

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

Thursday 16 January 2014

Present:	Ade Adebajo (Chair PM) Lizzie Amis Jonathan Boote Louca-Mai Brady Ann-Louise Caress Pam Carter Lynne Corner Simon Denegri (Chair AM) David Evans John Hughes Linda Laurie	Tara Mistry Una Rennard Carol Rhodes Lesley Roberts Diana Rose Tony Sargeant Patsy Staddon Veronica Swallow Christine Vial Amander Wellings Patricia Wilson
In attendance:	Ian Cook Pete Fleischmann Kay Pattison Sarah Buckland Sarah Bayliss Erica Ferry Helen Hayes Sarah Bite Marisha Palm Maryrose Tarpey	Health Research Authority Social Care Institute for Excellence Department of Health INVOLVE Coordinating Centre “ “ “ “ “ “
Apologies	Jo Ellins Tina Coldham Rosemary Davies Roger Steel Tony Williams	

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

Notes of Meeting held on 25/26 September 2013 and any actions arising

Simon announced that Martin Lodemore had been appointed to the post of Senior Public Involvement Advisor and will be based at the Coordinating Centre.

Matters arising

For updates on matters arising, see notes of the last meeting. Below are further updates on matters arising that were discussed at the meeting.

The NICE consultation on value based pricing has been delayed and will be implemented in Autumn 2014. This will be circulated when available.

The document reviewing standards for involvement in research is now available on the INVOLVE website (<http://www.invo.org.uk/about-involve/current-work/standards-for-public-involvement-in-research/>) and INVOLVE will tweet the documents.

The first meeting of the INVOLVE Advisory Board with new members was held in December 2013. Simon asked the new members if they wished to comment or reflect on their initial experiences. Members said it helped them to focus and comment in more depth and the opportunity was both positive and beneficial. INVOLVE group members were encouraged to talk to Advisory Board members if they had any issues they wished to be raised.

Action: The NICE consultation on value based pricing / assessment has been delayed. This will be circulated when available.

Declarations of conflicts of interest:

No conflicts of interest were declared.

2. Chair's hot topics

Simon Denegri covered three main topics in this section of the meeting:

- NHS England Research and Development Strategy Consultation consultation
- NIHR Strategy Board - VSAM (Vision, Strategy, Actions and Metrics) for public involvement and engagement
- NIHR public involvement review.

NHS England Research and Development Strategy Consultation

Simon introduced the Strategy and explained that it was out for consultation until 30 January 2014. He explained that as part of the Health and Social Care Act, NHS

England has to produce plans for how it intends to deliver against its' legal duty to support Research and Development in the NHS.

In addition to INVOLVE responding to the consultation, Simon will also be responding in his role as National Director for Engagement and Participation and has convened a small meeting for the 28 January (including Sarah Buckland) to meet with those who will be involved in writing the final version of the strategy (April 2014).

Simon asked members for their comments on the strategy and whether patient, public and carer engagement and involvement were sufficiently reflected.

Overall comments

- Some members commented on how they felt the document was confusing to read and jargonistic and suggested it should be re-written in a way that could be understood clearly by patients and the public or, at the very least, a separate lay summary produced.
- Members commented that the strategy lacked clarity at a strategic level for it to be achievable.
- Members felt the document could better articulate the challenges and opportunities for research in the current NHS research environment and did not adequately map how NHS England intends to connect with the NIHR (e.g. CLAHRCs, James Lind Alliance and INVOLVE).
- There also needs to be greater clarity re: the roles of the Academic Health Science Networks and the Collaborations for Leadership in Applied Health and Research Care (CLAHRCs) and their relationship with NHS England.
- It would be useful to provide a flow chart of the organisations who will be expected to deliver the strategy - including the involvement/ engagement/ participation activities.

Specific comments on the strategy's public involvement intentions

- Members welcomed that the strategy addressed the importance of public involvement and engagement.
- The use of the terms in the document referring to patient involvement, engagement and participation need to be defined. They are used interchangeably in a way that is not clear. Although reference is made to patient involvement the focus is mainly on participation in research studies. Greater clarity is needed in the document to define the types of activity being described.
- Public involvement and engagement is not integrated or embedded in the strategy but is described as separate to the other aspects of the strategy.
- There were only a couple of references to Involve (lower case) on pages 14 and 22 and it was not clear which 'involve' that the document is referring to or any mention of how NHS England intends to work with NIHR INVOLVE (upper case). Members felt it was essential that those involved in the development of the R&D Strategy, worked with NIHR INVOLVE in developing plans for public involvement.
- The strategy pays insufficient attention at a strategic level to the need to

collaborate with the public and how public involvement will inform the broader objectives of the strategy.

