
Notes of the Thirty first meeting of INVOLVE held at Skipton House, Elephant and Castle, London on 4th March 2004

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

In attendance: Carol Lupton
Vinod Kumar
Stuart Englin
Catherine Law
Jane Durham
Kay Pattison
Morton Phillips
Mala Rao
Chris Caswill
David Johnstone
Julie Beswick (PA to Mala)
Sarah Carr

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. Welcome, introductions and apologies

Nick welcomed the following to the group:

- Mala Rao who would be giving a presentation to the Group (Agenda Item 4) Julie Beswick, personal assistant to Mala Rao.
- Two new members of the Strategic Alliances sub group, David Johnstone and Ruth Sinclair. David is Director of Social Services at Devon County Council, and chair of the Association of Directors of

Social Services (ADSS) Research Group. Ruth is Director of Research at the National Children's Bureau.

Apologies had been received from:

- Peter Beresford
- Russell Hamilton
- Ruth Sinclair

This was the last meeting for Russell Hamilton and John Gabbay (who had both been with the Group for 5 years). Nick expressed his farewell and thanked them for all the support they had given to the group over the years.

Nick explained that Derek had decided to stand down from being the Vice Chair for personal family reasons, although he would continue to be a member of INVOLVE. Nick expressed his thanks to Derek.

Nick advised that a new Vice Chair would need to be appointed. Nick will meet with Sarah Buckland to discuss. However, if anyone is interested in becoming vice chair they should email Nick.

Nick reported on a series of 4/5 meetings that he had attended, chaired by Sir John Pattison – the Patients Benefit Working Party.

2. Notes of the meeting held on 4th December 2004 – annex A

Correction on page 5. Carol Lupton pointed out that point 3 of the notes did not include the point that she had made. This was that the Choice initiative did not refer to social care issues specifically.

3. Notes of any other matters arising

3a. Membership

Helen reported that there had been approximately 180 requests for application packs for membership of the INVOLVE sub-groups. The call for new members had been advertised widely via the INVOLVE website and newsletter, as well as other websites including umbrella voluntary organisations. It had also been emailed to researchers and others involved in public health research.

3b. Reference Group

Nick commented that there are still issues which the Group needs to think through about inclusion of others in INVOLVE. He proposed that a small group of INVOLVE members should prepare a think piece for the Group which

would be taken to the next Away Day for discussion. The think piece should explore a range of options of how to better involve service users in the work of the Group. This should include exploring what there is to be learnt from other organisations (e.g. the Joseph Rowntree Foundation). It should also consider the possibility of tapping into other existing reference groups.

Nick pointed out that this had also been discussed in the sub-groups meeting and asked if anyone would like to report back. Kate Sainsbury reported that the Empowerment sub-group sees this as being part of their remit for the effective inclusion of people. Kay Pattison pointed out that it might be useful to link this with the membership recruitment exercise, as some of the unsuccessful applicants may be interested in becoming involved in other ways.

It was regretted that Peter had not been able to attend the last meeting when the reference group proposal had been discussed, and it was important that it was fed back to Peter that there had been a full discussion of the issues.

Action: Nick to contact the sub-groups to create a small working party

3c. Chair's meeting at the Support Unit

Nick reported back to the Group about a meeting he and the chairs of the sub-groups had had with the Support Unit. The meeting covered the balance between the ongoing work of the Support Unit and the activities generated by the Group (over half of the Support Unit time is taken up with ongoing work). This needs to be borne in mind when discussing the work plan for next year. At the meeting it was also discussed how the Support Unit could better contribute to the Group. The Support Unit staff are in contact on a day to day basis with a range of organisations and individuals, but have limited mechanisms to feed back some of the issues raised to the Group. Nick commented that he had found the meeting very helpful and had agreed that the experience of the Support Unit should be heard in the main Group meeting. It had been agreed that there would be further meetings with Support Unit staff between main Group meetings on a trial basis. It was also suggested that periodically Support Unit staff could report to the Group on specific ongoing activities within the Support Unit.

4. The importance of public involvement in Public Health

Professor Mala Rao gave a presentation about public involvement in public health research. Please see attached presentation slides.

