

**Notes of the INVOLVE Annual Members Symposium
held at
The Hawkwell House Hotel
Oxford, OX4 4DZ**

25/26 September 2013

Present:	Ade Adebajo Lizzie Amis Rosemary Barber Jonathan Boote Louca-Mai Brady (day 1) Pam Carter Tina Coldham Lynne Corner Rosemary Davies Simon Denegri (Chair) Jo Ellins Jim Elliott David Evans	John Hughes Linda Laurie Tara Mistry Una Rennard Lesley Roberts Diana Rose Tony Sargeant Patsy Staddon Christine Vial Amander Wellings Patricia Wilson
Guest Speakers:	Gary Ford (day 1) Sian Rees (day 1) Louise Wood (day 2)	Director of NIHR Stroke Research Network Academic Health Science Network (AHSN), Oxford Department of Health
In attendance:	Yetunde Animashawun (day 2) Kay Pattison Roger Steel Tony Williams Ian Cook Sarah Buckland Sarah Bayliss Sarah Bite Erica Ferry Helen Hayes Marisha Palm Lucy Simons Maryrose Tarpey	Simon Denegri's Personal Assistant Department of Health Clinical Research Network (CRN) Department of Health Health Research Authority INVOLVE Coordinating Centre " " " " " "

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

Everyone introduced themselves and Simon welcomed Marisha Palm who joined the Coordinating Group at the beginning of September.

Gary Ford (Director of NIHR Stroke Research Network) and Sian Rees, (Patient and Public involvement and engagement lead, Oxford Academic Health Science Network) joined us later in the evening.

Louise Woods from the Department of Health joined us on day two of the symposium.

This was the last meeting for Rosemary Barber and Jim Elliott (who were present at the meeting) and also Ray Fitzpatrick, Hugh McLaughlin and Mark Petticrew (who were unable to make the meeting).

Day 2 was the last day for Lucy Simons at the INVOLVE Coordinating Centre. She was leaving to work for the University of Nottingham as a Research Associate/Fellow within the School of Community Health Sciences. She would however be doing a few extra days until December on the Learning and Development work.

Simon thanked them all for their contributions to INVOLVE and wished them well for the future.

Simon then announced who would be the new members of the INVOLVE Advisory Board, following voting by the members. They are: Lynne Corner, Linda Laurie, Tony Sargeant and Patsy Staddon. The Coordinating Centre will be getting in touch with them shortly to arrange a meeting in November.

Declarations of conflicts of interest:

No conflicts of interest were declared.

Apologies

Ann-Louise Caress
Ray Fitzpatrick
Pete Fleischmann
Hugh McLaughlin

Mark Petticrew
Carol Rhodes
Veronica Swallow

2. **Current NIHR / NHS scene: what it looks like and implications for public involvement**

Simon Denegri gave a presentation providing an overview on public involvement and current issues. He covered the following topics:

- A summary of some of the different events that he had recently spoken at, including the innovative 'Generation R' day which was designed and delivered by young people.
- His reflections on the main achievements of INVOLVE over the previous year, including:
 - Community building: the largest ever INVOLVE conference in 2012.
 - Practical tools: involvement cost calculator, invoDIRECT.
 - Working across boundaries: cross-NIHR public involvement meetings, Learning and support working group.
 - Influencing policy and practice: Plain English summaries, social care webinars, Health Research Authority.
 - Visibility and momentum: high number of visitors to www.invo.org.uk and a growing twitter presence.
- Some of the key NHS changes and what it means for involvement. The focus on patient experience and insight in service delivery, importance of accountability and the growing support for 'patient leadership' as yet largely undefined.
- Developments in the NIHR over the next two years: Increased pressure on delivery of the 'health and wealth' agenda - delivering growth. Continuing to push the pace of research. Taking forward the 'Adding Value' five pillars research framework which are all relevant to public involvement.

Following Simon's presentation members discussed a number of issues including:

Support for hubs: How should we be supporting public involvement at a local and regional level to ensure connectivity and joined up working between, for example Academic Health Science Networks (AHSNs), Clinical Research Networks (CRN), Research Design Services (RDS) and Biomedical Research Centres and Units (BRCs and BRUs).

