particularly on the topics of learning and development and young people.

#### **General update on INVOLVE activities**

##### **Coordinating Centre staff**

- Sarah Bite has started maternity leave.
- Marisha is continuing to work on specific projects. Other members of the Coordinating Centre have taken up some of Marisha’s work in the interim.

##### **INVOLVE publications**

- Sarah invited Group members to let the Coordinating Centre know if they would like hard copies of INVOLVE documents that have been published on the website, for example the invoNET roundtable and Senior Investigators reports.
- The slides from the user controlled research webinar are now on the INVOLVE website.
- The internal payment document has been updated to include clarification about new benefit details. The general payment document is also being updated.

**Action: Martin to send Group members the link to the revised internal payments document when it is published on the website.**

### **Bedford Citizens Advice Bureau (CAB) helpline**

The pilot helpline to provide advice on welfare benefits is nearly in place. The Department of Health through INVOLVE, NHS England, Social Care Institute for Excellence, Involving People (Wales) and others will all be contributing to the costs of the helpline. A question was raised about whether there was any scope for rolling this out for other organisations to use. Sarah responded that while this is possible in principle there is a concern that the CAB might be overwhelmed, so this will be reviewed after the pilot year. In the meantime, if people are experiencing real difficulties, we might be able to filter them through the contributing organisations.

**Action: Sarah Buckland to let Group members know when the Bedford Citizens Advice Bureau helpline is up and running.**

### **Social media**

The draft guidance on social media and the use of public involvement in research is currently out for review. The final version will be published in time for the INVOLVE conference. A Twitter feed is up on the website.

### **Values principles and standards for involvement**

A draft document is currently with some INVOLVE group members for comment. The Group working on this is chaired by Ade Adebajo.

### **National Institute for Health Research website**

Helen and Gill have been heavily involved in the development of the website. Amander Wellings and Lesley Roberts were thanked for commenting on the web pages.

### **Examples of involvement and efficiency**

Sarah reported that discussions at the National Institute for Health Research Strategy Board focused on the next comprehensive spending review and an increasing emphasis on efficiency and effectiveness for research. INVOLVE Group members were asked to send the Coordinating Centre examples of where public involvement had influenced efficiency and effectiveness.

**Action: Group members to send Sarah Buckland brief details of any examples of where public involvement has improved the efficiency and effectiveness of research.**

### **INVOLVE 2014 conference**

Martin outlined the conference programme, which will include pre-conference sessions for people new to the INVOLVE conference and an international networking session. Simon will give the welcome speech and Russell Hamilton will give the keynote. There will be an interactive question and voting session led by Sally Crowe, followed by nine parallel sessions and a plain English poster prize to be awarded at dinner on day one. Day two will include an overview of the Breaking boundaries review from Simon; a 'Question Time' session led by Tina, with Ade, Ann-Louise,

Maggie Wilcox and Peter Beresford on the panel; more posters and parallel sessions; and a soapbox during lunch. Just over 300 people have registered to date, including nearly all Group members. Group members discussed accessibility concerns and suggestions included using colours and shapes to identify rooms. Sarah advised that the Coordinating Centre would be working with Professional Briefings and a local disability group to plan for accessibility.

**Action: Martin Lodemore will be in touch with Group members to seek their assistance with the conference. Any members willing to chair or facilitate sessions to let Martin know.**

**Action: If members have any further suggestions for improving accessibility at the conference to get in touch with Sarah Buckland, Martin or Maryrose.**

### **Public involvement leads day**

Sarah reported that 100 people attended this event, the report of which has just been sent out for comment and will be published on the website. Some of the discussions from the meeting will be considered by the INVOLVE facilitated NIHR wide public involvement, engagement and participation strategy forum.

### **Learning and development working group**

This was a time-limited group, chaired by Simon. The Group is in the process of writing the final draft report and recommendations. The report will be sent to Russell Hamilton and others at the National Institute for Health Research.

**Action: Simon to ask the Breaking Boundaries panel to embrace the recommendations of the Learning and Development working group.**

### **Involving and engaging young people in research**

Helen demonstrated the children and young people web pages, which are currently under development. There is a page featuring current resources, which Jenny Preston and the CRN Medicines for Children advisory group will be commenting on. This group is also involved in the development of a second page focusing on the difference that involving young people will make to researchers. Group members welcomed these additions to the website, and several offered to discuss with Helen ideas for further developing the pages. Suggestions included involving young people in service redesign (Tara), sharing resources across different research teams and initiatives (Rosie) and involving parents and carers (Veronica and Louca-Mai).

