
**Notes of the forty seventh meeting of INVOLVE
held at
Avonmouth House, 6 Avonmouth Street, London SE1 6NX
Thursday 06 March 2008**

Present: Nick Partridge (chair)
Peter Beresford
Stuart Eglin
Mary Nettle
Jim Elliott
Ray Fitzpatrick
Angela Barnard
Anne-Louise Caress
Sophie Staniszewska
Diana Rose
Poonam Jain
Michael Turner
Ade Adebajo
Louca-Mai Brady
Hugh McLaughlin
David Evans
Tracey Williamson
Karen Collins
John Sitzia
Sue Banton
Richard Baker
Maria Palmer

In attendance: Tony Williams
Kay Pattison

Sarah Buckland (Support Unit)
Sarah Bayliss (Support Unit)
Barbara Dawkins (Support Unit)
Helen Hayes (Support Unit)
Roger Steel (Support Unit)
Maryrose Tarpey (Support Unit)

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

Declarations of conflicts of interest

Peter Beresford and Michael Turner expressed a conflict of interest as they were currently undertaking work for the Examples of User Controlled Research.

Introductions and welcome

Nick welcomed Tony Williams from the Department of Health who is Morton Phillips replacement

Apologies

- Hala Patel
- Simon Denegri
- Mark Petticrew
- Sarah Carr
- Rosemary Barber
- Patsy Staddon
- Susie Parr
- Patricia Ladly
- Marianne Miles
- Alison Faulkner
- Laura Serrant-Green

People leaving:

John Sitzia

Nick advised the Group that this was John Sitzia's last meeting; he joined Evidence Knowledge and Learning (EKL) in 2000 and the main Group in 2002 and so has been with the Group for over 6 years. Nick thanked him for his role as both a member and chair of EKL for several years and wished him all the best in his new role as Senior Assistant Director at the UK Clinical Research Network (UKCRN) which he started a few months ago.

Roger Steel

Nick also reported that this would be Roger Steel's last meeting, Roger has been with INVOLVE for just over 7 years. Roger would be taking up the post of Patient and Public Involvement Manager for the UKCRN working with Marianne Miles and would be leaving at the end of April. Nick thanked him for his work for INVOLVE and congratulated him on his new post.

Carol Lupton

Nick updated the Group that Carol Lupton, who was the Department of Health observer for the Policy Research Programme (PRP), had now left the Group. Patricia Ladly would be replacing Carol, although she had given her apologies for this meeting.

Changes to format of Group papers

Nick advised the Group that changes had been made to the formatting of the papers. The main differences were as follows:-

- Main Group meeting papers are on yellow paper (for those sent hard copies)
- Barbara produced a cover sheet for the whole day (in white)
- We no longer refer to documents as 'annexes', they are now called 'papers'
- We have produced a separate sheet with the ground rules

Action: Group members to feedback their thoughts on the new format for Group papers.

2. Notes of the meeting held on 13 December 2007

No corrections to be made. Nick thanked Kate Sainsbury for chairing the December meeting in his absence.

3. Notes of actions taken since the meeting and any other matters arising

The notes of the awayday report have been amended to read: 'There had been subtle changes from patient led to clinician focused provision'

Penny Cole from Dovetail Communications has produced a draft strategy. This is included as paper 8 in the Strategic Alliances working group papers. Please see paper 3. The draft Operational Plan will be discussed under agenda item 6.

4. Involving young people in research

Louca-Mai Brady and Hugh McLaughlin gave a joint presentation on involving young people in research.

- Louca-Mai described the work of the National Children's Bureau (NCB) and research undertaken by the organisation, which actively involves children and young people wherever possible.
- The NCB hosts the young people's reference group comprising 15 young people meeting four times a year. It was established by the Public Health Research Consortium with support from INVOLVE. The NCB also works with the Medicines for Children Network to help increase the involvement of children in the activities of the network, and also works with the Young Researcher Network, launched by the National Youth Agency.
- Hugh talked about ethical and practical issues in involving young people in research starting with the notion of childhood as a social construction. Children and young people have their own language, rights under article 12 of the UN Convention, and expertise about the experience of their own lives which is different to adult perceptions of that experience.

The following questions were asked by Group members and answered by Hugh and Louca-Mai:

Q. Had the speakers worked with young offenders and young asylum seekers?

A. Not yet, but there was some work coming up with young asylum seekers.

Q. What about payments and accreditation?

A. Accreditation is strongly supported, and work had been done with teachers on this. However, the issue of payments was more complex and linked with choice.

Q. What about approaches to recruitment of young people when there is such diversity?

A. You tend to recruit more young people than you need because there are different pathways for young people through involvement. The way to reach people is often by word of mouth with young people but you need to be prepared to respond and engage them very quickly.