Patient leadership: members suggested that the role of patient leaders needs time to develop and emerge - not clear yet what patients will be 'allowed' 'not allowed' to do plus an unclear level of resourcing for the development of patient leaders as for other local initiatives such as HealthWatch.

Clinical Commissioning groups (CCGs): currently a lack of focus or understanding within CCGs about their role in supporting research.

In conclusion, Simon emphasised the importance for INVOLVE of horizon scanning. We need to address the question "What do we want public involvement to look like in the next five - ten years?"

3. Updates on INVOLVE work programme (small groups)

Group members divided into groups to hear about progress on six of the current projects that form part of the INVOLVE work programme.

- NIHR School for Social Care and INVOLVE webinars
- Involvement cost calculator
- Examples of public involvement
- Plain English summaries
- Learning for involvement
- INVOLVE Conference 2014.

i. NIHR School for Social Care and INVOLVE webinars

Helen Hayes updated members on the joint INVOLVE and NIHR School for Social Care Research webinar series. These are based on the School for Social Care Research Methods Reviews, and the first one took place on Friday 13 September.

Mike Clark, Simon Denegri and Tina Coldham formed the first panel of three, and over 100 people registered to hear them speak. On the day, approximately 60 people signed in to watch the webinar. The slides, and the audio and visual files, will be uploaded onto the INVOLVE website.

Those who attended this update session asked for clarification about how a webinar works, and Helen explained that those who register are provided with a link and log in details. Participants are taken to a website where they can view the panel discussion whilst also being able to type questions.

The series has just begun and there are another five webinars that will take place toward the end of this year and the beginning of next, though dates have still to be agreed. The format is likely to include researchers speaking alongside a member of the public with whom they have worked.

ii. Involvement cost calculator

Lucy Simons described the features of the new Budgeting for involvement resource which was developed with joint funding from INVOLVE and the Mental Health Research Network (MHRN). The resource is available on both the INVOLVE and the MHRN websites and consists of an online cost calculator and an accompanying guide.

Members asked questions about some of the features of the resource and the information provided as well as how we were informing people that it is available. Members welcomed the resource as a useful tool for researchers when costing public involvement as part of their grant applications.

iii. Examples of public involvement

Maryrose Tarpey explained that in the past six months INVOLVE has developed two new sets of examples to contribute to the developing evidence base on the impact of public involvement in research. Each series offers a different perspective of impact:

a: ten examples of [public involvement in National Institute for Health Research \(NIHR\) research funding applications](#) drawn from a broad range of funded studies from across the NIHR. This new series illustrates the public involvement in each study, how members of the public were involved, and the difference it made to the application.

b: six examples exploring the impact of public involvement on research quality all from [invoNET](#) members prefaced by an introductory overview (www.invo.org.uk/wp-content/uploads/2013/08/invoNETexamples2013.pdf). These examples were commissioned by the INVOLVE Group's invoNET Task and Finish Group during 2012-13. The examples offer a range of different perspectives on public involvement in research, and report different approaches to research.

INVOLVE members at this session commended the examples and supported the Coordinating Centre's plan to compile and create a searchable database of the examples of public involvement in research that are currently held in INVOLVE's various publications and newsletters.

Members suggested that we should also:

- Consider developing additional examples of involvement in Clinical Commissioning Groups (CCG's), and primary care and social care research.
- Index the examples by using tick boxes such as the groups of people involved and the type of research.
- Distinguish between examples of involvement and examples of good involvement (although avoiding kite marking or indicating a hierarchy).
- Extract a range of quotes from the examples and reference them in their publications and other materials.

iv. Plain English summaries

Helen and Sarah updated INVOLVE members on the work they had been doing to develop guidance for improving the quality of plain English summaries for NIHR funded research. This was a piece of work initiated by the Department of Health that INVOLVE was asked to lead on.

