

**Notes of the sixty fifth meeting of INVOLVE
held at the
National Council for Voluntary Organisations
Regent's Wharf, 8 all saints Street, London N1 9RL
Thursday 9 May 2013**

Present:

Ade Adebajo	John Hughes
Lizzie Amis	Linda Laurie
Rosemary Barber	Hugh McLaughlin
Jonathan Boote	Tara Mistry
Ann-Louise Caress	Mark Petticrew
Pam Carter	Una Rennard
Tina Coldham	Carol Rhodes
Lynne Corner	Lesley Roberts
Rosemary Davies	Patsy Staddon
Simon Denegri (Chair)	Veronica Swallow
Jo Ellins	Christine Vial
Jim Elliott	Amander Wellings
David Evans	Patricia Wilson

Guest Speakers:

Amander Hunn
Suzannah Lansdell

In attendance:

Roger Steel	Clinical Research Network (CRN)
Michael Turner	Social Care Institute for Excellence (SCIE)
Tony Williams	Department of Health
Sarah Buckland	INVOLVE Coordinating Centre
Sarah Bayliss	“
Sarah Bite	“
Erica Ferry	“
Meraid Griffin	“
Helen Hayes	“
Marisha Palm	“
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 Louca-Mai Brady
 Kay Pattison
 Diana Rose
 Tony Sargeant
 Ray Fitzpatrick

2. Notes of Meetings held on 22 January 2013 and any actions arising

Inquiry into clinical trials

Simon Denegri reported that the evidence select committee were meeting later in May to debate publication and access to clinical trials data and what transparency looks like from the patient perspective.

John Hughes reported that GlaxoSmithKline (GSK) will be launching a webpage which will enable researchers to request access to data from its clinical trials. There will be an independent review panel of which John Hughes is a member.

Public involvement in the Academic Health Science Networks

The Academic Health Science Networks (AHSN's) are waiting to be designated but the announcement is expected soon. Proposals for public involvement in the plans of the AHSNs varies. The INVOLVE Coordinating Centre have produced a short internal document summarising the public involvement activities proposed by the AHSNs.

Actions:

- **INVOLVE Coordinating Centre to resend the internal document that summarises public involvement in the applications of Academic Health Science Networks (AHSN's) to INVOLVE advisory group members.**
- **Once the AHSN's have been designated Simon will write to them all to outline the potential value of public involvement to their work and to encourage them to develop their plans for involvement.**
- **Simon to discuss with the Department of Health effective ways to raise awareness of public involvement in research and the work of INVOLVE with Clinical Commissioning Groups.**
- **Coordinating Centre to produce a summary paper for the next INVOLVE Advisory Group meeting, updating members on activities and progress with the AHSNs.**

3. Information exchange – opportunity for INVOLVE group members to share current activities / issues of interest

Members gave verbal updates on relevant activities that they are involved in. One of the issues raised was around the language and terminology used to describe public involvement, engagement and participation in research and the common use of 'PPI'.

Actions:

- **Language and terminology around public involvement in research to be discussed by the INVOLVE Advisory Board as a possible topic for the Autumn INVOLVE group symposium.**
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4. Director's report and update on 2012 - 2013 Operational Plan (Paper 1)

Sarah Bite reported that invoDIRECT, an online map which shows groups and organisations that support public involvement in research, is now live on the INVOLVE website. The feedback has been positive and to date 29 groups and organisations had already added themselves to the map. Group Members are encouraged to pass information about the resource on to their colleagues, groups and networks. Postcards are available to help promote the map. invoDIRECT is viewable at www.invo.org.uk/find-out-more/invodirect.

Lucy Simons updated the group on issues around payment for involvement and reported on changes to the benefits system. Universal credit is being introduced in the north west of England and with this new benefit, some of the benefit barriers to involvement are being removed. Simon thanked Lucy for the hard work that she had done around this issue. An update about these changes is available on the INVOLVE website www.invo.org.uk/posttypepublication/payment-for-involvement/.

Sarah Buckland referred to the statistics on visitor numbers to the INVOLVE website. There were approximately 36,000 visitors each month in 2012-2013 and the conference pages of the website were currently the most popular website pages. Sarah also reported that INVOLVE was now tweeting regularly and had approximately 500 followers. It was discussed that tweeting is a useful way of promoting INVOLVE's resources and passing on information to a wide audience. Group Members who use twitter can follow INVOLVE at @NIHRINVOLVE.

Action: all Group members to sign up to twitter and follow INVOLVE – ambition is to have 1,000 followers by the end of the year. Recommend that others follow INVOLVE through #followfriday or #FF

5. Survey of INVOLVE Group Members' and Observers (Paper 2)

Sarah Buckland thanked all those members who had completed the survey. We had a good response to the survey with 27 of the 33 members and observers completing the survey. Overall, respondents were generally satisfied with the accessibility of INVOLVE group meetings and felt able to contribute well. Simon encouraged members to contact the Coordinating Centre if they experienced any difficulties or had any further suggestions. Some members commented how the feedback was very positive and the Coordinating Centre should celebrate this.

