
Notes of the Thirtieth meeting of INVOLVE held at The Commonwealth Club, London on 4th December 2003

Present: Nick Partridge (Chair)
John Gabbay
Kate Sainsbury
John Sitzia
Russell Hamilton
Derek Stewart (vice Chair)
Mary Nettle

In attendance: Catherine Law (Observer)
Summer Hawkins (shadowing Catherine Law)
Kay Pattison (Observer)
Jane Durham (Observer)
Morton Phillips (Observer)
Carol Lupton (Observer)
Imogen Evans (Observer)
Chris Caswill (sub group member)
Alison Faulkner (sub group member)
Sophie Staniszweska (sub group member)
Stuart Eglin (sub group member)
Anna Dixon (Department of Health)

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)

1. Welcome, introductions and apologies

Nick welcomed the following to the group:

- Anna Dixon who would be talking about the NHS and social care Choice consultation
- Imogen Evans from the MRC, who was standing in for Joan Box and Elizabeth Mitchell

- Summer Hawkins who was shadowing Catherine Law

Apologies had been received from:

- Sarah Carr
- Peter Beresford
- Robert Johnstone
- Harry Cayton
- Mike Kelly
- Deborah Tallis
- Vinod Kumar

Nick explained that Harry had decided to leave the Group, but it had been agreed with Sir John Pattison that he would become an advisor to the group.

Nick advised that Ray Jones who had agreed to rejoin the group had since decided that due to pressure of work he cannot now rejoin.

2a. Away day - Notes of the meeting held on the 1st – 2nd October 2003 – annex A and any other matters arising

There were not any corrections to be made to the minutes of the Away day business meeting.

2b. Notes of any other matters arising – Benefits report

Roger reported that he had received a copy of a report from Shaping Our Lives written by Michael Turner, about the difficulties of the benefit system and payments to people involved in work around public involvement. The report had been written at the request of Stephen Ladyman MP, following his talk at the Shaping Our Lives Conference. The report was currently with Stephen Ladyman and so not yet publicly available, but Roger asked the group for ideas on the best ways to disseminate the report once it becomes available.

It was agreed that it was difficult to comment until the report was publicly available.

Action: Nick, Roger and Sarah to decide how best to take this forward once the report was available.

2c. Notes of any other matters arising – Conference plans

Kate reported that the conference would be on the 10th and 11th November 2004, in Nottingham. She advised that there would be speakers on both days as well as a theatre group. Kate requested the Group's help with suggestions for keynote speakers and asked them to send their ideas to the Support Unit.

Action: Support unit to email the group for suggestions.

Kate advised that the theme of the conference would be the cycle of research. The Group would be asking for people to submit abstracts about involvement in one of the stages of the research cycle. She reported that the Conference Planning Group would be making the final decision but would value any suggestions. She advised that so far the suggested titles had been:-

- Round about research
- Balancing the research cycle
- Widening the ...
- Spreading the word
- Navigating the research cycle
- Revolutionary Research

The following further suggestions were made during the group meeting:-

- Involve Revolve
- Spin cycle
- Hood winked! Is consumer involvement in the Research cycle a reality?

Action: Support unit to email the group for further suggestions

2d. Notes of other matters arising – away day

Nick thanked the Support Unit and Derek for all their hard work to make the away day a success.

3. Presentation Choice, Responsiveness and Equity in the NHS and Social Care.

Nick welcomed Anna Dixon to the meeting to discuss the Choice consultation exercise being undertaken by the Department of Health. He suggested that the Group would be particularly interested in discussing issues around research evidence and choice. For example, whose research evidence is used in making decisions about treatments (and the lack of an evidence base in some areas such as homeopathic medicines) as well as the information needed to enable people to make choices about participating in trials.

Anna advised that the three main questions that were asked were as follows:-

1. What choices do patients and users have?
2. What information and support is provided to enable patients and users to exercise this choice?
3. What changes are needed to create these choices and make Health and Social Services more responsive?