Simon reminded Group members that Louca-Mai and Jenny Preston had presented on this topic at the INVOLVE symposium. The INVOLVE Advisory Board had then discussed three potential actions for INVOLVE arising out of the symposium discussions:

- Undertake a mapping exercise
- Produce a package of information signposting people
- Help strategically by bringing organisations together.

Simon asked Group members which of these they would like to focus on. It was agreed that we are already working on producing a package of information through the new web pages. There was common consensus that bringing organisations

together was the best place to start and that a mapping exercise might come out of this. If we wanted to hold a bigger event, that would need to be built into next year's plans but we could convene a small group to begin discussions.

**Action: Helen Hayes to further develop INVOLVE webpages on involving young people. To include discussions with Rosie Davies and Louca-Mai about initiatives they are involved in.**

**Action: Coordinating Centre to explore bringing a small group together to discuss organising an event to help strategic thinking to support involvement of young people in research.**

---

## **5. Information exchange**

Written updates from Group members were included in the papers for this meeting. The following Group members provided verbal updates: Amander, Carol, Veronica, Ann-Louise, Lynne, Jonathan and Diana. David thanked everyone for sharing their useful updates and encouraged members to email each other to obtain further information about items they are particularly interested in.

**Action: Group members to email Ann Louise if they would like a copy of the training needs analysis survey mentioned in her written update.**

**Action: Lynne Corner to circulate details of forthcoming Voice North event in November.**

**Action: Jonathan Boote to send details of a paper that he has just had accepted so that INVOLVE can circulate to Group members.**

**Action: INVOLVE to update Ground rules for INVOLVE meetings to amend the reference to switching off mobile phones to putting mobile phones on silent.**

---

## **6. Evaluating PPI in the NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre (speaker: Jonathan Boote)**

Jonathan's presentation included the following topics:

- The background to the Greater Manchester Primary Care Patient Safety Translational Research Centre and the work it does.
- The Centre's website: [www.population-health.manchester.ac.uk/primary-care-patient-safety/](http://www.population-health.manchester.ac.uk/primary-care-patient-safety/)
- Patient and public involvement in the work of the Centre.
- Evaluating the impact of patient and public involvement in the Centre – the evaluation methodology, challenges to the evaluation, concerns raised and some interim quantitative data. Jonathan will be presenting more findings at the INVOLVE conference.

Group members were then invited to ask questions and comment on Jonathan's presentation.

**Action: Jonathan Boote to email his PowerPoint presentation to INVOLVE for circulating to Group members.**

---

## **7. Future topics for INVOLVE Group meetings**

At the last Advisory Board meeting it was agreed that there should be a rolling list of topics for discussion at INVOLVE meetings. INVOLVE members will be invited at meetings to suggest topics which would then be used to assist the INVOLVE chair and Advisory Board members in planning for future group meetings. David encouraged Group members to think creatively about potential topics to explore at future meetings.

Suggestions included:

- Discussing the process of involvement in the context of patient benefit and patient experience as a result of involvement.
- Methods for undertaking evaluations of public involvement within new structures.
- Costs and consequences: benefits, consequences and health economics related to public involvement in research.
- How public involvement can be linked with mandatory training and the mechanisms for doing this.
- Resourcing of patient and public involvement in the new landscape, particularly the resourcing of groups.
- How we can move forward and where we want to be in 5-10 years time but also retaining what we have and the threats and challenges to this.
- Co-applicants – guidelines for researchers and co-applicants and work being undertaken in this area.
- Debate about the good things we can promote and the bad things we can stop happening.
- Invite speaker from York Centre for Reviews and Dissemination (CRD) on evidence based patient and public involvement.

**Action: Suggestions from Group members for future discussion topics at INVOLVE meetings to be incorporated into a rolling list of ideas to be considered at Advisory Board meetings.**

---

## **8. Any other urgent business**

### **Trainees Coordinating Centre conference posters**

The Trainees Coordinating Centre is looking for members of the public to judge plain English in the posters submitted for their conference, which will be held on 10-11 November 2014. The deadlines for this are quite tight with the shortlist to be agreed 24-26 September. Group members were asked to let the Coordinating Centre know if they were interesting in judging the posters.

---

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

26-27 November 2014: INVOLVE Conference, National Exhibition Centre, Birmingham.

Wednesday 21 January 2015: INVOLVE Advisory Group meeting, King's Fund, London.

---