Helen reported that following the initial review and consultation which led to the draft guidance and recommendations, INVOLVE held a stakeholder workshop in July with representatives from across the NIHR. At the workshop participants discussed the implementation of the guidance and ways to raise awareness of this work with researchers. Helen reported that further work was ongoing to finalise the guidance

and we were establishing an implementation group to help us take forward the work.

v. Learning for involvement

Lucy gave an overview on the work of the learning for involvement group which was set up by INVOLVE and launched in March 2013 by INVOLVE as a cross-NIHR working group chaired by Simon Denegri. It is intended to run for a fixed term of one year ending in March 2014. INVOLVE advisory group members Amander Wellings and Tony Sargeant are members of the working group. See www.invo.org.uk/about-involve/current-work/learning for more information about the group and its membership.

The group intend to produce a number of outputs by March 2014. These include:

- documenting the essential principles for learning for involvement
- exploring the contribution of a competency-based framework for learning for involvement
- testing learning needs assessment tools for individuals and organisations
- testing methods for supporting lay reviewers of funding applications.

The next meeting of the working group is in Nottingham in October and will include a session on 'competency frameworks'. An event is planned for Spring 2014 to report back on what has been achieved.

Members who attended the session (including Amander and Tony), highlighted the group's commitment to the principle of 'situational learning' and recognising the importance of making it easier for people to access the resources they require to be able to fulfil the role they are being asked to take on. They stressed that this should include mentoring and peer-support.

One suggestion made was that the group explore the possibility of developing a 'situational learning' tool to help 'calculate learning' - similar to the recently developed [involvement cost calculator](#) tool that helps researchers budget for involvement.

vi. Conference

Sarah Bite updated the group about the plans for the 2014 conference. Several venues have been considered and the cost, capacity and availability of each option explored. The venue had not yet been booked, but the NEC in Birmingham is a likely venue.

The group suggested that people with accessibility requirements visit the venue before the conference to provide ideas of how we can make it most accessible for our delegates.

Marisha described the key discussions that took place in the first Conference Planning Group meeting and the ideas around the content and themes. These included the changing NIHR landscape and the health and wealth agenda.

Action: Coordinating Centre to inform Group members when the venue and

dates of the conference are confirmed

4. Open space discussions

The discussions from the Open Space sessions will be sent round separately.

5. Academic Health Science Networks

Gary Ford, the Director of the NIHR Stroke Network, presented to the group about the current NIHR organisations and the key changes that have been taking place. Gary explained the importance of innovation to the NHS and how England has been poor at adopting and developing innovation in the UK. The Academic Health Science Networks have been set up to fulfil this role. Information was also provided on the roles of the Clinical Research Networks, the Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) and the Academic Health Science Centres (AHSCs).

Gary explained that the AHSNs will play a crucial role in speeding up the translation of research into practice which will complement the roles of the AHSCs which work on a smaller scale and focus on earlier stages in the transition. Not all AHSNs will contain an AHSC.

The AHSNs do not have a large budget, so will drive their work through collaborations with partners. There are 15 AHSNs in total, eight with full designation which will receive £3million, and seven with partial designation which will receive £2million.

Gary provided information on the Oxford AHSN vision and how it will be delivered. Gary summarised the Oxford AHSN approach to public involvement which includes involvement in the delivery structures and processes of the organisation, developing person-centred care and supporting person-centred research and innovation.

Gary identified the key challenges for the AHSNs as needing time to succeed, bringing together a wide range of partners, developing informatics systems, being relevant, articulating their purpose and patient and public engagement in innovation.

Gary also described the vision of the NIHR Stroke Research Network and reported that its 5 year aims identified in 2010 had been achieved. These have included an increase in recruitment to studies and an increase in the percentage of acute trusts with stroke services active in research.

Gary concluded his talk by discussing the opportunities for the AHSNs, which included developing a common purpose amongst the partners, facilitating service transformation, integrating and empowering patient and public engagement and delivering a shift in the partnership of the NHS with the life science industry.

