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

David welcomed Sarah Qureshi who had recently joined the UK Clinical Research Collaboration and was attending this meeting as an observer, and Kate Miller from the Economic and Social Research Council, who was covering for Melanie Knetsch.

He also welcomed two guest speakers, Sophie Auckland from the NIHR Guys and St Thomas / Kings College, Biomedical Research Centre and Angela Rogers from the NIHR Bone Biomedical Research Unit at Sheffield.

David advised the Group that Karen Collins had decided to step down from membership of INVOLVE for personal reasons. Karen has been a valued member of INVOLVE and the Empowerment working group for 6 years. David thanked Karen for her contribution to INVOLVE.

Declarations of conflicts of interest:

No conflicts of interest were declared.

Introductions and welcome:

Apologies

Apologies had been received from:

Nick Partridge

Sue Banton

Stuart Eglin (am only)

Diana Rose

Poonam Jain (am only)

Ray Fitzpatrick

Kay Pattison

Simon Denegri

Vanessa Pinfold

2. Notes of the meeting held on 11 March 2010 and actions taken since the meeting

Two questions were asked about responsibility for patient and public involvement on the Office for Strategic Coordination of Health Research (OSCHR) Board and the E-health stakeholder engagement workstream.

Action: Tony Williams to respond to the questions asked about future PPI involvement in the work of OSCHR.

David reported that Nick Partridge had been invited to give an oral presentation to the Working Group for the Academy of Medical Sciences review of the regulation and governance of research at the end of July.

Action: INVOLVE members were invited to send any comments on the review to the Coordinating Centre.

3. Involvement in Biomedical Research

Sophie Auckland, Biomedical Research Centre (BRC) User Involvement Manager, NIHR Guys and St Thomas / Kings College London, Biomedical Research Centre and Angela Rogers, NIHR Bone Biomedical Research Unit (BRU), Sheffield.

Sophie Auckland provided an overview of public involvement across Biomedical Research Centres and Units and then spoke about the specific public involvement work she is undertaking as the Patient and Public Involvement (PPI) lead for Guys and Kings College BRC.

She explained that the BRCs and BRUs hold an annual national conference for PPI leads to discuss common issues and share resources where appropriate. The most recent conference was hosted by Guys in April 2010 where there was agreement to pool materials, case studies and examples via the NIHR Portal and develop collaborative policies e.g. on expenses. One of the issues highlighted by delegates was the variable level of resourcing available to PPI leads. In some BRCs and BRUs there are full time funded PPI posts (like Sophie Auckland's at Guys) and in others PPI is one of a number of tasks (as for Angela Rogers in Sheffield).

Speaking of her work at Guys BRC, Sophie described how initially she had needed to focus on public engagement about biomedical research before moving on to public involvement initiatives.

Angela Rogers followed by giving a detailed explanation of PPI at the Bone BRU in Sheffield and the processes they worked through to form a Lay Advisory Research Panel and the time it took (just over a year) to get fully established. She spoke about what she believed were the key criteria for successful involvement including access to resources, emphasis on partnership working, feedback and the successful recruitment of the right people for the type of involvement on offer.

Both said that they reimbursed expenses for involvement but that their Foundation Trusts policies on payment and within which the BRCs and BRUs are situated, differed to NIHR's guidance and they did not pay individuals for their involvement.

This presentation was followed by a number of questions from Group members. It was noted that the involvement to date focused more within research already designed and not yet on research priority setting or commissioning of biomedical research. The principle of not offering payment was raised by members and linked to questions about ensuring diversity and broadening of involvement to local

communities. In a response to a question about how best to measure and record public involvement in BRCs and BRUs, Sophie and Angela spoke of their current plans to record public involvement throughout the research cycle and write up case studies to provide examples of what they are doing. They also agreed that currently much of the public involvement activities in BRCs and BRUs are consultative but that gradually as confidence develops, there will be more partnership working as is happening at Sheffield Bone BRU.

4. Directors Report and budget update

The following additional information was provided by the Coordinating Centre team:

Sharing Innovative Practice Workshop Report

Sarah Buckland informed the Group that the INVOLVE report of the Sharing Innovative Practice Workshop held in January 2010 had just been published and that a hard copy was being sent to all Group members. An electronic version could also be downloaded from the publications pages of the INVOLVE website:
<http://www.invo.org.uk/pdfs/TrainingSupportWEB140610.pdf>

UK Clinical Trials Gateway

Philippa Yeeles updated the Group on the development of this web-based resource. It was being developed by the National Institute for Health Research for members of the public wanting to find information about clinical research and opportunities to participate in clinical research.

It aimed to contribute towards fulfilling the Government's commitment in the NHS Constitution that the NHS would ensure that patients, from every part of England, were made aware of research that was of particular relevance to them.

The site is being developed in a number of stages, the first of which has just been completed. Testing of the first phase (primarily functional testing) would take place shortly. Any INVOLVE members who wished to do so, were invited to take part in the user testing. As soon as the web link to the test site was made available to the Coordinating Centre, it would be circulated to Group members. Phase 2 would focus more on the content, look and feel of the site.

