
**Notes of the forty third meeting of INVOLVE
held at the King's Fund, Cavendish Square, London W1
Wednesday 21 March 2007**

Present: Nick Partridge (Chair)
Kate Sainsbury (Vice Chair)
Sue Banton
Peter Beresford (part of meeting)
Stuart Eglin
Karen Collins
John Sitzia
Tracey Williamson

In attendance: Carol Lupton
Marianne Miles
Simon Wilde
Hala Patel

Sarah Buckland (Support Unit)
Sarah Bayliss (Support Unit)
Barbara Dawkins (Support Unit)
Sofie De Broe (Support Unit)
Helen Hayes (Support Unit)
Jane Royle (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 advised the Group that Sofie De Broe would be leaving the Support Unit in April. He thanked her for her contribution and wished her well for the future. Nick welcomed Hala Patel from the Medical Research Council (MRC) who was Dawn Duncan's replacement. She was attending with Simon Wilde as an observer.

Apologies

- Sarah Carr
- Alison Faulkner
- Mary Nettle
- Susie Parr
- Kay Pattison
- Mark Petticrew
- Morton Philipps
- Vanessa Pinfold
- Rachel Purtell
- Bob Revell
- Sophie Staniszewska
- Deborah Tallis

2. Notes of the meeting held on 14 December 2006 – annex A

No corrections are to be made.

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

Nick Partridge reported that several Group members had volunteered to give presentations about the work that they were involved in. These would be incorporated into future meetings.

Nick advised that a questionnaire would be sent out to all Group members shortly to seek their views on Group meetings and to identify suggestions for improvement.

Nick reported back on the recent UK Clinical Research Collaboration board meeting and discussions around the Cooksey report. He also reported that Liam O'Toole had been temporarily seconded part-time to the Office for Strategic Co-ordination of Health Research (OSCHR) as Chief Executive. Nick also briefly informed the meeting that reports of two studies would shortly be available. One study is funded by the Medical Research Council to explore public attitudes to the use of personal data and one is funded by the Wellcome Trust, looking at the governance of biomedical research.

Making user involvement work: supporting service user networking and knowledge – Peter Beresford

Peter Beresford gave a presentation on research he had recently completed with Fran Branfield, Eamonn Andrews and others from Shaping Our Lives. The research was funded by the Joseph Rowntree Foundation (JRF). The research findings and full report 'Making user involvement work: supporting service user networking and knowledge' (2006) JRF can be downloaded from www.jrf.org.uk. Key points from the presentation and subsequent discussion are outlined below.

This was a user-controlled research project exploring two activities seen as central to making user involvement work:

- i) networking – service users being able to get together to work collectively for change and mutual support and
- ii) knowledge – the importance of making known their own experiences, views and ideas.

The research included an initial survey of service users and service user organisations, followed by in-depth individual interviews and group discussions including two specifically with black and minority ethnic service users and one with a group of women with experience of alcohol problems.

The following were some of the main findings:

- Service users and service user organisations, recognised the importance and benefits of networking both in terms of improving their quality of life and sustaining effective involvement. However the ability to network is often hampered by isolation and insecure and inadequate funding and resources.
- Service users find themselves having to compete for funding with big charitable organisations and each other. This also seriously limits capacity development particularly of involvement by black and minority ethnic service users and those with significant access requirements.
- Service users felt that their knowledge was not generally valued or taken seriously by professionals, policy makers and services.
- Service users suggested that both their networks and knowledge could be strengthened by i) a properly resourced national database of service-user organisations and a national user-led network offering support, information exchange, contacts, advice on good practice and a national voice ii) the development of user-led training and education iii) a commitment to change in services, and iv) the inclusion of diverse service user perspectives.

During the discussion reference was also made to a research report by Peter Beresford, Lesley Adshead and Suzy Croft on 'Service users' views of specialist palliative care social work' (2006) Findings, Joseph Rowntree Foundation.

4. Agenda setting (paper from Empowerment sub-group) – annex C

Roger Steel introduced the paper on 'Influencing the research agenda nationally'. This issue had been discussed within the Empowerment sub-group, and the sub-group wished to bring the discussions to the main Group.

The paper discussed the current situation and highlighted the gaps. Kate Sainsbury thanked Roger for the paper and asked the Group to consider discussion of the two key questions:

1. Should INVOLVE be seeking to improve the level of involvement of people who use health and social care services in the setting of research agendas at a national level?
2. If so, what are the potential pathways for influencing?

Discussion

The following suggestions were made:

- there should be a mapping exercise where the different levels are explored in order to identify the ways to influence research and which different opportunities and strategies there are for individuals and organisations to contribute to the research agenda
- the Empowerment sub-group should write an article for a journal or other media, based on the paper

Action: Empowerment sub-group to take the 'Influencing the Research Agenda' paper further by considering the implications, developing a framework and identifying how organisations fit within the framework.