Following Gary's presentation there was a wide ranging discussion covering issues such as:

- the wealth agenda
- AHSNs in areas without CLAHRCs or AHSCs will need to undertake their work through different routes
- the importance of accessing the patient voice where it is already available
- the need to improve the reporting of research findings back to patients.

Members then had the opportunity to discuss some of the issues raised in small groups.

DAY 2

6 Public involvement and the growth and wealth agenda

On day 2, Louise Wood ran a session on public involvement and the growth and wealth agenda. She highlighted how the NIHR was established 7.5 years ago as a result of the 'Best research for best health' strategy. It promotes the health and wealth of the nation through research. Wealth in this instance is not just about money, but also about quality of care and quality of life.

Louise then asked for 5 volunteers from the audience to demonstrate the implications of research leading to improved health and wealth for an individual, their family (/carer), boss, local business owner and the treasury.

The benefits included the family member / carer being released from their duties, the boss not having to provide sick pay, reduced costs for NHS and more money for local businesses like sandwich shops if someone is in employment.

Louise spoke about the support that is provided to the life sciences industry, which seeks to bring in industry funding to the country and place the UK in a competitive global position. The industry has a turnover of approximately 50 billion, making it one of the most important businesses in the UK.

The plan for growth was published in 2011, and one of the businesses was life sciences. A UK life sciences industry paper was also published, and the NIHR featured heavily.

The Department of Health funds the infrastructure for health research, e.g. the Clinical Research Network (CRN), and the Collaborations for Leadership in Applied Health Research and Care (CLAHRCs). Public involvement and engagement are fundamental to this infrastructure.

Louise finished by taking questions. There were concerns around budgetary boundaries and the continued dichotomy between health and social care. The point was also made that patients and public can help to connect some of the dots of infrastructure, driving capacity and capability.

7. Reflections on growth and wealth agenda and AHSN discussion

Following the sessions by Gary Ford and Louise Woods, INVOLVE members reflected on the content of the presentations. The following actions were proposed following the discussions:

Actions:

Conference Planning Group to consider having a discussion / debate at the INVOLVE 2014 Conference on the wealth agenda and public involvement.

INVOLVE to send a communication to Professor Dame Sally Davies on public involvement and the wealth agenda, summarising discussions at the Symposium - to share draft with Group members.

INVOLVE to respond to NICE consultation on value based pricing which will be launched alongside its implementation in January 2014.

8. Business meeting

Simon thanked Rosemary and Jim for their contributions to INVOLVE over the last six years and presented them both with a card and small gift as a token of our appreciation. We look forward to them still being involved as associate members.

Advisory group meeting notes

The notes were approved as an accurate account of the meeting.

Matters arising

Helen Hayes reported that we currently had 980 followers on Twitter and Simon proposed a new target of 1,250 followers.

Simon reminded everyone that there had been a change of date for the next meeting to 16 January and an email had been circulated to everyone.

Director's Report

Sarah Buckland asked if there were any queries relating to the Director's Report.

A request was made for the dates for the INVOLVE webinar series be circulated earlier, and we agreed to ensure that we circulated these well in advance of future events.

Helen Hayes reported that the next webinar will be based on the methods review of research with black and ethnic minority groups and we hope to have both audio and visual available.

Clarification on the NIHR data standards group was requested. Maryrose reported

that NIHR formed a cross NIHR board whose remit was to define a core set of agreements to share data with others. The group meet once a month and are led by Peter Knight. Good examples will be shown to other parts of the NIHR and there will be five meetings to pool data.

The single equality scheme has been put on hold for the moment as Lucy is leaving. Helen Hayes is helping with the planning, but we have not yet established how to take this forward.

There was a discussion on finances and it was agreed that in future a finance report would be provided at meetings.

Actions:

Coordinating Centre to aim to exceed the target agreed at the last INVOLVE Group meeting of having 1,000 twitter followers by April 2014.

Coordinating Centre to include information on financial expenditure of the INVOLVE budget, in the Director's report for future INVOLVE group meetings.

