

**Notes of the thirty fifth meeting of INVOLVE held at
The Kings Fund, London on 8th March 2005**

Present: Nick Partridge (Chair)
John Sitzia
Kate Sainsbury (Vice Chair)
Peter Beresford
Ruth Sinclair
Vinod Kumar
Stuart Eglin

In attendance: Tracey Williamson
Catherine Law
Tony Stevens
Chris Caswill
Karen Collins
Sue Banton
Lester Firkins
Maria Palmer
Kay Pattison
Joan Box
Alison Faulkner
Robert Johnstone
Susie Parr (part of meeting)
Michael Turner
Maxine Stead

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

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

No conflicts of interest were reported.

Nick welcomed Michael Turner and Maxine Stead to the meeting. Maxine is from the UK Clinical Research Network Coordinating Centre. Either Maxine or Janet Darbyshire will attend as an observer at future meetings (they are taking the lead within the UKCRN CC for public involvement).

Apologies had been received from

- David Johnstone
- Derek Stewart
- Mary Nettle
- Morton Philipps
- Sarah Carr

Nick reported that Jabeer Butt had resigned from Empowerment sub-group due to work commitments.

Nick advised the members that the Accessibility working group would be meeting at the same time as the main Group and some of these members would join the Group meeting later in the afternoon after their meeting had finished.

2. Notes of the meeting held on 08 December 2004 - annex A

There were no corrections to be made to the minutes held on 8th December 2004, except for Commonwealth should read Commonwealth Club

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

Sarah reported that the paper listing details of all the Group members links and contacts had been distributed and the Support Unit would be exploring how best these could be used.

4. Definitions of User Controlled Research - presentation by Michael Turner and Peter Beresford - annex C

Nick welcomed Michael Turner and Peter Beresford to present the findings of their work looking at definitions of user controlled research. He advised the Group that all members should have received the summary and conclusion from the report (annex C) and the M&E sub-group members should have received a full copy of the draft report. He advised the Group that the report was being reviewed by some members of the advisory group (who were involved in commissioning the work) as well as external peer reviewers. Please see the attached presentation overheads.

The following is a summary of some of the questions raised and the responses from Michael and Peter:

- *What is the distinction between user controlled and user led work?*

There was little discussion in the focus groups. Other terms also used are survivor research and emancipatory disability research. User controlled research was used more commonly than user led research. In the past some service users have been dismissive of the term user led research, whereas others use it interchangeably with the term user controlled. Control was a much clearer word.

- *The relevance of user controlled research to acute NHS Research?*

People who they usually have contact with are those whose lives have been affected over a long period of time. Acute NHS research involved a different perspective. However, access and involvement issues were similar. More imagination was needed as to how it might be possible for people experiencing acute care to undertake research with other people.

- *Whether the problems experienced by user controlled researchers were unique to user controlled research or encountered by others and whether some of the solutions were more generic or very specific to user controlled research?*

The political response of user controlled research is a response that relates to a sense of the political nature of the issues people are engaging with personally and more broadly. There are tensions between building bridges and alliances between user controlled and mainstream research and seeing such research as a separate activity. Views differ as to how distinct user controlled is and how much it is part of a continuum with other research. Sometimes user researchers need space that is their own so that they can work out their position without being dominated by others.

- *Whether the research shed any light on the tensions and difficulties that arise in collaborative research versus user controlled research?*

What is frequently lacking in collaborative research situations is any safety and security. There needs to be a partnership or it ends up with a negative outcome.

Nick thanked Peter and Michael for their presentation.

5. What's new in the Department of Health (NHS R&D and PRP?)

Kay highlighted the implications of the impending general election to the work of INVOLVE and the Support Unit.

Kay also referred to the Freedom of Information Act which came into force on January 1st 2005 and applied to all public bodies including the Department of Health and Universities.

Action: Kay to send the Support Unit details of the rules for operation during an election

Action: Support Unit to explore training for group members and Support Unit regarding the Freedom of Information Act.

Kay then gave a brief presentation outlining recent changes in the Department of Health. Copies of an A3 plan of the new structure of the Department of Health R&D Department were given out at the meeting.

She reported the following –

- R&D has been reduced by more than half and no longer had the regional office structure. INVOLVE needs to think how best to influence R&D now this structure has been changed.
- Professor Sally Davies is the Director of R&D and has an interest in public involvement having been Director of R&D in London.
- Russell Hamilton is Deputy Director of Research & Development – Policy. He is very aware of the public involvement agenda and very committed to it.
- Noreen Caine is the new Deputy Director of Research & Development – Delivery. She was a Trust R&D Manager in Cambridge before she joined the DH and has local knowledge. She was involved in research commissioning and has come from the NHS.
- Peter Sneddon is the Head of Research Programmes and is the person reporting to Noreen on the work of the group through Kay. Peter came to the Department of Health from the Wellcome Trust.

Kay told the Group that Sally Davies is devising a strategy for involving significant others. She advised members that the UKCRC is considered to be one of those significant others of which Nick Partridge is a member. She reported that another group of significant others is the UK Clinical Research Network and the first of these networks was the National Cancer Research Network (NCRN) which Derek Stewart was very heavily involved in. She informed the Group that the NCRN had just won the contract for the UK Clinical Research Network (UKCRN). This would be based at the University of Leeds who also hold contract for INVOLVE Support Unit. The contract for the Medicines for Children Network has just been given to Liverpool University (Ruth Sinclair is taking the lead on public involvement within this network).