There was some discussion about:

Section 60 and the Data Protection Act
The Public Health Research Consortium

The Group discussed how service users and members of the public could contribute to ensuring that topics of concern to the public are addressed by the Consortium. The Consortium is in the very early stages of being established and it will cover three broad areas: tackling health inequalities, risk and health, and incentives and regulation.

Carol Lupton reported on four ways in which INVOLVE is going to be involved in the Consortium.

- Philippa Yeeles from the Support Unit attended the initial Public Health Seminar in February.
- Philippa has been invited to join the commissioning panel for the Consortium advising the panel on user involvement issues.
- Representatives from INVOLVE are going to work with PRP officials to advise on how the public involvement strategy might be developed most effectively.
- Once the Consortium has been established, the DH is going to consider a meeting or seminar with Consortium members to further discuss ways of working with INVOLVE around these kind of issues.

Members asked about the criteria for selection of the Consortium. Philippa reported that public involvement is not a criteria of funding, although the issue is considered important by the Policy Research Programme at the Department of Health and that they had been very keen to ensure that INVOLVE is involved in the discussions. There was some concern expressed that public involvement was not a condition of funding and the Group felt that the PRP should ensure that public involvement was taken seriously in decisions about who should receive the funding. There was the risk that only lip service would be given to ensuring true public involvement. It was also felt important that issues around inclusivity were addressed and that strategies for reaching out to the wider community were considered as well as public awareness about research.

Action: Philippa Yeeles from the Support Unit will represent INVOLVE on the Commissioning Panel for the Consortium. INVOLVE to encourage the commissioning panel to fully address the importance of public involvement in the Consortium.

A related area of importance was ensuring that the Group responded to the Choosing Health consultation.

Action: Nick and the Support Unit to respond to the Choosing Health? - Government consultation.

5. Conflicts of interest (Annex C)

This paper had been produced by Maryrose Tarpey following discussions at the last Group meeting. Nick asked for any improvements or suggestions for the paper.

The issue of circulating papers and minutes from the Group, where they included information about items where there were conflicts of interest was discussed. It may be inappropriate for some members to receive certain documents, where they had expressed a conflict of interest.

Action: Maryrose to consider how the Support Unit should address this issue.

It was suggested that the main area where issues around conflicts of interest need to be considered was in the commissioning of work. There was some discussion around the differences between actual conflicts of interest, potential conflicts of interest and perceived conflicts of interest. There was also consideration of financial, personal and emotional conflicts of interest. There needed to be a balance that did not make the system too complex to adopt, that was fit for the purpose and appropriate to ensure that there was the right protection for public money as well as for the protection of professional integrity.

It was not that conflicts of interest should be avoided, as it is inevitable that conflicts will exist, but that where they were known, they should be declared. It was therefore suggested that if in doubt, individuals should declare any potential or perceived conflicts of interest, and that it was the responsibility of the individual to declare.

Action: A standing agenda item to be introduced for all meetings, requesting any conflicts of interest.

6. Report of Skills Audit (Annex D – Confidential item)

This paper was produced by Philippa Yeeles, to summarise the findings of the Skills Audit of members of INVOLVE. This report is confidential to the Group, apart from the details provided to go on the Membership pack. Nick opened this item for discussion for any comments and reflection.

One suggestion in the audit was that there should be more frequent Group meetings. This has been taken on board, and this year the away day meeting will be preceded by sub-group meetings in the afternoon of the 5th of October.

It was suggested that it might be useful to periodically update the Skills Audit.

Action: Chairs of the sub-groups to be sent responses from members about any training or support needed as well as any specific areas that members would like to become more involved in.

Sarah advised the group that the Induction Pack / Information Pack for Group members is being revised and updated, and everyone will be sent the revised version shortly. Anyone who would like to change their entry in the pack, or who has not had their photograph taken should contact Philippa at the Support Unit.

Action: Support Unit to send out revised copies of the Information Pack

One other point raised by a member in the Skills Audit was that too many matters of detailed internal process were discussed in the Group meeting.

Action: Nick to explore with Sarah whether many of the discussions around the internal process of the Group could be dealt with by email between meetings, allowing more time for discussion around public involvement issues in the meeting.

7. Budget Update (annex E)

Morton estimated that there would be an underspend in the Group budget of between £60,000 and £80,000 this year. Sarah explained that there were still invoices due in over the next few weeks which would reduce the underspend. All invoices and claims for the financial year should be sent to Morton by the middle of March to allow for processing time.