Anna then described the outcome of this consultation. (Please see attached overheads).

Nick then asked the group for their questions or comments. The following issues were raised:

- The problems of deficit in certain areas where services are not available to particular groups of people, even where they are widely available to others (eg dental treatments for people with severe learning difficulties)
- The value of linking complaints with research
- The extent to which the public are interested in research
- Availability of information and choice around being able to participate in trials
- The importance of supporting health professionals to enable them to support, involve and empower people.
- PCTs are not being given a choice as they are being required to sign contracts with private providers, which will take money away from the NHS where research is taking place, thus leading to less research.
- There is little choice in mental health treatments and services.
- It is important to ensure that the results of research are fed into service provision and that choices are widened.
- Informed choice should include making people aware of the benefits of research.
- There is a need for a better evidence base of people's experiences

Anna advised that in the consultation exercise, they had tried to reach a wide range of groups, but sometimes the specificity got lost in reporting the findings. She felt that the NHS needed to be more personalised to individuals needs.

Action: Support unit work to consider how we can make best use of this information. To email Anna's email address to the group (Anna.Dixon@doh.gsi.gov.uk).

4. Membership of Involve (Appendix B)

Nick presented this paper on changing the way that members are recruited to the sub-groups. Nick reported that there were a number of questions to consider:

Recruitment to sub-groups

- whether members agree with the process suggested?
- Any alternative suggestions?

Recruitment to the main group

- whether to leave unchanged or
- whether the Group should approach Sir John to consider a different way of nominating members to the main group

There was general agreement that it was important to change the process of recruitment to be more transparent and to open membership to a wider group of people. The main discussion was around the process. Issues that were discussed included: how widely the advertisement for new members should be distributed; the need to ensure that when a member left, that someone was replaced with someone who could bring a similar set of skills and / or experience; the importance of producing a role rather than a job description for potential new members; the potential role in influencing our groups in the recruitment of members.

Actions:

Advertisements for members should be through the Support Unit mailing list and other relevant, easy to access, and cost free networks (eg UKPHA?)

To produce a 'role' description for new members

5. Reference Group (Appendix C)

This paper had been produced by Peter Beresford and Roger Steel at the request of the Group. Peter was unfortunately unable to be present at the meeting, but Roger presented the paper.

Some of the reasons for supporting a mechanism for wider involvement were expressed by members as:

- The way in which the Group works is not always appropriate for all people
- Some people do not feel able to contribute to INVOLVE because of the Group's style of working
- The importance of capturing knowledge, learning and points of views from people who are either not happy with the Group's style of working, or who have different views to those of current Group members

However, there were many concerns around the proposed plan for a reference group for INVOLVE. They were as follows:

- The view that INVOLVE was itself a reference group and so questioning the need for a further reference group
- The risk of negating the value of members of the main group
- Ambiguity around the role of the reference group (whether it was to be a consultancy, advisory or a decision making group)
- Lack of clarity as to what problem the reference group was trying to address and what the function would be
- The reference group as proposed would still be limited in enabling wider involvement in the Group (with a suggested membership of approximately 15)
- The scale of structure and support that would be needed to maintain such a reference group

It was felt that the proposal to change the mechanism for the recruitment of new members would help in widening involvement in the Group. However, the view was also expressed that the Group should continue to look to improve how it included people. There was also some discussion around whether there was an alternative model for eliciting the views of others, such as round table meetings or seminar days.

Actions: Plans for the reference group would not be implemented. The Group to consider other ways of involving service users in the work of the Group. Roger to discuss with Peter Beresford.

6. Budget Update (annex D)

Morton reported that the contracts for the work to capture the experiences of the True project, and for the Definition of User Controlled Research had both been signed. Morton predicted that the allocation for 2003 would be fully spent.