Hugh suggested that it might be helpful for a discussion with the Conference Planning Group (CPG) to ensure the issues which are specific to young people are represented at the conference.

Action: CPG to consider how to ensure issues relevant to involving young people are included at the conference.

5. Reports from working groups

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

Strategic Alliances	- Stuart Eglin
Evidence, Knowledge and Learning	- Sophie Staniszewska
Empowerment	- David Evans

Please see separate minutes for each working group.

6. INVOLVE Operational Plan 2008 / 2009

Nick invited feedback from the working groups on the draft Operational Plan. He highlighted that many activities are already committed to, but it was important to consider the balance of activities and how they can be realistically met. Some activities have no budget as they are not yet clearly defined and need further discussion.

Stuart Eglin, commented on the achievements of the Group given the limited budget and questioned whether the Group should be asking for additional funding. The Department of Health has said that although the budget is fixed for now, it is open to bids for additional projects.

Strategic Alliances made several suggestions as to how they felt the Operational Plan could be improved in the future. They reported that they would value a clearer statement of why we are doing what we are outlining and more clarity on our overall work priorities. They suggested that the Operational Plan should include project aims, length of time for each piece of work and expected outcomes, and that there should be less focus on the budget and more on coordinating the momentum gathering around public involvement across the National Institute of Health Research (NIHR) and the Policy Research Programme (PRP) research programmes.

Stuart informed Group members that the Support Unit were currently short staffed and so delivery timescales of some of the work planned may have to be adjusted. Members agreed that it would be useful to think through the implications for the Support Unit when considering ideas for future work and that it was important to recognise the stresses and strains of the Support Unit. Stuart advised the Group that Strategic Alliances' members requested that it would be helpful to clarify the role of the main Group in relation to the Operational Plan and the activities of the three working groups. Nick explained that the working groups do the work and the main Group is the forum for broad discussions and knitting together of the various strands of work.

David Evans reported that the Empowerment working group wished to add 'Social Inclusion / Exclusion' to their part of the Operational Plan without a budget attached at present. This activity would include potential work with black and minority ethnic communities.

Sophie Staniszewska drew attention to the continuing success of invoNET and the need to increase the budget for this work by an additional £2,000.

7. Future development of INVOLVE

Working group chairs outlined key points from their morning discussions around the future development of INVOLVE.

7.1 Evidence, Knowledge and Learning

Developing the knowledge base – the development of a programme of research to generate evidence on the impact of public involvement in research

Sophie reported that working group members considered this to be a valuable and important research programme and were fully supportive of developing a programme and requesting support and funding for this to be taken forward by the Department of Health.

She advised that the following areas were important to consider in developing evidence on the impact of public involvement:

- Different methods for evaluating
- Innovative ways of evaluating
- Exploration of the different impacts that might emerge from different methods
- Different forms of evidence
- Definition of evidence and impact
- Different methods for different interventions
- Capturing the time it takes for impact to take place
- How do we measure evidence and can it be done robustly
- Need for qualitative and quantitative research
- Critical discussion and guidance to move the debate forward
- Development of routine measurements for public involvement in research e.g. with databases, publishers, authors
- Impact of public involvement in research dissemination
- User valued outcome measures generated by service users

Pluralistic evaluation – relevance starts from the assumption that different players have different goals – may not all be trying to achieve the same thing. Overt acknowledgement that there are different values and guides in public involvement in research.

The programme would also need to address the following:

- Primary research
- Implications for policy
- Consideration of the audience for this work – for whom do we need evidence (funders, commissioners, research community, members of the public)?
- Economic evaluation and capacity building
- Evaluators of the future – how to evaluate better

Action: Further discussions on plans for a research programme to take place online and by email prior to the Chairs meeting on 03 April 2008.

Monitoring and capturing information about public involvement in research.

Sophie advised that discussions took place about what is currently happening to build knowledge around public involvement in research. It was noted that the Support Unit has had initial discussions with the National Institute for Health Research, Research for Patient Benefit Programme, to explore how to best use the information they receive about public involvement in research from their grant application forms.

7.2 Empowerment

Developing champions of good practice for public involvement

David reported that discussions had taken place around:

- Who are champions, how to identify champions, who should support champions and is champion the correct term or would the term ambassador be more appropriate.
- A number of different ambassadors were identified e.g. INVOLVE members, Sally Davies, those with public involvement in research as a formal responsibility in their role as well as individuals working through personal commitment.
- Different dimensions to consider when discussing ambassadors. They might be in NHS, public health or social care but also in different sectors such as higher education, voluntary sector, journal editors, funding and

commissioning and regions such as national, regional and local. Work is required to identify existing champions and develop new ones.