- There is no information on the governance arrangements re NHS England and the potential contribution the public can make to transparency.
- Strategic level definitions are absent on the collaboration between public involvement in research and service delivery.

Action: Simon and INVOLVE Coordinating Centre to respond to the draft strategy on behalf of INVOLVE. Response to be circulated to INVOLVE members.

Action: INVOLVE to invite NHS England to give a talk about their research strategy to the INVOLVE group.

Action: INVOLVE members to contact Simon Denegri if they are interested in contributing to discussions with the Head of the Patient Insights Team at NHS England on public involvement and Patient Reported Outcomes (PROMS).

NIHR Strategy Board - VSAM (Vision, Strategy, Actions and Metrics) for public involvement and engagement

Simon explained that the NIHR Strategy Board was committed to refreshing and reviewing priorities for the NIHR over the next two years and to define objectives and metrics that act on these priorities. A core part of this agenda, includes defined objectives for public involvement and engagement across the NIHR to give it greater focus and tangible actions to deliver. Simon explained that the NIHR wide public involvement strategy group facilitated by INVOLVE and chaired by Simon had been discussing these priorities.

At the INVOLVE group meeting, Simon outlined the broad strategic objective for this work as being to develop capacity and capability for involvement through greater NIHR wide working. He outlined the three main areas being proposed:

- Increasing opportunities for sharing knowledge and expertise across NIHR
- Improving strategic coordination of public involvement at a local level
- Developing frameworks to support involvement.

He invited discussion on these broad areas as well as some of the specific actions being proposed, which included an event to bring together public involvement leads across the NIHR, supporting public involvement at a local level and raising awareness and supporting organisations to develop payment policies. Some suggestions from Group members included adding support for learning and development and seeking to influence NHS England on payment issues.

Action: Simon Denegri and Sarah Buckland to revise the draft Strategy and Actions for the NIHR VSAM (Vision Strategy Actions and Metrics) on public involvement and engagement and circulate to INVOLVE Group members for information.

NIHR public involvement review (Paper 2)

The NIHR has initiated a review to develop a strategy for the long-term development and delivery of public involvement across NIHR. The review panel, chaired by Simon has had an initial meeting to consider the draft terms of reference and discuss how the panel will involve others in its work. The review will conclude within six months, with a report and recommendations to Sally Davies, Chief Medical Officer and NIHR's senior management team. The panel will discuss its likely conclusions with INVOLVE members at the symposium in May.

Members would continue to discuss the review this afternoon in greater detail with a session chaired by Ade Adebajo (Agenda Item 6).

Action: Simon to send the agreed terms of reference of NIHR review panel to INVOLVE members, 24 hours in advance of making them public.

3. INVOLVE meetings and role of Group members

Simon introduced paper 3 on the role and purpose of INVOLVE group and INVOLVE members and invited comment on the two issues raised in the paper:

- How can we as members of INVOLVE and as an INVOLVE Group, influence those around us to make things happen?
- Are there new ways of working we should be embracing (e.g. opening meetings to others using social media)?

Helen was asked about responses to the request she had sent to INVOLVE Group members asking about details of events or talks where they had spoken about the work of INVOLVE and public involvement in research.

Action: Helen to update members on the feedback she received from Group members on events or talks where they had spoken about the work of INVOLVE and public involvement (once she has collated the information).

There was some discussion around whether Group meetings should be opened up to enable a wider audience to listen to or participate in discussions as well as whether different mechanisms could be used for meetings (such as video conferencing). There was little enthusiasm expressed for either making the meetings more open (e.g. by others being able to remotely observe meetings) or for changing the ways of running meetings (for example less face to face contact).

Members briefly discussed the five different roles of INVOLVE members and Group meetings outlined in the paper. The paper was welcomed as helping to clarify the different roles of members and encouraging them to reflect on their role. Several commented that they felt there had been a positive shift in the content of Group meetings away from discussions on process to a greater focus on INVOLVE and Group members role to influence others. Nevertheless it was helpful to occasionally reflect on process. One member reflected on how there was a greater emphasis in discussions on the NIHR but this was probably inevitable.

A few issues were raised about INVOLVE and Group members being expected to be able to resolve and / or address all issues of concern raised by others and the need to make people aware of the limited budget of INVOLVE.