Simon identified there was a challenge with the Open Space sessions. While most members felt these were useful and Simon was pleased with how they were working, he welcomed ideas for how to take forward ideas that were generated in these sessions. However, he also noted that as an organisation, it would not be possible for INVOLVE to take on all these ideas and areas for future actions. Feedback from some members was that it wasn't always necessary to have an action as it was a forum for useful discussion.

There were some areas where higher levels of dissatisfaction about group meetings were expressed, especially around the transparency of decision making within INVOLVE and what happens as a result of discussions at INVOLVE group meetings. Simon said that for this and future meetings, the agreed actions would be recorded immediately after the meeting and sent out to members within a few days. Simon hoped that the introduction of the Advisory Board would also improve the transparency of decision making. There was a suggestion made that the papers for the group meetings could make clear what decisions needed to be made. This would make the discussions more action and outcome focused.

Members asked about whether members who are not part of the Advisory Board would have access to the discussions which take place at these meetings. It was agreed that the notes/minutes of the Advisory Board would be circulated to all INVOLVE Advisory Group members.

Action: Notes/minutes from the INVOLVE Advisory Board would in future be circulated to all members.

6. Establishing the INVOLVE Advisory Board (Paper 3)

Simon outlined the value and role of an Advisory Board for INVOLVE. He outlined the key roles of the Board which were to:

- advise on and monitor INVOLVE's Strategy and Work Programme
- advise on policy, resources / budget for INVOLVE
- advise the Chair and Co-ordinating Centre.

Simon proposed that membership of the new board would be:

- INVOLVE Chair
- INVOLVE Chairs and Vice-Chairs as at 01/13
- 3 members of the INVOLVE Group
- INVOLVE Director and Senior Staff
- DH Observer.

Length of membership would be a three year term of office other than for the Chair, INVOLVE staff and Department of Health (HR) Observers.

Advisory group members welcomed the opportunity to discuss the proposal and membership of the Board. Group members discussed some questions and concerns that they had around the role of the Board, in particular the importance of transparency and decision making and the relationship of the Advisory Board to the main group.

Actions:

- **Notes of INVOLVE Advisory Board meetings to be circulated to all INVOLVE group members.**
- **Final terms of reference to be developed and agreed by members of the new Advisory Board however Simon will circulate an “off the shelf” draft terms of reference to provide a broad understanding of the function of the new Board.**
- **The three new members of the INVOLVE Advisory Board to be selected by interested individuals putting themselves forward with a short proposal explaining why they are interested in being a member of the Board. All proposals to be circulated to Advisory Group members with a confidential survey monkey poll for voting.**

7. Public health and public involvement - Mark Petticrew

Mark gave a presentation on public involvement in public health research highlighting some of the challenges it presented, examples of research with public involvement and the role of public involvement in public health research.

Mark identified the following as some of the challenges for public health research:

- Most 'public involvement' is 'public engagement' but the terms involvement, engagement and participation are used interchangeably.
- The term 'public' can be used to describe patients, citizens, policy makers and taxpayers.
- Public health is not just about health interventions.
- Difficulty in engaging / involving people who do not have a particular illness or agenda and identifying motivation for people to become involved.
- Participation rates in epidemiological studies (the patterns, causes, and

- effects of health and disease conditions in defined population) are declining.
- General disillusionment with science.
- Over surveying of certain groups in society.
- Lack of accountability of researchers to the communities they research.

The presentation inspired a wide reaching discussion including issues around:

- Local communities carrying out their own research.
- Involvement of communities in identifying research questions.
- Challenge of working within different research theories and paradigms.
- Hierarchy of research evidence.
- Appropriateness of different types of research for answering different research questions.
- Role of public involvement and engagement in helping to generate evidence and how to get more timely use of evidence.

Mark's powerpoint slides were circulated to Group members with the action points from the meeting.

8. Amanda Hunn, Health Research Authority (HRA) and Suzannah Lansdell Science Wise - Expert Resource Centre (ERC)

The Health Research Authority (HRA) <http://www.hra.nhs.uk/> was set up in December 2011 as an NHS Special Health Authority. The purpose of the HRA is to protect and promote the interests of patients and the public in health research.

Amanda Hunn from the HRA and Suzannah Lansdell from Sciencewise-ERC (Expert Resource Centre for Public Dialogue in Science and Innovation) <http://www.sciencewise-erc.org.uk/> gave an interesting and informative powerpoint presentation to the INVOLVE Group about a piece of work that the HRA had recently commissioned 'Patient and Public Engagement Project'. The project was carried out by IpsosMori and Sciencewise-ERC to seek the views of patients and the public about their work and how they should be able to influence the HRA in future. The project involved both a survey and focus group discussions. There were two types of focus groups / workshops, those with members of the public who met more than once as well as one off focus groups with patients. The survey involved interviews with 1,116 members of the public.