- The development of a scheme for ambassadors would need to be responsive to the needs of different audiences. Infrastructure and resources would be needed to support them.

David advised that there was a suggestion of a three tier approach:

- Basic ambassador level – self selection – open to all – resources provided of toolkits and check lists
- 2nd level of those who are perhaps instigating change in an organisation – more intense support needed through for example learning sets and networks
- 3rd level – those in a strategic role – intense one to one support – recognition perhaps by INVOLVE fellowships or recognition as part of NIHR faculty.

David explained that it was recognised that these resources and the support would be in addition to the current support already provided by the INVOLVE Support Unit.

Action: Further discussions on the development of ‘ambassadors’ are to take place on the Empowerment Discussion Forum.

7.3 Strategic Alliances

Development of regional support and capacity building for researchers and the public

Stuart reported that his group were asked to focus discussion about the ways in which INVOLVE will work to support public involvement within the new ten Research Design Services (RDS) due to replace the old Research and Development Support Units (RDSUs) by October 2008.

He advised that at the INVOLVE awayday in October 2007 RDSs were identified as potentially one of the ways INVOLVE could support the development of ‘hubs’ for public involvement in research across England. One of the results of these discussions was the inclusion of a statement about the importance of a commitment to working with INVOLVE to support public involvement in research in the tender document for RDSs.

He explained that each RDS would be expected to have a lead person responsible for public involvement in research. Whilst INVOLVE would not

provide direct training on behalf of RDSs or give direct advice to researchers on behalf of RDSs it is envisaged that INVOLVE would provide support and equip RDSs (via their public involvement leads) with the knowledge and skills to give advice and training on active public involvement through providing:

- Training workshops for trainers and advisors in RDSs
- A 'phone a friend' service where advisors need additional support and information
- INVOLVE publications for distribution to researchers and for their own reference
- An editable electronic copy of the INVOLVE 'public leaflet' for adaptation for their own equivalent corporate leaflet if requested
- Information on current and planned developments by INVOLVE and updates on the public involvement environment nationally
- A national forum for public involvement leads in RDSs to share experiences, support and information

He reported that a suggestion was made that this new workstream would require at least one additional post within the INVOLVE Support Unit if it is to properly develop the links and support the work of RDSs. Discussion went on to consider other models for supporting RDSs including the idea of having a more decentralised approach – i.e strategically place INVOLVE staff within regions to create INVOLVE 'hubs'; perhaps link up to the various Public Health offices of the regions.

In addition, working group members discussed the importance of ongoing monitoring of public involvement amongst Research for Patient Benefit (RfPB) grant holders. Suggestions included, encouraging grant holders to report public involvement activity in their progress reports as well as auditing a sample of projects to track public involvement.

Action: INVOLVE to consider applying for further resources from the Department of Health to develop work with the Research Design Services and to explore the possibility of a secondment in the short term.

8. What's new in the Department of Health

Kay Pattison's update began by referring to the National Institute for Health Research (NIHR) website news page: <http://www.nihr.ac.uk/news.aspx> as a good way to keep up to date with new developments. She highlighted the following news items:

- Funding opportunities for taking forward research

The budget increase for 2008/2009 provides opportunities for taking forward research including public health and social services as well as clinical research.

- **NIHR Research Design Services (RDS)**

The paragraph included from INVOLVE in the brief for the RDS reflects the importance of the work of INVOLVE and its role in supporting the work of these new centres.

- **NHS R&D transitional funding**

As part of the implementation of the Best Research for Best Health research strategy, 2008/2009 is the final year of Transitional R&D Funding. For the future, researchers will have to bid directly for NHS research funding through the new NIHR schemes.

- **New NIHR Coordinating Centre**

In future the NCCHTA (National Coordinating Centre for Health Technology Assessment) will be one of a number of NIHR research programmes under the umbrella of the newly formed **National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETS-CC)** based in Southampton. The Service Delivery and Organisation (SDO) Programme will also be transferred to NETS-CC.

NETS-CC have begun recruiting for additional members of staff for a number of new NIHR research programmes as well as for the newly configured SDO programme.

9. Directors report

Sarah thanked Roger for the hard work, knowledge and experience that he had brought to INVOLVE. She explained that the Support Unit would be several posts down when Roger leaves and she was looking to advertise in the near future. She was also looking at the possibility of getting consultants to complete discreet pieces of work.

10. Any other business

There was no further business.

11. Dates of future meetings – please note the change of dates

Tuesday 03 June 2008

10 and 11 September 2008 (awayday)

Tuesday 16 December 2008 – **cancelled**

Tuesday 20 January 2009 – **new date to replace cancelled meeting**

INVOLVE Conference: 11 and 12 November 2008