NIHR Clinical Research Network (CRN) Portfolio

Philippa Yeeles reminded the Group that the CRN Portfolio is a database of information about NIHR supported research studies (currently over 2,500) that can be accessed by the public: <https://portal.nihr.ac.uk/Pages/Portfolio.aspx>

The NIHR Information Systems Programme had been asked to produce a requirements specification which would be used as part of an invitation to tender for the development of a replacement Portfolio database. As part of this process, Roger Steel, Mary Nettle and Philippa Yeeles had recently participated in a small workshop that had focused on identifying public involvement requirements for the specification.

Action: Coordinating Centre to circulate a hard copy of the Sharing Innovative Practices workshop report to Group members

Action: Coordinating Centre to circulate Group members with information about user testing of the UK Clinical Trials Gateway – Phase 1

5. Systematic review of literature on public involvement in research – Sophie Staniszewska

Sophie Staniszewska gave a presentation on a systematic review, funded by the UK Clinical Research Collaboration (UKCRC), that she is currently finalising.

The focus of the review was looking at the evidence in relation to public involvement in health and social care research on:

- Definitions and conceptualisation
- Theoretical underpinnings
- Measurement of impact of Patient and Public Involvement
- Impact – what difference has it made?
- Outcomes – has PPI contributed to the outcomes of the study?

Sophie outlined the methods used in the review and raised the challenge of finding and accessing the evidence base and the number of papers that were identified in searches.

The evidence base was found to be complex, mainly qualitative research and with little critical evaluation. Definitions of involvement were not always included in studies which focused on process. Reporting of public involvement in research could be improved by more detailed descriptions including negative impacts.

Sophie advised that based on this review for the UKCRC they have developed guidance for reporting, which is contained in the main report. They are also drawing together the findings of the review along with a sister review on public involvement in health and social care services to develop guidance for the reporting of public involvement both in research and services. It is hoped that this will contribute to improving the quality of reporting public involvement and building and strengthening the evidence base.

The presentation was followed by questions and discussions with Group members who were interested to hear about the process and challenges of managing the data and the theoretical thinking that developed during the process. Reporting of public involvement was discussed and how best to encourage researchers to write in detail about the public involvement within the project in their full reports.

6. Feedback on discussions from working groups

The following chairs of each working group gave a post card report from their group:

Strategic Alliances	- Maria Palmer (on behalf of Stuart Eglin)
Evidence, Knowledge and Learning	- Sophie Staniszewska
Empowerment	- David Evans

Please see separate meeting notes for each working group.

7. Reports from Observers

NIHR/DH – Tony Williamson

Professor Dame Sally Davies is now interim Chief Medical Officer. A permanent appointment is expected to be announced during the summer.

With the change of government and plans to reduce the deficit, all budgets are very tight and all contracts are being looked at to identify savings. The Department of Health remains optimistic that the ring-fence for the NIHR budget will continue. However, there are currently no new contractual arrangements being entered into.

Christine Holmes, from the Research Governance section of the Department of Health will be attending a meeting with Department of Work and Pensions colleagues on Wednesday 23 June, to clarify the outstanding points from the social security legislation introduced in October 2009 around involvement for people on benefits. She has asked for INVOLVE attendance but if this does not occur this time she will seek a further meeting.

NIHR Clinical Research Network (CRN) Coordinating Centre – Roger Steel

The Way Forward review was still the main priority for the CRN CC. For those not familiar with the project it is a review process to get clinical research networks to work more coherently on patient and public involvement. A panel had been convened which included people external to CRN CC and internal people. The panel had taken part in a two day process where 35 people had spoken with the panel. The conversations had focused on what they were currently doing in the networks. Roger reported that the process had allowed people to be heard both within their own networks and across/outside individual networks.

The plan is to follow up the dialogues with a workshop so people can meet together to talk through how they will work together in the future. He felt there is a real will for working together which has been brought about by the Way Forward process. Due to the squeeze on budgets, there is some uncertainty about the funding of the review process.

Otherwise, work is continuing with the Primary Care and Comprehensive Research Networks. The speciality groups are looking at specific areas and helping to problem solve and advise on portfolio studies.

Portfolio 2 (the second version of the NIHR research portfolio) is in development and it will include data on patient and public involvement. Issues they are working on include making the participant information sheets and lay summaries available as well as addressing issues around accessibility and transparency.

Economic and Social Research Council (ESRC) – Kate Miller

In the past few years the focus at the ESRC has been on public engagement in research, mainly through researchers getting engaged with the public while in receipt of a research grant. They now plan to get the public involved in setting research priorities. They will be able to influence where the ESRC directs its funding and ensuring public attitudes and values are taken into account. This has not happened systematically across the ESRC before. Kate was currently developing guidelines for other staff when working on research calls to enable them to take public views into account.

8. Any other urgent business not included on the agenda

There was no further business.

9. Dates of future meetings

- 21/22 September 2010 – INVOLVE Awaydays
- INVOLVE Conference 16/17 November 2010
- 26 January 2011 – INVOLVE Group meeting
- 11 May 2011 – INVOLVE Group meeting