There was some concern expressed over the size of the underspend, and in particular Monitoring and Evaluation were concerned about the level of slippage on their budget. Some of the reasons for the slippage in Monitoring and Evaluation was that there had been delays with two pieces of commissioned research. The Folk.Us evaluation was going out for re-advertisement and the User Controlled research had not started as early as planned, due to delays in the applicants being able to start the project.

Action: Support Unit to produce a short report explaining why the Monitoring and Evaluation budget had slipped so much.

There followed a brief discussion about the difficulties of operationalising the budget for each year, when the budgets are not agreed before April of each year and the time delays in commissioning research. Kay raised concerns about the resource and time consuming nature of commissioning research and suggested the Group needs to consider whether or not commissioning research is appropriate for the Group. Such activities limited the Group spending on other activities.

Kay also stressed that it was important that the quality of work produced is taken into account and that maybe the Group should not be concerned if it

cannot spend all of the budget. However, if the Group asks for more than it can spend year on year, then the budget is likely to be cut.

8. Reports from sub-groups

Monitoring and Evaluation

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

- The revised cut down version of the RCT booklet should be completed by the end of the month.
- A team at Exeter University is undertaking the evaluation of the London Primary Care projects. The proposal has gone to a MREC (Multi Research Ethics Committee) and two researchers are being recruited. It is planned that the main field work will start in March 2004.
- Definitions of User Controlled Research. Shaping Our Lives (with Folk.Us) were awarded a grant of £15,000 to carry out the work. The work is being sub contracted to a freelance service user researcher. Sarah and Alison Faulkner plan to meet with Peter Beresford to discuss the plans for the work alongside Carol Lupton's query from the last Group meeting about whether the work will be able to produce a useful working definition of user controlled research. However, it has not been possible to arrange a meeting yet.
- Folk.us evaluation. The first commissioning round was not successful and the evaluation has been re-advertised with a closing date of the 12th March. A decision will be made by the Advisory Group on 10th April 2004.
- Peer Review Workshop. This workshop is planned for the 24th of March. It is part of the Toronto Group Seminar series. The sub-group questioned why this work had come under the Monitoring and Evaluation sub-group, and felt that the sub-groups should be stricter about which sub-groups commissioned pieces of work.

Empowerment

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

- The sub-group will be looking for a new member to replace Russell Hamilton who is leaving the Group.
- An information leaflet for researchers wishing to involve the public in public health research is to be written.
- Additional money is being given to the Toronto Group seminar series for report writing to make the five series of seminars more complete. The sub-group was also looking to budget for the production of leaflets about each of the five seminars.
- The sub-group had discussed the dissemination of the TRUE Report. An Executive Summary is ready for printing and wide distribution. The sub-group also looked at the report written by Alison Faulkner to capture the

experience of the people involved on the TRUE report - Colliding Worlds. The report is nearly ready. It was discussed that the video would not be used. As a result of the TRUE research, a workshop will be held in April.

- A further draft is needed of the Guide to Involving Young People.
- There was a brief discussion on inclusiveness and terms and conditions for public involvement.

Strategic Alliances

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

- There was a discussion around the Skills Audit, and whether it was possible to map the different perspectives that members bring to the Group.
- Issues around NHS ethics committees were discussed and the difficulties in getting some of the concerns of service users about ethics committees addressed. It was suggested that it might be helpful if Nick wrote to Sir John Pattison about our concerns.
- There was a discussion about the commissioning work which Jane Royle has been involved in, and plans to develop guidance around commissioning research.
- The sub-group discussed the issue of the sub-groups underspend and whether earlier planning and more collaborative work might overcome some of the difficulties.

It was raised that the Empowerment sub-group had discussed the importance of tackling issues around Occupational Health and public involvement in research. This was an issue that had been highlighted in the TRUE report. The Strategic Alliances sub-group had added this to their list of possible activities for 2004 / 2005.

9. Plans for 2004/2005 (Annex F, G, H)

In the morning the sub-groups had discussed their plans for 2004 / 2005. The proposed plans were listed on flip charts followed by a discussion and clarification.

Empowerment sub-group

The sub-group felt they were committed to a number of activities which had the same level of priorities, therefore the activities are grouped and then given as priority one for activities which have to be done and two for activities which are less important.