There were a few comments by some INVOLVE members on specific aspects of the materials and resources provided by INVOLVE:

- there are now too many INVOLVE postcards which reduced their impact and value
- the need for more Frequently Asked Questions on the website covering current issues of the moment
- the research projects database was not sufficiently user friendly in encouraging people to provide information on their projects
- it was time consuming to enter information into invoDIRECT.

Marisha Palm reported that the Coordinating Centre is currently revising the mechanisms and content required of entries to the research projects database. Ade reminded members that we had agreed to review invoDIRECT after a year. This would provide the opportunity to identify areas for improvement.

There was little time for discussion of paper 4 - Update on March 2013 survey of INVOLVE members, which included suggestions for future agenda items for Group meetings. Simon suggested that he would like to suggest that in the near future there should be a discussion around involving young people in research.

Action: Advisory Board to consider a session on involving young people at a future INVOLVE group meeting.

4. Update and discussion of INVOLVE work plan 2013-2016

Group members were provided with a paper which outlined the INVOLVE work plan for 2013-2016 and provided updates on current pieces of work. Simon asked Members for suggestions of additional pieces of work to undertake next year.

The following additional potential areas of work for 2014-2015 were suggested:

- The involvement of young people in research, including considering updating the INVOLVE guidance on involving young people in research.
 - Developing connections between public involvement in research and service delivery - to promote debate and facilitate the development of shared values and common language around public involvement, engagement and participation.
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5. Information exchange – opportunity for INVOLVE group members to share current activities

INVOLVE members had an opportunity to provide verbal updates on issues and activities that they are currently involved in. A range of topics and areas of work were discussed. In particular several members described the development of public involvement in their local areas. Another topic raised was the public involvement requirements of the School for Social Care Research contract and the Academic Health Science Networks.

Action: INVOLVE Coordinating Centre to clarify with the Central Commissioning Facility the public involvement requirements for the NIHR School for Social Care Research contract and the Academic Health Science Networks.

6. NIHR Review of public involvement in research (Paper 2) discussion

Ade Adebajo chaired the afternoon part of the meeting which covered the NIHR review of public involvement in research introduced by Simon earlier in the day.

Each of the tables first discussed the review in small groups and then with the whole group. The following feedback was provided by Group members:

Operation of review and panel

- The panel should provide clear guidance on how people can contribute.
- It would be useful if the review panel provided a template of the type of information it would like others to feed into the review.
- The biggest challenge will be to get the evidence to the review panel in the short time they have. Also a huge area to cover and the panel will not be able to consider everything.
- There was a feeling that the people on the panel were not reflective of the public involvement community and were largely professional.
- INVOLVE should be involved in contributing evidence.
- INVOLVE should be giving a steer to the focus of the review.

Suggested areas for review panel to cover

- One of the big issues is resourcing and infrastructure around public involvement - the review should be looking at resources (money, people) and where the money for public involvement is located.
- It would be useful to have a framework to look at the key changes in public involvement, learn lessons and reflect on them.
- It should be a time to build on INVOLVE's strengths and raise the bar for the future.
- INVOLVE has played a leadership role and it may be that its' remit should be broadened to include the implementation of research.
- Involvement should be looked at in terms of the new landscapes.

- Is the review an opportunity to consider the monitoring, assessment and quality of PPI? For example are researchers following through on the public involvement they describe in their funding applications?
- Local to national and national to local is important; depth and breadth of opportunity is important.
- The review could map out all public involvement that is going on across the NIHR and get examples of where it is working and where it is not (although this could take too long).
- Need to collect views from people from NIHR infrastructure and encourage them to be honest about how difficult it is in some areas to do good public involvement - they need to be honest and transparent about what would be useful.
- The amount of public involvement does not indicate the quality of this involvement.
- There is still box ticking happening and it is important to follow up on what public involvement has been done and how it has been assessed.
- Public involvement staff are still not being trained, developed or supported; there is no clear career path.

Action: Ade Adebajo and Sarah Buckland to review the notes from the discussion and send Simon and the Review panel a summary.

Action: Review panel to be asked to produce a template providing a steer on the information others should feed into the review.

Action: Patricia Wilson offered to collect information from others about the review at her series of four dissemination meetings reporting on the findings of the RAPPORT study during March and April 2014.

7. Discussion topics

INVOLVE group members chose one of three sessions to attend.

i) Raising awareness about the work of INVOLVE and public involvement in research

Creative ways to engage audiences around public involvement

Marisha provided information about whiteboard animation and the group watched a demonstration of an example animation. The group discussed how it could be used to reach different audiences. Members of the group reported that they found it focused and engaging. They agreed that they could be targeted for particular audiences and they would need to be topic specific, short and focused.

