

**Notes of the sixty fourth meeting of INVOLVE
held at the
National Council for Voluntary Organisations
Regent's Wharf, 8 All Saints Street, London, N1 9RL
Tuesday 22 January 2013**

Present:

Ade Adebajo	Linda Laurie
Lizzie Amis	Una Rennard
Rosemary Barber	Carol Rhodes
Jonathan Boote	Diana Rose
Louca-Mai Brady	Patsy Staddon
Ann-Louise Caress	Veronica Swallow
Pam Carter	Christine Vial
Tina Coldham	Amander Wellings
Rosemary Davies	
Simon Denegri (Chair)	
Jim Elliott	
David Evans	
John Hughes	

Guest Speakers: Sylvia Wyatt

In attendance:

Kay Pattison	Department of Health
Tony Williams	“
Roger Steel	Clinical Research Network (CRN)
Michael Turner	Social Care Institute for Excellence (SCIE)
Sarah Buckland	INVOLVE Coordinating Centre
Sarah Bayliss	“
Erica Ferry	“
Helen Hayes (am only)	“
Sarah Bite	“
Lucy Simons	“
Maryrose Tarpey	“

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

Declarations of conflicts of interest:

No conflicts of interest were declared

Apologies

Richard Baker
Lynne Corner
Jo Ellins
Ray Fitzpatrick
Pete Fleischmann
Hugh McLaughlin

Tara Mistry
Mark Petticrew
Lesley Roberts
Tony Sargeant
Laura Serrant-Green
Patricia Wilson

2. Notes of Meetings held on 19/20 September and any actions arising

There were no actions from the last meeting.

3. Academic Health Science Networks

Simon described the Innovation Health and Wealth Agenda which led to the development of the Academic Health Science Networks (AHSNs). He explained that the key purpose of the AHSNs is the identification, adoption and spread of innovation and best practice. The networks will be a collaboration of the NHS, academia and local authorities. There will also be links with other organisations including the Clinical Research Networks and the Collaborations for Leadership in Applied Health Research and Care (CLAHRC).

Simon also described his recent visit to Denmark with John de Pury, from the NHS Confederation, and others from England involved in the AHSNs, where they learnt about the Danish approach to placing the citizen at the core of innovation and diffusion.

Sylvia Wyatt, from the Young Foundation, provided further information about the AHSNs and explained that there will be 15 in England which, as well as focusing on the adoption and spread of innovation, will also have a function to create wealth. Sylvia discussed how she would be encouraging networks to work with INVOLVE and raising how public involvement can inform the functions of the AHSNs.

A number of INVOLVE Advisory Group Members reported their involvement in the development of their local AHSNs. David Evans described a meeting that has taken place to help develop public involvement in the West of England AHSN. Diana Rose reported that the South London AHSN has been exploring opportunities for public involvement. Ann-Louise Caress has been leading on public involvement for the Greater Manchester AHSN. Ade Adebajo described that he has recognised a need to be proactive in the development of public involvement in the Yorkshire and Humber AHSN bid.

Action: All Group members to explore the public involvement in their local AHSN by the next INVOLVE group meeting

4. Chair's hot topic – Reporting clinical trials data

Simon reported that we intended to submit a response to the Commons Select Committee Inquiry into clinical trials. The questions from the inquiry were:

1. Do the European Commission's proposed revisions to the Clinical Trials Directive address the main barriers to conducting clinical trials in the UK and EU?
2. What is the role of the Health Research Authority in relation to clinical trials and how effective has it been to date?
3. What evidence is there that pharmaceutical companies withhold clinical trial data and what impact does this have on public health?
4. How could the occurrence and results of clinical trials be made more open to scrutiny? Who should be responsible?
5. Can lessons about transparency and disclosure of clinical data be learned from other countries?

Simon explained that we planned to highlight how the open reporting of clinical trials was a matter of public concern as well as the need to feed back results to trial participants. He asked for other reflections from INVOLVE Group members on responding to the inquiry. Group members supported this response as well as to highlight the need for greater inspection and regulation. Group members also suggested that it should be made clear to the inquiry why it is important that trials data is made public and the potential impact on patient treatment. There was also a brief discussion of how the UK compares with other countries.

