
**Notes of the Fifty first meeting of INVOLVE
held at
The Kings Fund, London
Tuesday 21 April 2009**

Present: Nick Partridge (Chair)
Stuart Eglin
Mary Nettle
Anne-Louise Caress
Sophie Staniszewska
Poonam Jain
Patsy Staddon
Rosemary Barber
Diana Rose
Ade Adebajo
Hugh McLaughlin
Angela Barnard
David Evans
Richard Baker

In attendance: Tony Williams – Department of Health (DH)
Kathy Mann – 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
Barbara Dawkins – Support Unit
Helen Hayes – Support Unit
Maryrose Tarpey – Support Unit
Lucy Simons – Support Unit
Philippa Yeeles – UK Clinical Research Collaboration
(UKCRC)

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 Philippa Yeeles, Joint Director of Operations, UKCRC who would be giving a presentation. He also welcomed Catherine Mann from the Department of Health who would also be part of the Conference Planning Group.

Nick reported that this was Chris Caswill's last meeting; Nick thanked him for all his hard work. He also advised the Group that Mary Nettle and Peter Beresford had been invited to stay on the INVOLVE Group for a further two years.

Apologies

Apologies had been received from:

- Chris Caswill (attended working group meeting)
- Hala Ahmed
- Kay Pattison
- Karen Collins
- Laura Serrant-Green
- Susie Parr
- Alison Faulkner (attended working group meeting)
- Sue Banton
- Peter Beresford
- Jim Elliott
- Louca-Mai Brady
- Tracey Williamson
- Simon Denegri
- Maria Palmer
- Vanessa Pinfold
- Mark Petticrew
- Sarah Carr (attended part of working group meeting)
- Ray Fitzpatrick
- Karen Postle

2. Notes of the meeting held on 20 January 2009 and actions taken since the meeting

Nick reported that at the last meeting the only action was for him to circulate the INVOLVE response to the National Institute of Health Research (NIHR) and Medical Research Council (MRC) 'Setting the National Ambitions for Health Research'; this had been done.

He also updated the Group to let them know that INVOLVE had commented on the draft strategy from the Office for Strategic Coordination of Health

Research (OSCHR) 'identifying and prioritising UK health research opportunities over the next decade'. Nick read a quote from the response: 'The draft strategy outlines ten areas which your invited experts identified as meriting significant opportunities for health research. It is ambitious in its scope and purpose. However we note that no reference is made to public involvement either in the development of the research strategy itself or as part of the cross-cutting framework intended to implement the research programme.

The strategy aims to directly impact on health outcomes and patient benefit using new and developing research approaches. Consequently we recommend that the final version of the strategy reflects this by including a commitment to embed public involvement within each of the work streams.

We would be happy to work with colleagues at OSCHR to develop a suitable process by which public involvement can be ensured'.

Nick highlighted that the INVOLVE Support Unit is now to be called the INVOLVE Coordinating Centre. This followed feedback from Group members that 'Support Unit' didn't adequately describe the Unit's role and would bring them in line with other Coordinating Centres.

3. Directors report

Coordinating Centre staff provided an update on the recent activities of INVOLVE.

Helen reported that in June 2008 we had been invited to recommend to the Methodology Research Programme suggestions for topics for funding within the programme. We recommended there was a need for research looking at methods for assessing the impact of public involvement in research. The proposal has been developed and discussed by the Methodology Panel during the last 12 months and we have recently been informed that the funding brief will be advertised in the next couple of months.

Action: Helen to circulate the Methodology Programme funding brief to Group members when advertised

Sarah reported on the Survey of Research Ethics Committee lay members which has recently been completed on behalf of the National Research Ethics Service (NRES). She would be discussing the implications of the findings of the survey at the next meeting of the NHS NRES Service User and Carer Group.

Action: Sarah Buckland to discuss the findings of the NRES survey at the next meeting of the NHS NRES Service User and Carer group.

Lucy reported that she was currently revising the INVOLVE payment guide with the help of Judy Scott. It was suggested by one Group member that the fees should be increased. Sarah reported that she would be reviewing the rates with the National Institute for Health Research (NIHR) Research Programmes.

