
**Notes of the forty fourth meeting of INVOLVE
held at the National Council for Voluntary Organisations
Regents Wharf, 8 All Saints Street, London N1
Thursday 14 June 2007**

Present: Nick Partridge (Chair)
Kate Sainsbury (Vice Chair)
Peter Beresford
Stuart Eglin
Karen Collins
Mary Nettle
Alison Faulkner
Mark Petticrew
Susie Parr
Deborah Tallis
Maria Palmer
Chris Caswill

In attendance: Carol Lupton
Marianne Miles
Hala Patel
Bill Davidson

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

No new conflicts of interest were reported.

Introductions and welcome

Nick welcomed Bill Davidson from the Department of Health who would be giving a presentation on the Mental Capacity Act – Implications for research.

Nick advised the Group that Tracey Williamson was now on maternity leave and her baby was due imminently.

Nick congratulated Peter Beresford on his OBE and Deborah Tallis on attaining her PhD.

Apologies

- Sarah Carr
- Kay Pattison
- Morton Phillips
- Vanessa Pinfold
- Bob Revell
- Sophie Staniszewska
- Jane Royle
- Simon Wilde
- Tracey Williamson
- John Sitzia

Change of name:

Members were advised that it had been agreed by the Chairs to change the name of the sub-groups to working groups. It was felt that this title more accurately reflected the purpose and work of the groups. All paper work will in future refer to working groups, rather than sub-groups.

2. Notes of the meeting held on 21 March 2007 – annex A

No corrections are to be made.

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

Membership

Nick reported that there had been an excellent response to the adverts for new members, with 180 applications being received. The final set of interviews for

new members were planned for the following day, and Nick felt confident that the new members would be a rich mix of people.

Nick advised that there would be an induction day in London for the new members on the 28th September. He hoped that existing members would be able to attend.

INVOLVE Strategic Plan

Nick reported that there had been about half a dozen responses so far to the consultation for the Strategic Plan. The deadline was 25th June.

UK Clinical Research Collaboration (UKCRC)

Nick reported that he had attended a UK Clinical Research Collaboration (UKCRC) board meeting the previous week, where there had been an update on public involvement within the UKCRC and UK Clinical Research Network (UKCRN). Nick highlighted some of the activities from the presentation. For example: there were now patient and public involvement posts in all the topic specific networks; a UKCRN patient and public working group and executive group and a UKCRC patient and public involvement project group, had also been established. In addition, the UKCRC were piloting patient / public members on various UKCRC advisory groups. Several projects were also being developed under the umbrella of the UKCRC PPI project group, including the People in Research website, which was jointly created by INVOLVE and the UKCRC. Some of the challenges ahead were in developing and supporting public involvement in the primary care and comprehensive research networks, as well as agreeing and resourcing a consistent approach across the UKCRC and UKCRN to offers of payment for involvement, and promoting and supporting public involvement across the whole of the UKCRC. The UKCRC is currently developing a strategy for patient and public involvement. Sarah Buckland is a member of the working group established to identify and oversee the process of strategy development.

4. Mental Capacity Act – Implications for research Bill Davidson – Department of Health

Bill Davidson gave a presentation to the Group. The main points are highlighted below:

- The Mental Capacity Act (MCA) has implications for participants in research, although it was not written specifically for research.

- The MCA says that it should be assumed that people have mental capacity until proven otherwise.
- Where it is found that people lack capacity, decisions should be made according to statutory 'best interests' which take into account the known wishes, feelings, beliefs, values and any written advance statements by the incapacitated individual. There is protection from liability for carers and professionals with certain safeguards.
- Section 42 (4) applies specifically to research, and states that consent should be sought for any kind of 'intrusive' research. (This is a different and broader term than 'invasive'). The MCA does not cover clinical trials of medicinal products as they are already covered by the European Directive on Clinical Trials.
- Where there is a lack of capacity and research is needed, the decision should be made by an "appropriate body". For example, a Research Ethics Committee (REC) for Clinical Trials is recognised as such a body by the Secretary of State.
- Researchers have a responsibility to explore different methods of communication to ensure that all reasonable steps have been taken to establish whether someone has capacity.
- Researchers have a legal duty to abide by the act and the code of practice.
- The research has to have direct benefit to the person that lacks capacity – if not then the risks to that person have to be negligible.