As part of this agenda item, Simon also raised the issue of the All Trials Registered petition (www.alltrials.net) and whether INVOLVE should sign this as an organisation. Group members were broadly in support of the statements but various reservations were raised against INVOLVE signing the petition. Members suggested that INVOLVE was in a unique position and should instead use the processes in place available to INVOLVE to influence the agenda and to instead raise our concerns about the publishing of data with the Department of Health. There were also some concerns that whilst important this was tangential to the primary focus of INVOLVE.

Actions:

Simon and Sarah to submit response to Inquiry into clinical trials.

Simon to discuss issues raised by All Trials Registered petition with the Department of Health.

5. INVOLVE Group meetings 2013

Simon reported back on the discussions at the INVOLVE chairs meeting on developing the Operational Plan and the work of the INVOLVE Group. He explained that he wished us to move away from producing annual operational plans, to developing a broad plan and work areas, up until 2016. The Coordinating Centre would define activities within the broad work areas to be delivered over the next 18

months.

Register of interests: INVOLVE Group members will be invited to sign up to work areas that they are interested in contributing to. INVOLVE staff will use this register to know which members are interested in supporting which work areas/projects – this will be used to set up project specific advisory groups when required, as well as to invite contributions to the different areas of work. The work of these groups will operate outside of the quarterly INVOLVE group meetings.

Group meetings: In place of Task and Finish Groups, the morning part of the meetings will be used as an opportunity to get a wider view / discussion on specific projects, work areas or current emerging topics that the Coordinating Centre are working on. Members will have the option of taking part in one or more of these discussions during the morning.

INVOLVE advisory board: During 2013, the Chairs' meeting will transition into an advisory board. It is planned that this will include the current chairs plus some other members. A method for members to elect those who would join the advisory board will be developed.

Simon explained that the purpose of the revised process for Group meetings, was to enable group members to hear and discuss a wider range of work than the present Task and Finish groups allow, but also give greater opportunities, for those who want them, to contribute to specific pieces of work. It is also intended that this approach will enable INVOLVE to move work on and keep pace with the changing / shifting environment.

Some Group members raised reservations around the proposed new approach and the importance of ensuring that all members had an opportunity to contribute. Simon explained that this new approach would be monitored and kept under review to ensure that the involvement and contribution of Group members was not lost.

Action: INVOLVE work plan to be discussed at the next INVOLVE chairs' meeting and circulated to INVOLVE members.

6. Survey of Conference Participants and Plans for 2013 (Paper 2)

Members had been sent the report of the post-conference survey. The survey asked for delegates' ideas for values that should underpin INVOLVE's work and to respond to the three priorities that Group members had identified for INVOLVE for 2013-14. Simon summarised his impression of the survey results:

- There was a strong pull towards the broad quality agenda including learning and development.
- Clarity over what we mean by involvement, engagement and participation is required.
- Respondents felt that INVOLVE should be doing more to raise its profile and to drive INVOLVE forward as an organisation.
- Respondents were encouraging INVOLVE to have strong principles and be

bold - there was lots of support out there for INVOLVE and we should draw confidence from successful events such as the conference.

In the discussion with members, it was noted that some survey respondents were suggesting areas of work that we either do already or are beyond our reach and remit. It was also felt that a lot of the work we produce is not widely known about. INVOLVE members emphasised that there is an important need to publicise INVOLVE and let more people know we exist and what support we can provide. Members suggested that alternative and innovative channels of communication for people who don't like written materials may be needed.

Discussions highlighted that at INVOLVE we can't tackle this on our own and we need to be clear about what others can also do. We need to demonstrate in our messages that INVOLVE is not about doing all the involvement, but encouraging others to work with us. INVOLVE should think about how best to work with others to deliver involvement and maintain an enabling, facilitating role that will shift and share responsibility. Simon described how he planned to bring people together from across the NIHR to discuss developing more strategic coordination of public involvement.