Date of next meeting

16 January 2013.

9. Learning for Involvement – what I wish I'd known

In this session Lucy asked members to reflect and discuss in small groups at their table what they wished they had known before first involving people or getting actively involved in research. They were also asked if they would write down any of these thoughts on cards which we could then use as part of the Learning for Involvement work.

10. Language - gaining a shared understanding

Simon introduced this session by highlighting the current definitions that INVOLVE uses for involvement, engagement and participation and then posed the question: How can we encourage greater shared understanding of the language we use at INVOLVE to define public involvement, engagement and participation in research ?

Some of the topics covered in the discussion included: confusion over the terminology; lack of clarity as to what researchers are expecting from those they involve; issues around whether people should be 'representative'; distinction between shared meaning and shared understanding (shared meaning is important even if people use different words to describe); need to not be preoccupied with language but be clear what we mean.

Simon said that he didn't want to redefine the language we use but there was a need for greater clarity as what the important issues are, and asked for volunteers to help take this work forward.

Action: Coordinating Centre to invite 4-5 people to work with Simon Denegri to discuss how best to get messages out to the wider community on definitions of public, involvement, engagement and participation.

11. Standards for public involvement in research - group discussions

Marisha Palm introduced this session by outlining the work we had already undertaken to review what others have written about values, principles and standards for public involvement in research. INVOLVE members then divided into three groups to:

- review the principles we had outlined and discuss whether they accurately reflect the literature and/or if there are any gaps
- consider the purpose and benefits of developing public involvement values, principles and standards
- discuss whether the principles might be adapted to form generic standards and/or whether they would be a useful starting point to adapt into standards within different contexts.

Below is a list of some of the comments from the group discussions:

Positives

- Standards could support consistency.
- They could provide a non-prescriptive way in which people should be treated, and establish a set level at which people could aim.
- Examples of good practice are empowering and examples in a self-contained, easily accessible format would be a positive step.
- They would allow the public to know what they should expect.
- Articulating good behaviour can promote good behaviour.
- People in public involvement want to know the standards they should be working towards.

Concerns

- Standards could lead to an expectation of policing / kite marking, and this is not a role that INVOLVE could or should fulfil.
- They could look good on paper but people would need a certain level of awareness to meet them.
- They can put members of the public in a difficult position when they are not adhered to.
- They could be daunting or discouraging to those new to public involvement.
- There could be something militant about promoting standards rather than

- emphasising complementarity and involvement as a cooperative effort.
- To develop a set of standards acceptable across the NIHR would require considerable work and time to achieve.

Practicalities

- The rewards for both researchers and the public will have to be recognised.
- People could self-assess, but those who do the best work are the ones most likely to do this thoroughly and successfully.
- The term guidance indicates that people could take it or leave it, while standards indicates that there is certain activity that is acceptable.
- There is a question around developing minimum to excellent standards (bronze, silver, gold).
- Standards only work if someone has endorsed them from the bottom up and the top down.
- The gap with guidance is how to operationalise standards, and how to make sense of things in context.
- A generic set of standards is unhelpful; have to be context specific, e.g. research projects, commissioning processes, types of research.
- The term 'minimum expectations' could be used rather than standards.
- A baseline is important, i.e. when establishing partnerships they need to clearly state: 'we will' and 'we expect you to.'
- Value in looking outside health and social care research.

Members agreed that the values and principles identified would most helpfully be used as a framework to develop a tool for reflective practice which could be peppered with vignettes.

Such a tool could include short examples of involvement and practical information about each standard, for example what it means to be transparent or respectful.

Action:

Coordinating Centre to invite members to join a small advisory group to take forward the work on values, principles and standards for involvement.

12. Feedback, final discussions, any other business

INVOLVE members thanked the coordinating centre for organising the Symposium and requested that a thank you letter be sent to the venue especially to the very helpful staff.

Sarah Buckland advised the group that she would be sending out a survey to group members to allow her to evaluate the event.

Action:

Coordinating Centre to write to the hotel thanking them for the excellent

service provided.

Coordinating Centre to send out a short feedback survey to INVOLVE members to feedback on the symposium.