5. Report of the experiences of involving service users in forensic mental health research – Alison Faulkner

Alison Faulkner spoke about a project she had recently completed for the National Forensic Mental Health NHS Research and Development programme. She told the Group that the aim of the project was to capture the experiences and learning from four forensic mental health research projects, all funded by the programme, that had involved service users in different ways in their research. She reported that the lead researchers of all the projects and service users from two out of the four projects were interviewed.

She reported that all of the projects successfully involved forensic mental health service users in their research. Both the service users and the researchers were very positive about their experience of carrying out the research. She went on to

say that there were benefits to the research itself, the service users and the researchers involved and wider benefits for raising awareness about people using forensic mental health services. The challenges and time required to develop relationships and trust was highlighted in all projects.

Alison reported on the different ways of learning to share power and control in the research process that were developed by the projects. One project had developed a democratic voting system and another ensured that service users were not out numbered in the group.

The researchers and service user researchers made recommendations, which are outlined in the report, for people planning to undertake similar work.

A report of the experiences and learning from the projects has been produced '**Beyond our Expectations**' which will be available via the invoNET library on the INVOLVE website.

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

Carol Lupton reported on what's new in the Department of Health and provided the following updates:

Research for Patient Benefit Programme (RfPB)

26 projects had been funded and the second round of applicants would be told by the end of June 2007 whether they would receive funding or not.

Research for Innovation Speculation and Creativity (RISC)

This was a new responsive mode funding stream for new and radical ideas for health research that might not otherwise get funded. The first round was launched on 2nd April, deadline for submissions was 29th May, decisions to be announced at the end of July 2007.

Programme Grants for Applied Research

29 awards were given in the first funding round with a total value of £45m. These awards covered mental health, medicines for children, diabetes, stroke and neurodegenerative diseases.

Biomedical Research Centres

Funding had been awarded for 11 Biomedical Research Centres and 2 Research Centres for NHS Quality and Safety establishing the development of new treatments.

Service user and carer review

This was being led by Harry Cayton from the Department of Health (DH). The DH is reviewing its entire policy programme to ensure that service user / carer insights are at the centre of all its work programmes.

During discussion the importance of achieving consistency across the research programmes in relation to public involvement was noted. The Support Unit are looking into carrying out some work to monitor the information provided by applicants to the Research for Patient Benefit Programme, on their plans for public involvement.

7. Directors report – annex C

- **Budget update – Annex D**
- **Monitoring the work of Involve – annex E**

Sarah Buckland reported on some of the recent activities of the Support Unit:

- Jane Royle has been seconded part-time to the Service Delivery and Organisation Programme (SDO) to support them in their work to take forward public involvement within the programme.
- The Support Unit has been doing some work with some of the Research and Development Support Units to assist them in their work around public involvement.
- Sarah Buckland is a member of the Nursing sub-panel for the Research Assessment Exercise (RAE) and has been involved in preliminary meetings as part of this work.
- The Support Unit has been doing some work to develop a joint statement with the National Research Ethics Service (NRES) to clarify when ethical approval is needed for active involvement.
- There has been considerable interest in the Public Information Pack (PIP)
- Sarah reported that there was an under spend for 2006/07 as the conference costs were less than anticipated as a result of the large numbers attending. She advised that for 2007/08 a greater amount of work was budgeted for, to ensure the full budget would be spent.

8. Reports from the working groups

Verbal reports were received from the following:

Empowerment
Strategic Alliances

Kate Sainsbury
Stuart Eglin

Please see the individual minutes from each of these groups for details.

Action: Support Unit to ensure that all Group members are asked to complete the form developed by Strategic Alliances to collect information on activities undertaken in connection with INVOLVE.

9. Any other urgent business not included on the agenda

There was none

10. Dates of future meetings

9/10 October 2007 – Awaydays
13 December 2007

Other dates

28th September – Introduction day for new members
13th February – invoNET workshop