Action: Coordinating Centre to review the payment rates for public involvement with the NIHR Research Programmes

Lucy advised the Group that the Milton Keynes Citizens Advice Bureau Involvement Helpline was now set up to provide a service to members of the public involved with INVOLVE, the NIHR Research Programmes and the Research Design Services.

Nick hoped that all Group members would use the service if needed and promote it to the NIHR Research Programmes and the Research Design Services.

Action: Lucy to circulate details about the Milton Keynes Citizens Advice Bureau Involvement Helpline

Sarah commented that the slides included in presentation packs for INVOLVE Group members had printed incorrectly. However the electronic version originally sent out was correct.

Ann commented that according to the forms for the Research for Patient Benefit (RfPB) programme a NHS partner was needed which was difficult for user led research.

Sarah reported that she was attending a workshop for lay panel members of the RfPB and would raise this.

It was suggested that a NHS partner was probably just a financial requirement.

Action: Coordinating Centre to follow up to see how difficulties for user led research could be facilitated with the RfPB programme.

Sarah reported that INVOLVE had been contacted by a number of the newly formed NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRCs).

There was discussion around the role INVOLVE was taking in supporting CLAHRCs.

It was reported that the Service Delivery and Organisation Programme (SDO) are commissioning an evaluation on CLAHRCs but this doesn't explicitly include evaluating public involvement. However this may be a separate piece of work.

Action: Coordinating Centre to find out from SDO if there are plans for evaluation of public involvement of the CLAHRCs.

4. 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.

After Sophie reported on the Evidence, Knowledge and Learning one suggestion for a good way to disseminate findings, especially from the conference, was to use U-tube or Facebook.

Action: Coordinating Centre to look into the option of using different media for disseminating findings

After Stuart reported on Strategic Alliances the following ideas were suggested for making links:

- Influencing academic PhD students
- Influencing journalists
- Liaise with Academic Health Science Centres (Kings, UCL, Imperial, Cambridge, Manchester)

In response to David's report on Empowerment the following discussions took place:

- examples of local mapping that was going on around the country
 - The importance of supporting service users who wish to get involved.
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5. Operational Plan

INVOLVE Group members discussed the Draft Operational Plan 2009 / 2010 which they felt reflected their plans for 2009 / 2010.

Concern was expressed as to how the unforeseen opportunities and activities will be funded and as to whether the Group should be looking for additional funding from the Department of Health. Following discussion it was noted that the Department of Health were committed to patient and public involvement in research and that historically they had assisted with additional funding when required.

The Report outlines in the background section how the activities relate to the seven strategic priorities of INVOLVE. This breakdown was felt to be helpful however it was agreed that if the activity fits neatly into one or two of the strategic objectives then it would be sufficient just to be listed under these headings.

The following comments and amendments were suggested to the report:

It was suggested that a valuable addition to the report would be to showcase and demonstrate the influence and impact INVOLVE is having within the research community.

Appendix 1 – Empowerment: Item C – Empowering and supporting researchers and service users in health and social care research should be changed to read ‘all’ under areas covered.

The Director to consider if any minor amendments are required to the report following working group discussions earlier in the day.

To add additional sentences on the work INVOLVE is carrying out with the NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) and the UK Clinical Research Collaboration (UKCRC).

Action: Coordinating Centre to make amendments to the Operational Plan as suggested.

6. Philippa Yeeles, Joint Director of Operations, UK Clinical Research Collaboration (UKCRC): Public involvement in strategic decision making

Philippa Yeeles gave a powerpoint presentation reporting on a UKCRC workshop held in March 2009 to consider public and patient involvement in strategic decision making. Paper copies of this powerpoint presentation were handed out at the meeting and are available as a separate document.

This workshop aimed to explore issues that had been raised by some members of the UKCRC Patient and Public Involvement Board who sit on various boards linked to strategic decision making groups within research organisations. It also follows up our discussion at the January 2009 INVOLVE meeting when members highlighted some of their reflections on the challenges of membership of various boards linked to implementation of the NIHR strategy.