Members suggested that it is important to consider who we are targeting with the whiteboard animation. A useful way forward could be to consider doing a pilot by creating a whiteboard animation and gathering feedback about who looks at it and uses it. Also gather information on what would appeal and what would not appeal to target audiences.

Guidance on use of social media for public involvement

Marisha explained that INVOLVE is receiving more enquiries about using social media for public involvement in research and discussions about this are also taking place at many of the events we attend. The group discussed how the use of social media has become more prevalent and how it can be used to reach a wide range of people.

It was suggested that guidance could be particularly useful for involving young people in research. It was noted that there are online forums already set up for many different health conditions. Members agreed that a guidance document should give plenty of examples of how people have used social media for public involvement. The guidance document could include information about the value, opportunities and the pitfalls of using social media for public involvement in research.

One suggestion was to look at what other organisations, eg charities, are doing and any guidance they have produced around social media for public involvement.

Getting the message out to students and early career researchers

The group had a range of ideas about ways to reach students and early career researchers. These included accessing researchers through the following organisations/departments:

- Trainees Coordinating Centre (TCC)
- University training departments
- Doctoral schools run by Economic and Social Research Council (ESRC)
- Research Design Services
- University/trust research departments
- Ethics committees
- Public involvement faculty leads in Universities
- Council of deans.

Action: Consider piloting a whiteboard animation and gathering feedback.

Action: To look into the value of using social media for public involvement in research.

Action: To circulate revised INVOLVE presentations slides when they have been finalised.

ii) Developing a database of examples of involvement in research

Helen Hayes introduced the project workplan to develop an INVOLVE database of examples of public involvement in research in 2014/15. She explained that INVOLVE currently holds many examples and narratives of public involvement in research in different areas such as on the INVOLVE website, in publications and the newsletters.

The proposed development of a database of examples would aim to:

- contribute to the evidence base

- make the examples easier for people to find
- inform the Briefing notes for researchers
- allow us to review the examples - what we can learn from them, how useful they are, what role they play in developing the evidence base and identify gaps.

The project will be led by Helen who will start the project by compiling, indexing and categorising the examples currently held by INVOLVE. This will be followed by development of a searchable online database.

Members supported the project and discussed how to define an example of involvement (as opposed to a case study) and what to include in the online database. They suggested that the examples, no matter how short, would ideally include some, if not all, of the following details:

- the context of the involvement covering both research projects and processes (eg commissioning)
- the approach(es) to involvement
- description of 'how' people were involved
- reflections on impact; and
- lessons learnt.

It was agreed that 2006 should be the start date for inclusion of examples on the database. Members also agreed that the entries did not need to be standardised or conform to a set template.

Action: Group Members who attended the discussion on this topic, agreed to continue to be involved in the project (Lynne Corner, Patricia Wilson, Ade Adebajo, Jonathan Boote, Una Rennard).

iii) Updates on INVOLVE work plan 2013-2014

This session was an opportunity for Group members to ask questions and find out more about the range of projects and other activities of the Co-ordinating Centre. Various issues were discussed including payment for involvement, the role of group members, contributing to the agenda for INVOLVE group meetings, and the language used around involvement and engagement.

Action: Sarah Buckland to discuss with Simon Denegri, ways for group members to contribute further to setting agenda items at Group meetings.

Action: Sarah Buckland to liaise with Simon to arrange a meeting with interested INVOLVE members to discuss how to get messages out to the wider community on definitions of public involvement, engagement and participation.

8. Directors report

Sarah Buckland provided an update on some areas of the Coordinating Centre work. It was noted that the INVOLVE budget information had been included in the Director's report as requested by group members.

An amendment to the Director's report was suggested.

The payment guide for involvement was briefly discussed and it was agreed that it is important to update this in line with the expected changes to the benefits system this year.

Helen Hayes reported that she will be organising some training for Coordinating Centre staff and INVOLVE members to discuss diversity and equality issues. The outcomes from the session will be looked at later this year.

Action: To amend Director's Report page 4 to read 'An invoNET shared learning event is being planned for March 2014'.

Action: Diversity and inclusion work - Coordinating Centre will be organising in the near future some training for Coordinating staff and INVOLVE members on diversity and inclusion to increase our skills, knowledge and expertise.

9. Any other urgent business not included on the agenda

Ade congratulated Patricia Wilson on her move from Hertfordshire to Kent to take up the position of Chair at the University of Kent.

10. Dates of future meetings

7-8 May 2014 INVOLVE Annual Symposium.
10 September 2014 INVOLVE Group Meeting
26 - 27 November INVOLVE 2014 Conference