7. Reports from sub-groups

Empowerment

Kate gave a postcard report of the sub group meeting:-

- The sub-group had commissioned some research into training that was available for service users to become involved in research. Amendments to the report will be completed by the 21st January 2004.
- The sub-group had asked for some guidelines on involving young people in research. Draft guidelines have been produced and the work is nearing completion.
- The sub-group is producing a couple of leaflets on involvement in public health research. One is for researchers and the other for the public. They both aim to raise awareness about public involvement in public health research.
- In 2004, the sub-group would like to fund the report of the four seminars held by the Toronto Group.

Strategic Alliances

Nick gave a post card size report from this sub-group:

- The sub group discussed ethics committees and the work of the Central Office for Research Ethics Committees (COREC). INVOLVE has requested to attend a meeting of OREC managers to discuss public involvement and ethics. They are waiting to be giving a date.
- Follow up disability awareness training for Group members was discussed. A provisional date of the 10th March had been set but not many members are able to attend.
- The sub group had discussed keynote speakers and a title for the conference
- Membership of the sub group had been discussed. The group collated various names, which would be passed on to Nick and Sarah.
- The group discussed their concerns regarding the paper on the reference group.

- The report of the research commissioning workshop had been distributed to all who attended the event. The sub group discussed ways of taking this work forward. One suggestion was for a follow up workshop in 2004.
- Philippa is to prepare a paper for the main group on developing Involve's public health strategy. The sub group discussed plans for 2004/2005.

Monitoring and Evaluation

John gave a postcard report of the meeting: -

- The booklet on involvement in Randomised Controlled Trials will be completed by the end of March.
- The evaluation of public involvement in the London Primary Care projects is to be undertaken by Nicky Britten (University of Exeter) and colleagues at Folk.us and North and East Devon NHS, Research and Development Support Unit. The contract is to be with the Department of Health rather than the University of Leeds.
- The User controlled work is to be undertaken by Shaping Our Lives in conjunction with Folk.us.
- The evaluation of Folk.us is yet to be commissioned. The original application process resulted in the decision to re-advertise the brief.
- The sub-group discussed issues around conflicts of interest and the need for probity and clarity in the processes adopted.
- The possibility of producing some form of INVOLVE peer reviewed publication was discussed.

Carol raised some concerns re the focus of the User Controlled research. It was suggested that these could be best taken forward by discussion with John Sitzia.

The Group discussed the need to draw up guidelines and a register of conflicts of interest. There was no concern that current processes were not being properly conducted, but it was felt that it would be important to have written procedures.

Actions: The Support Unit to produce guidelines and a register by the next meeting. Nick, Kay and John Sitzia to provide the Support Unit with examples.

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

Kay Pattison gave a 5-minute presentation about the impact of the group on the Forensic Mental Health Programme. (A copy of the slides are attached)

Carol Lupton reported on the work of the Policy Research Programme (PRP). They were carrying out an evaluation of the new social work degree where user involvement is built into the course. Secondly she described the learning disability research initiative. She reported there were 12 projects and each project had been asked to involve service users and carers in some way in the research. Carol was working with a group of people with learning disabilities who were going to undertake an evaluation of the involvement in the projects. The group would be led by people with learning difficulties who would take all the key decisions about the work. Financial assistance was being provided by Values into Action. She reported that the major difficulties had been caused by organisational structures, making it hard to put their commitment into practice.

Carol then went on to discuss the Research Governance Framework and the consultation process around the implementation of the plans for social care. The consultation had included discussions with service users organised by INVOLVE. The next stage was the publication of the plan as well as options for ethics review.

Carol reported that she would be working with Involve re Public Health and a meeting had been set with Catherine Law in the New Year to discuss this.

9. Directors Report

Kate commented that she and Derek had had some informal discussion about the possibility of a similar set up to INVOLVE being established in Scotland.

Mary asked when the Briefing Notes would be ready. Sarah reported that they hoped they would be ready by Christmas.

10. Any Other Urgent Business

None reported

11. Dates of Next Meetings

- March 4th 2004
 - June 2nd 2004
 - October 5th and 6th 2004 (please note the change of date)
 - December 8th 2004
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