When reviewing the priorities for 2013-14, it was noted that we should not just focus on quality improvement as there are still those that have yet to see the value of involving people. It was felt that a balance needed to be struck between our work getting more specialised and needing to have wider impact.

Simon summarised some of the messages from the discussion that we should consider:

- a need for greater strategic coordination including standards for public involvement
- importance of knowledge, evidence and monitoring.
- providing support for public involvement
- publicising the work of INVOLVE.

7. Update on INVOLVE 2012 Conference

Feedback

Maryrose Tarpey and Sarah Bite summarised the feedback on the INVOLVE 2012 Conference feedback based on three key sources:

- i) the conference feedback form
- ii) twitter feed and
- iii) individual emails from conference delegates.

i) The feedback form in the delegate pack was completed by 102 delegates commenting on the content, venue and organisation of the conference. Key points highlighted in the forms included praise for the conference programme. For example, Iain Chalmers' plenary speech was rated highly by many delegates as being particularly interesting. Other delegates noted that the discussions at the conference were generally of high quality, relevant and topical. Joint presentations and

workshops run by both researchers and service users were singled out as being particularly successful. The dedicated poster viewing times were also praised as being particularly valuable, especially when print outs of the posters were available.

Feedback focusing on the venue and organisation included comments on overcrowding - that there were too many people for the venue which led to the conference feeling busy and chaotic. Other delegates felt that this had created a lively and exciting buzz. The queues for food in the dining hall and the lack of sound-proofing in smaller rooms was criticised. Some said that Nottingham remains difficult to get to.

ii) The '#INVOLVE2012' twitter feed during the two days of the conference was successful, with over 500 tweets reporting on the content of conference sessions.

iii) After the conference, a number of e-mails were sent to the Coordinating Centre providing specific feedback from individuals.

Budget

The conference costs are still being finalised, but it is expected that there will not be an overspend. The balance of expenditure was different to previous years, with more money spent on audio-visual resources and filming, less on other costs such as postage and printing.

Dissemination

The 2012 Conference pages on the INVOLVE website are being updated. The new pages will include all the presentation and workshop abstracts from 2012 and previous conferences and will be searchable by name and year. A gallery will show a section of photos from the conference as well as the slideshows from the keynote speeches.

A series of film clips will also be available on the conference area of the INVOLVE website. Several of the film clips discuss public involvement relating to particular topics, for example data analysis and research priority setting. Other clips are of the keynote speakers discussing the conference. A selection of these clips were shown at the meeting.

8. Diversity and Inclusion Update (paper 3)

Lucy briefly described the approach to developing a Single Equalities Scheme as set out in paper 3. Members were asked to contact Lucy if they had any suggestions for an independent consultant / consultancy to carry out some of the project work as well as whether they were interested in being involved in the project.

Action: Group members to contact Lucy Simons with any suggestions for independent consultants who might assist in developing a Single Equalities Scheme for INVOLVE, as well as whether they are interested in being involved in the project.

9. Director's Report

Sarah Buckland and the Coordinating Team briefly updated on a couple of new projects underway. These included a piece of joint work with the Mental Health Research Network (MHRN) currently being undertaken to help researchers budget for public involvement in their grant application. INVOLVE Group members, Christine Vial and Amander Wellings, will be part of a wider advisory group for the project.

10. Report from: Clinical Research Networks (Roger Steel)

Roger Steel reported that the reorganisation currently taking place with the Clinical Research Networks will lead to regional based networks instead of topic based networks. Details for the new networks are still being worked out but he said public involvement will be high on the agenda.

11. Reports from Task and Finish Groups

The following chairs of each Task and Finish group gave very brief reports summarising the morning discussions:

invoNET - Tina Coldham

Support for learning and development – David Evans

Mapping public involvement networks and activities across England - Ade Adebajo

Please see separate meeting notes for each Task and Finish group.

12. Any other urgent business not included on the agenda

Jonathan Boote mentioned that there is a free one day PPI workshop in Sheffield on 7 March which is open to anyone from NIHR organisations.

13. Dates of future meetings

9 May 2013

25-26 September 2013

10 December 2013
