
**Notes of the thirty ninth meeting of INVOLVE
held at the
The British Library, 96 Euston Road, London
Wednesday 15th March 2006**

Present: Nick Partridge (Chair)
John Sitzia
Kate Sainsbury (Vice Chair)
Peter Beresford
Stuart Eglin
Sophie Staniszewska
Lester Firkins
Maria Palmer
Sue Banton
Karen Collins
Deborah Tallis
Marianne Miles
Alison Faulkner
Bob Revell
Vinod Kumar
Susie Parr

In attendance: Amanda Edwards (SCIE) - speaker
Joan Higgins (PIAG) - speaker
Kay Pattison

Sarah Buckland (Support Unit)
Barbara Dawkins (Support Unit)
Helen Hayes (Support Unit)
Roger Steel (Support Unit)
Jane Royle (Support Unit)
Maryrose Tarpey (Support Unit)
Philippa Yeeles (Support Unit)
Sarah Bayliss (Support Unit)

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

Declarations of conflicts of interest

No new conflicts of interest were reported.

Introductions

Nick Partridge welcomed the guest speakers, Amanda Edwards, Head of Knowledge Services, Social Care Institute for Excellence (SCIE) and Joan Higgins, Chair of the Patient Information Advisory Group (PIAG).

Nick welcomed two new temporary sub-group members:

- Bob Revell (new member of Strategic Alliances) Head of Service – Assessment and Care Management, Barnsley Social Services
- Rachel Purtell from Folk.Us in Exeter (new member of Empowerment (unable to attend the meeting))

Nick congratulated Peter Beresford for being appointed a member of the Academy of Learned Societies for the Social Sciences.

Apologies

Apologies had been received from:

- Carol Lupton
- Tracey Williamson
- Mary Nettle

Farewells

Nick reported that Robert Johnstone and Kirstine Knox were leaving the Group. Nick thanked both of them in their absence for the contribution they had made to INVOLVE and in particular to the Empowerment sub-group.

2. Notes of the meeting held on 29th November 2005

There were no corrections to be made to the minutes.

3. Notes of actions taken since the meeting (See Annex B)

Nick congratulated Maryrose Tarpey on her new appointment as Public Involvement Co-ordinator at the INVOLVE Support Unit.

Nick reported that he planned to stand down as Chair of INVOLVE. He advised members that there would be an open access process to appoint a new Chair, which would be advertised. He anticipated that interviews would take place in the summer, with a handover in October.

Kate Sainsbury requested that the recruitment process involved the Director of the Support Unit along with INVOLVE members.

Action: Kay Pattison to raise with Sally Davies the suggestion that the Director and INVOLVE members be involved in the recruitment process

4. Public involvement and the Social Care Institute for Excellence (SCIE)

Amanda Edwards, Head of Knowledge Services (SCIE)

Amanda Edwards gave a presentation on the work of SCIE and service user and carer involvement. She emphasised that SCIE is keen to maintain and continue to develop links with INVOLVE.

The presentation (attached) covered:

- Knowledge reviews
- SCIE practice guides
- social care online <http://www.scie-socialcareonline.org.uk/>
- SCIE Partners Council
- SCIE publications

Amanda identified the following, as some of the challenges for SCIE:

- Not privileging one source of information over another when undertaking knowledge reviews
- How to access the relevant sectors, and methods for distributing information
- Ensuring that the information they produce is relevant and detailed enough to be used in practice
- The lack of infrastructure for developing social care research.

Discussions covered:

- Service user and carer involvement in developing guidelines for undertaking systematic knowledge reviews (currently being revised)
 - Service user and carer representation on SCIE advisory groups
 - Promotion of service user and carer involvement in social care research
 - Use of terminology e.g. different types of knowledge, such as policy knowledge
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5. Discussion on the Academy of Medical Sciences report - Personal data for public good: using health information in medical research (2006)
Presentation by Professor Joan Higgins, Chair of the Patient Information Advisory Group (PIAG).

Joan Higgins described the purpose and work of PIAG and then went on to discuss the report by the Academy of Medical Sciences (see attached slides of presentation)

Comments about PIAG in the AMS report:

- PIAG should promote their role as facilitators of research
- PIAG should fast track research applications
- There are not enough active research representatives on PIAG
- There should be the possibility of appealing against PIAG decisions

PIAG's response was:

- Processes do need to be streamlined
- Proportionality between privacy and the public good is important, however, people go to the NHS for their healthcare. Whilst many are pleased to be involved in research, consent to participate in research should not be assumed
- The public must be reassured that information given is given in confidence and will be protected. Therefore controls are necessary.

The way forward:

- More research needs to be done on public attitudes to the use of patient data
- PIAG needs to raise awareness of its role and increase transparency
- PIAG are working with the UK Clinical Research Collaboration (UKCRC) on a DH toolkit to help researchers navigate their way through the research application process.

Issues and questions raised in the discussion:

- Commercial research and the use of patient data
- Consent for children participating in research

- The need for clearer guidance for researchers on the use of patient information
 - Who should seek consent from patients – the researcher or practitioner?
 - The role of PIAG in looking at the accessibility and clarity of patient information
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6. What's new in the Department of Health (NHS R&D and PRP)

Kay Pattison gave a brief summary of Best Research for Best Health - the Department of Health's 5 year Research and Development Strategy for the NHS in England. Kay reported that patients and the public are at the centre of the strategy and this reflects the input from INVOLVE and the development of the patient and public involvement agenda over the last 10 years. The following points were emphasised:

- INVOLVE needs to consider how it can influence all areas of the National Institute for Health Research
- The importance of ensuring that public involvement is an integral part of the Central Commissioning Facility processes
- The need to maintain and develop the established links that INVOLVE already has with the Service Delivery Programme and Health Technology Assessment Programmes.

Questions and discussion focussed on how the Central Commissioning Facility could help user researchers to link with appropriate NHS researchers, and the difficulties of developing such partnerships.

7. Director's Report

It was highlighted that there were minor errors in the budget totals.

Karen Collins reported her concern about letters that had been sent out to the managers of all Cancer Networks regarding future funding for consumer panels.

Action: Sarah to investigate errors in the budget.

Action: Sarah to liaise with Marianne to explore concerns raised re. funding of cancer consumer panels

8. Conference Update

Professor Sally Davies, Director of Research & Development at the Department of Health, has accepted the invitation extended to her to be keynote speaker at INVOLVE's conference on Wednesday 6th September 2006.

The 2006 conference will have themed sessions as well as the usual parallel sessions. These sessions will be longer to allow for greater discussion. Key issues raised will be brought to a plenary session on day 2.

9. Reports from sub-groups

Verbal reports were received from the following:

Empowerment	Kate Sainsbury
Strategic Alliances	Stuart Eglin
Evidence, Knowledge and Learning	Sophie Staniszewska

Please see the individual minutes for notes of these meetings.

10. Operational Plan for 2006 / 2007 - Annex G

Nick reported that the sub-group chairs met in January to discuss the priorities highlighted by the sub-groups at the INVOLVE meeting in November. It was decided that all committed activities and the top priority identified by each sub-group, should be taken forward to form the Operational Plan for 2006/2007.

It was raised by one group member that the process of prioritisation and limited budget meant that some activities rated as high importance by the sub-groups could not be taken forward.

The Group approved the 2006 / 2007 Operational Plan.

11. Any other urgent business

None reported

12. Dates of future meetings

11th / 12th October 2006

Thursday 14th December 2006

INVOLVE Conference 6th – 7th September 2006