Priority level 1:

	Budget
Training Workshop (planned for April 2004)	£5,000
Leaflet for researchers to give to the public (a tool for researchers who want to involve the public in their work).	£3,000
Toronto Group Dissemination leaflets (short information leaflets on individual Toronto seminars).	£2,500
Accessibility budget. To include printing and dissemination of Guide for Involving Young People (£2,000)	£12,000

Priority level 2:

	Budget
Work to promote involvement of black and ethnic minority communities and young people	£5,000
Ongoing development for training capacity (building on training workshop and TRUE report)	£5,000

Monitoring and Evaluation Sub Group

The sub-group decided to list their activities into three groups. Those that the sub-group is committed to / must do, monitoring activities and new ideas.

Must do:

	Budget
Definitions of user controlled research	£15,000
Evaluation of Folk.us	£20,000

Monitoring activities:

	Budget
Monitoring user involvement in NHS Trusts and PCTs (Information submitted to controls assurance team)	-
Monitoring of user involvement in NHS and R&D Programmes (work undertaken by Jane Royle)	-
Monitoring Support Unit activities	-

New ideas:

	Budget
Scoping study to explore and review publication of public involvement in research articles (3-4 month scoping exercise)	£10,000

Researchers Forum for those interested in researching public involvement in research. Informal meeting to develop plans (£3,000) followed by seminar (£10,000) Organisation (£2,000)	£15,000
Qualitative Evaluation of public involvement in research committees. Preparation of brief. (£50,000 to undertake work in 2005 / 2006	£2,000

Strategic Alliances

The sub-group divided their activities into four groups. Those that the sub-group is committed to, recommended activities, activities that need further development, and activities which do not involve any cost this year and/or which will be considered for 2005 / 2006.

Activities committed to:

	Budget
INVOLVE Conference 2004 / 2005	£35,000
Guidance on public involvement in commissioning process	-
Development of a strategic plan for involvement in public health research	-

Recommended activities:

	Budget
Discussion forum (email or web based)	-
Inclusion of others in the work of INVOLVE	-
Guidance for public involvement in social care ethics bodies	-
Scoping work on the feasibility of a network of service users, commissioners and researchers who wish to get involved in, or involve people in their work.	-

Activities to be developed further:

	Budget
Work in the area of social care (unspecified)	-
<i>Education occupational health re. public involvement</i>	

Considerations for 2005 / 2006

	Budget
Activities building on the Strategic Plan for public health	-
Guidance for commissioners on user controlled research (based on definitions of user controlled research work)	-

It was agreed that Nick would take away the suggestions from the sub-groups and in discussion with Sarah and the chairs of the sub-groups, make the final decisions on which activities can be taken forward. Decisions will also take into account the priorities outlined in the Strategic Plan and the workload of the Support Unit.

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

Kay gave an overview of the National Asthma R&D Programme. (See attached overheads)

Carol reported that at a recent Policy Research Programme meeting they had discussed how they might be able to work with INVOLVE more systematically. Carol has produced a short document which provides information on who does what in the wide range of Public Health commissioning activity within the PRP (**See ,,, attached**). Carol offered to give a presentation on the work of the PRP in the future.

Carol also brought with her copies of the Learning Disability research initiative newsletter for those who were interested.

Carol gave a brief overview of the PRP restructure, explaining that the liaison officer level staff would stay the same and they would be responsible for the commissioning function.

11. Director's Report

Copies of the 2nd edition of the Briefing Notes for Researchers and the Call for Participation in the INVOLVE National Conference were available for Group members to take away. The report of the Commissioning workshop is available from the Support Unit.

Members of the Support Unit had recently visited Legacy Faborio (a group of families involved with organ and tissue retention). Whilst some members of Legacy Faborio are taking legal action against the Department of Health, the organisation of Legacy Faborio is not doing so an organisation.

12. Any other business

It was suggested that it would be helpful to know which Support Unit members are taking the lead on which activities.

Action: Sarah to provide a summary of responsibilities once the Operational Plan for 2004 / 2005 is agreed.

13. Dates of the next meeting

Wednesday 02 June 2004

05 and 06 October (away day)

Wednesday 08 December 2004

INVOLVE National Conference 10 and 11 November 2004.