Action: Empowerment sub-group to consider writing an article based on the paper

5. Membership recruitment

Nick reported that INVOLVE would shortly be recruiting for new sub-group members. It was hoped to recruit 12 new members. Nick Partridge requested all Group members to encourage people to apply.

There was a brief discussion around two questions:

1. What are the gaps in our membership?
2. How and where should we advertise?

Gaps in membership

The following were some suggestions from members of current gaps in membership: people from black and ethnic minority groups; people perceived as traditionally hard to reach; individuals bringing a social care perspective; sceptics of public involvement; representatives of industry; individuals from emergent research areas.

The following were suggestions for where INVOLVE could advertise for new members: journals, emails, websites e.g. People in Research, UK Clinical Research Network, Guardian, contacts from the INVOLVE conference.

Action: Group members to circulate the membership adverts and encourage people to apply. Support Unit to take forward the advertising for new members.

6. Reports from sub-groups

Verbal reports were received from the following:

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| Empowerment | Kate Sainsbury |
| Strategic Alliances | Stuart Eglin |
| Evidence, Knowledge and Learning | John Sitzia |

7. Involve Strategic Plan – annex D

The Group discussed the draft Strategic Plan prior to it being sent out for external consultation. This would be the first time INVOLVE has consulted externally over its strategy.

There were some amendments suggested:

- In section '3. The Changing Environment' it was thought that the content of this section should include more about the social care and public health research environments.
- In section '6. Achieving Our Vision' 6i 'Developing stronger links with user researchers' should be added.

The idea of consulting externally was welcomed by the Group and suggestions were given of who it would be important to send the draft to. There was some discussion as to whether we should be asking specific questions of organisations we are consulting. It was thought that we should not ask too many questions but allow organisations to respond as they saw fit.

It was suggested that the main document should be shortened and be in a separate document to the appendix.

Action: Support Unit to revise the Strategic Plan prior to circulating for consultation

8. Involve Operational Plan – annex E

Group members discussed the draft Operational Plan for 2007/08 and considered if it was clear and achievable. Three of the pieces of work, one from each of the sub-groups, which involved identifying examples of work in different fields of public involvement in research, have some common characteristics. It was agreed that the Support Unit should ensure that they compliment and contribute to each other.

Action: It was agreed that the Operational Plan should be approved for 2007/08.

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

Carol Lupton gave an update on public health and social care.

Public Health

The young person's reference group for the public health research consortium has three meetings scheduled. The first meeting was in February 2007. The Group has funding until October 2007. It is important that the momentum to invest in the young people's time does not get lost.

There is currently a competitive tender for 5 new centres of public health excellence. The purpose of the centres will be to generate a stronger infrastructure and capacity in public health. The budget will be £20m over a 5 year period. This is under the umbrella of the UK Clinical Research Collaboration (UKCRC).

Social Care

Working with the Social Care Institute for Excellence (SCIE) a new research register has been set up. One of the required fields is whether there has been user involvement and in what ways. This will provide an opportunity to monitor across the social care field the proportion and nature of public involvement. It will also be useful for user and carer organisations to see what research is happening in social care. Very importantly it will be a cross national register and it will combine adult and social care. Carol encouraged Group members to look at the SCIE website www.scie.org.uk and make comments on how the register could be improved.

The care services minister, Ivan Lewis, is exploring ways to enhance social care more generally including the development of social care centres of excellence and a research journal.

There has been a consultation on what needs to be done to develop capacity in social care. A group has been sponsored to see how this will dovetail with the Commission for Social Care Inspection.

There is a question about the need for a cross national social care ethics committee. There is a lot of hostility about any new committees. If the research is user led the responsibility is with the user to get ethics approval and there is an issue about where you would go.

Date for diary

On 22 June 2007 there will be a show case event on social care research commissioned by the Department. This will be at the British Library (details to be confirmed). A question was raised about whether there will be public involvement in the presentations about the projects. Carol confirmed that the presentations would be short but that presenters would be asked to mention public involvement.

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- 10. Director's report – annex F**
- **Budget Update – annex G**
 - **Monitoring the work of Involve – annex H**

Sarah reported that the Public Information Pack would be available by the end of March and the Support Unit would be happy to send these out to those who would like a copy.

She reported that our work with the UK Clinical Research Collaboration

in developing the website 'People in Research' continues. The website became publicly available in February and it is now being piloted.

She reported that a second meeting had taken place with the Central Office for Research Ethics Committees to discuss future work and we had been liaising with them in planning an event that took place on 15th March, to bring together ethics committee members and service users and carers to share their understanding of ethical review.

Sarah asked the Group if they found the Group budget papers helpful or if it could be set out in a more helpful way. Sarah asked for comments to be sent to her.

Sarah advised that copies of 'Beyond Our Expectations', a report by Alison Faulkner on the experiences of involving service users in forensic mental health research, were available at the Support Unit if anyone would like one.

11. Any other urgent business not included on the agenda

There was none.

12. Dates of future meetings:

14 June 2007
9/10 October 2007
13 December 2007