After briefly giving some background information on the UKCRC's main activities and showing the extent to which each of the workstreams has public involvement Philippa focused on the workshop. She provided:

- a working definition of strategic decision making as:
‘The process of identifying options and selecting between them in order to make choices with long term implications for an organisation or for an activity – broadly the difference between writing a menu for a restaurant and choosing from a menu.’
- a summary of the discussions at the March 2009 workshop:
The workshop was attended by about 20 people all involved in strategic decision making as patient or public members with research organisations. They identified core, shared challenges of performing these roles and began to think about what would be helpful to support the role, building capacity and next steps needed to be undertaken for development work on this issue.

Philippa finished her presentation by emphasising that for future sustainability any work undertaken in 2009 will need the active support of INVOLVE and asked for INVOLVE members views on taking this work forward.

In the discussion that followed members made it clear that they viewed this as an important area of work for INVOLVE to commit to. INVOLVE needs to be prepared to provide a leadership role to other UKCRC partners on this issue. However we also need to look at what it will entail in practice and how this work will be resourced.

A report of the workshop will be available shortly and will be circulated to INVOLVE members.

7. Reports from Observers

Melanie Knetsch, Economic and Social Research Council (ESRC)
Melanie presented information about the ESRC and the Science in Society programme. She noted that the ESRC fund a diverse range of research topics which create challenges as the different disciplines have different needs. They have developed a series of definitions to help clarify what is meant by public involvement.

Stakeholder – anyone who could be affected/influenced by research (e.g. government, other funders, academics, business, 3rd sector and the public)

User – anyone who can potentially apply the results or output of the research directly to their policy, practice or working environment

Engagement – an umbrella term for any Science in Society activities from science communication in science centres or festivals, to public dialogue (the latter is close to involvement).

She noted the ways in which the public were currently involved in the ESRC, including the cross council life-long health and wellbeing initiative (the public involved with this programme had changed the name from the ‘Ageing’ programme). Further developments were planned, including assessment of the impact for the user in research funding applications, users and the public

are getting involved with commissioning, and members of the public were joining advisory panels at strategic levels. She noted that any changes need to happen across the council. She believed this required a change in the internal culture of the ESRC and therefore would take some time to implement.

Tony Williamson, National Institute for Health Research (NIHR)
Tony was delighted to announce that Kay Pattison had been awarded her PhD from the University of York.

The NIHR had recently marked its third birthday and Tony summarised some of the ways in which the NIHR was affecting the research agenda, for example, the Biomedical Research Centres, the Central Commissioning Facility and NIHR Evaluation, Trials and Studies Coordinating Committee. Other recent developments include:

- NIHR Research Methods Fellowships and Internships. £2 million has been announced for developing methodologies for applied health research in areas such as statistic, health economics and clinical trial design. These were not just for researchers in health care but also for people from other areas who are interested in developing their expertise in applied health research.
- A new Biomedical Research Centre in Leicester had been announced focusing on cardiovascular disease
- A range of bids were currently available including one for Technology Assessment Review (TAR) teams.

Roger Steel, NIHR Clinical Research Network Coordinating Centre (CRN CC)
Roger reported that the Coordinating Centre and topic specific research networks had recently had their four year reviews. It was an interesting process and he was currently looking at the patient and public involvement (PPI) feedback. The emerging issues were that PPI had hit the ground and while it was established in all networks it was not yet fully embedded. He thought there needed to be a change of thinking to bring senior people from the networks into PPI. This would ensure everyone is clear what PPI is about and the PPI leads get the support they need. A clear theme of isolation for the people working in PPI posts was apparent.

He reported it was an exciting time for PPI in the CRN CC as they were developing a new strategy. Derek Stewart has been appointed Associate Director for PPI in the CRN CC while Roger Wilson was still acting as an adviser, especially to industry. Marianne Miles has now returned from maternity leave.

Nick noted that members of INVOLVE had been involved with the reviews and it would be helpful if Roger could feed back what had come out of this process, either at the away day or the next INVOLVE Group meeting.

8. Any other urgent business not included on the agenda

None.

9. Dates of future meetings

09 and 10 September 2009 (awayday) – Latimer Conference Centre
Wednesday 09 December 2009 – The King’s Fund