Their presentation focused on the findings from the various focus groups on people's views on patient and public involvement in the HRA. The focus groups included members of the public, specific patient groups recruited from some of the NIHR Topic Specific Clinical Research Networks, and participants of Phase 1 clinical trials. As part of the presentation, Amanda identified areas where patients and the public agreed as well as where their views differed.

Following the presentation there was a wide ranging discussion covering a number of issues including:

- How the HRA can contribute to transparency in the way research is conducted, for example if a company is known not to have published research findings in the past, should ethical approval be withheld?
- In the public focus groups, there was an assumption that the HRA should have 'experts' making the decisions, whereas the patient focus groups were much more aware of the importance of inputting other forms of expertise into the HRA.
- The suggestion that where there has been public involvement in writing patient information sheets this should be included in the information given to patients (to provide reassurance to potential participants).
- It is important for the HRA to inform the public of its role in safeguarding the design and conduct of research studies and why public involvement has an important contribution to make at a strategic level to help strengthen that role.
- Members suggested that the HRA should not be seen to actively promote participation in research, as this could give rise to a potential conflict of interests for the HRA.
- Beware of one-off snapshots to elicit views of either public or patients.
- Important to get the key role of proportionate regulation right (not too little, not too much).

The powerpoint slides were circulated to Group members with the action points from the meeting.

9. INVOLVE work plan 2013 onwards - discussions and expressions of interest (small groups) (Paper 4)

Strategic themes

Simon introduced the final version of the INVOLVE work plan and outlined the stages that had led to its development including initial discussions at the INVOLVE symposium in September 2012, a survey of conference delegates, further discussions at the INVOLVE January Group meeting, and at the Chairs' meeting.

INVOLVE members then divided into three groups and Coordinating Centre staff outlined the activities in the plan. Simon explained that after the meeting we would be emailing out to members asking them to identify areas of INVOLVE work that they would be interested in contributing to (some projects will involve membership of an advisory group, or contributing throughout the project, for others it may involve just contributing or commenting on specific aspects of a project).

Below are some of the suggestions made by members as part of these small group discussions:

invonet

- Members suggested that there was potential to involve invonet members

on the database of case studies / examples project.

Database of case studies / examples

- In compiling and cataloguing INVOLVE case studies / examples in a searchable database it may be useful to explore what worked in the examples and explore typologies of involvement.
- One INVOLVE member suggested that in developing the database we should consider the issues raised in a book: 'What are the questions you can answer best using case studies?' (Yin R., (2009) **Case Study Research: Design and Methods**, Fourth Edition, Sage Publications Inc.).
- Need to consider the accuracy of our use of the term 'case studies' for this work. It could be more appropriate to refer to 'vignettes', 'examples' or use some other description.

invoDIRECT

- Do we need to think about our responsibility to patient groups? For example, if we advertise patient groups (via invoDIRECT) that may increase demand for their input into research.

Facilitating NIHR wide coordination of public involvement

- Developing standards for public involvement - it may be helpful to look at funding bodies for their guidance on standards for involvement.

Developing partnerships and alliances

- What role does INVOLVE have in closing the loop between involvement in research and the NHS (for example HealthWatch and Clinical Commission Groups)? Important to include the NHS as a key organisation to develop alliances with.

10. Discussion topics

INVOLVE group members chose in advance of the meeting to participate in 2 of the following 3 topics:

- Payment for involvement (paper 5)
- Raising awareness with researchers about the work of INVOLVE and public involvement (Paper 6)
- INVOLVE 2014 Conference (Paper 7).

See separate notes of the discussions from these groups.

11. Amander's Levels of Patient and Public involvement Significance

At the last Open Space session in January 2013 Amander introduced her ideas for 'ALPS' - Amander's Levels of Patient and Public Involvement Significance which we decided to try out at the end of this meeting. ALPS is a self-reflective tool for feeding back members' personal experiences of a meeting or event. We tried out two slightly different approaches. First, members used voting pads to answer four questions on their influence and contribution to discussions during the meeting. The responses were instantly visible on the projector screen.

- 72% voted that they found it easy it to contribute to the discussions at the Group meeting
- 76% voted that they felt they had a lot or some influence on discussions at the meeting
- 84% voted that they felt the discussions were influenced by a public perspective and 86% that they were influenced by a researcher perspective.

The second approach was a take away sheet with a 'mountain graph' and questions that continue the theme of mountaineering. Each of the questions link the experience of a meeting to aspects of such an expedition, encouraging personal reflection and learning to draw on personally for future meetings. Amander encouraged members to try this out for themselves in other meetings they attended.

12. Any other urgent business not included on the agenda

There was no other business.

13. Dates of future meetings

25-26 September 2013

16 January 2014