Kay reported that the new structure reflected the budgets. She advised that 533 million has been attributed to the NHS R&D budget and 34 million for the Policy Research Programme. Only a small amount goes to Public Health Research. She felt that industry was by far the biggest funder of R&D, so she felt that Sally Davies's desire to link well with industry was important.

There followed some discussion about how INVOLVE should engage with industry. Nick reported that at a recent meeting of the UKCRC board, representatives from pharmaceutical companies had signed up to public involvement in clinical research, so he felt we now had a tool to work with.

6. Conference update

Kate reported that the Conference Planning Group met on the 13th January 2005 to reflect on the 2004 conference. Kate reported on progress with the Conference report which is planned to be completed by Easter. Kate thanked all members of the conference planning group (CPG). A new planning group would be established in Autumn 2005. The new planning group would need to include people with a range of knowledge and expertise and include researchers and research managers as well as service users to ensure that the differing needs were fully taken into account in planning the conference. The conference needed to provide open but safe spaces where people could discuss things that were difficult for them. Kate suggested there could be a discussion around new members to the next Conference Planning Group at the June Group meeting. She asked that if any one was interested on joining this group, to let the Support Unit know.

At the last Conference Planning Group meeting they had agreed that the next conference would again be over two days and continue to take place every two years. She informed the Group that Lester Firkins would continue as a member

of the group and be the link with the Strategic Alliances sub-group. Kate would remain as chair for the 2006 conference.

Nick thanked Kate and all those who had helped with the conference.

Action: Item for agenda for June meeting – discussion re. new CPG members.

7. Director' s report – annex D

UKCRC

Sarah reported that Nick had attended the UKCRC Board meeting in January and presented a paper jointly produced with the Medical Research Council and the Association of Medical Research Charities on guiding principles for public involvement in the UKCRC. She advised that the board had agreed that the UKCRC core team would work with UKCRC partners to develop mechanisms for public involvement.

Sarah advised members that Philippa had produced a brief paper highlighting some of the issues of concern in relation to liabilities and responsibilities of public involvement in research. This paper had been sent to the UKCRC, with a view to initiating discussions with the Regulatory and Governance workstream, who are looking at honorary contracts as part of their work to streamline regulatory procedures. Sarah has been asked to join the UKCRC Regulatory and Governance workstream.

James Lind Alliance

Sarah reported that Members of the INVOLVE Support Unit met with Iain Chalmers, Patricia Atkinson and John Scadding in December, to discuss the work of INVOLVE and the Alliance. She advised the Group that the first meeting of the Shadow Steering Group for the Alliance took place in January and an orientation meeting took place in March between Asthma UK and the British Thoracic Society, in preparation for a first event.

Lester Firkins also attended the orientation meeting and gave a brief feedback on progress:

- The JLA offers clinician and patient organisations guidance and support through a number of exploratory/preparatory meetings held prior to the event.

- The JLA provides an independent chairperson and the venue for the event.
- Ownership of the proceedings of the event itself lies with the clinician-patient partnership. It is these newly forged alliances between clinician and patient organisations which will then take forward their agreed agenda.
 - It is planned that asthma UK and the BTS will be the first two organisations that use the JLA forum. It is hoped that this will encourage other alliances between clinicians and patients to develop.
 - Lester will probably be the Chair for the Asthma UK and BTS event.

Budget

Sarah advised the Group that she anticipated that overall, there would be a small overspend, with estimated expenditure of approximately £128,000. She advised members that the budget allocated for 2004/2005 was £125,000. (Whilst the budget report indicates activities totalling £136,500, this was to ensure that the budget was fully spent.)

8. Reports from sub-groups

Verbal reports were received from the following:-

Empowerment	Kate Sainsbury
Strategic Alliances	Stuart Eglin
Monitoring and Evaluation	John Sitzia

Please see the individual minutes for notes of these meetings.

9. Operational Plan 2005 / 2006 - annex G

Nick reported that the chairs met in January to discuss priorities that were highlighted by the sub-groups at the December meeting. He advised that the operational plan is based on those decisions. He reported that job sheets will be finalised over the next couple of months and milestones identified.

He informed the Group that there was a potential shortfall in the capacity of the Support Unit to undertake the work. The impact of INVOLVE's success has created more work especially with the UKCRC and James Lind work, however this will be taken forward with Kay and with Leeds University.

Stuart suggested that there should be work sheets for all pieces of work that were being undertaken, even where there was no budget available e.g. UKCRC and James Lind Alliance.

There followed some discussion over the workload of the Support Unit with suggestions for how this could be reduced (e.g. seeking alternative funding, assistance from Group members, not undertaking all of the tasks identified).

The operational plan was agreed, subject to work sheets being drawn up for the James Lind Alliance and UKCRC work.

Action: Worksheets for the JLA and UKCRC work to be added to the Operational Plan

10. Any other urgent business not included on the agenda

None

11. Dates of future meetings:

Tuesday 07 June 2005	Royal College of Nursing
Tuesday 29 November 2005	Royal College of Nursing
Awayday - 05 / 06 October 2005	Weetwood Hall in Leeds

Nick advised the Group that sub-group meetings would be held in the afternoon of the 5th October. The awayday itself will start at 6.00pm and run until approx 4.00pm the next day.
