

Notes of the twenty eighth meeting of Consumers in NHS Research held at The Kings Fund, London on 6th March 2003

Present: Nick Partridge (Chair)
Peter Beresford
Harry Cayton (Vice Chair)
Elizabeth Clough
John Gabbay
Kate Sainsbury
John Sitzia
Russell Hamilton
Derek Stewart
Sarah Carr

In attendance: Catherine Law (Observer)
Kay Pattison (Observer)
Elizabeth Mitchell (Observer)
Deborah Tallis (Observer)
Jane Durham (Observer)

Stuart Eglin (Observer)
Robert Johnstone (Observer)

Sarah Buckland (Support Unit)
Barbara Dawkins (Support Unit)
Helen Hayes (Support Unit)
Roger Steel (Support Unit)
Sarah Bayliss (Support Unit)
Jane Royle (Support Unit)

1. Welcome, introductions and apologies

Nick welcomed the following to the Group:

- **Sarah Carr** who was attending for the first time (she is sharing the role with Mike Fisher)
 - **Stuart Eglin** was attending for the first time as an observer, he has just joined the Strategic Alliances sub-group
 - **Robert Johnstone** attended as an observer, it was his first meeting as a member of Empowerment sub-group
- Nick made the following further announcements about membership:
- **Harry Cayton** was standing down as Vice chair of the Group although he would be staying on the Group. Nick thanked him for all his support.
 - **Derek Stewart** was welcomed as the new vice chair of the Group. He said he was delighted to be taking over from Harry as vice chair.

- This was **Elizabeth Clough's** last meeting, she was thanked for her considerable contribution to the Group.
- **Russell Hamilton and John Gabbay** will be staying on another year; Nick advised them he was delighted.
- Nick informed the Group that **Vinod Kumar and Mary Nettle** had been approved by Sir John Pattison to become new members of the main Group.

Apologies were received from Carol Lupton, Mike Fisher, Alison Faulkner, Jabeer Butt, Mary Nettle, Mike Kelly, Vinod Kumar and Morton Phillips.

2. Notes of the meeting held on the 10th December 2002

These were attached as annex A. There were corrections on page 2 item 2. Notes of the away day 16th/17th October under the heading Empowerment, the following statement was changed to: 'there was a need for greater clarity at a consumer level of the work of the Department of Health and the impact of our work upon it'.

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

Name change

Sarah Buckland reported that she had met with Sir John Pattison the previous week. Sir John had approved the new name 'INVOLVE' for the Group, although he suggested that it should have 'NHS' rather than 'health' in the strap line – to make it clear that the Group is linked to the DH and NHS and not a private health care organisation.

The new name for the Group has finally been decided as 'INVOLVE' with the strap line – Promoting Public Involvement in NHS, Public Health and Social Care Research.

Action: Support unit to develop a plan and timescale for the adoption of the name change with the least amount of cost. From the next meeting the Group would start to use the new name.

COREC (Central Office for Research Ethics Committees)

Elizabeth advised that members of the Group would be invited to present at the next OREC managers meeting in April/May.

4. Honorary contracts for consumers

John Sitzia started the discussion on this topic by reporting that the Research Governance framework requires NHS organisations to ensure that non-NHS employees, conducting research on NHS premises, with NHS patients or NHS staff, patient data or materials, hold a honorary NHS contract. Worthing and Southlands Hospitals NHS Trust, where John works, is the host organisation for the TRUE Project, which was funded by the Empowerment sub-group. Seven mental health service users work as research assistants on the project, each holding an honorary contract with the Trust.

John gave an account of the internal process required to raise these contracts for the TRUE project service user researchers. Despite long advance notice to the Human Resources department, the process was protracted and somewhat stressful. A particular 'barrier' was that the Occupational Health department requested that all seven user-researchers attend for a screening interview. Several of the user-researchers were made anxious by this request but moreover found the actual interview experience very distressing and excessive for their part-time research 'assistant' role in the project. A minority had found it a positive experience as they had managed to get through a 'normal' employment process and had been declared fit to work. The contracts were finally sorted out, but lessons needed to be learnt. The project team is putting a report together to give to the Human Resources department at this Trust to tell that department about *their* experiences of the process, with the aim that the process is improved for future service users. It is also hoped that this experience can be shared with the wider community and other Trusts.

Deborah Tallis reported similar experiences with mental health service users who wanted to train as researchers within another Trust. They could not get past Occupational Health problems and ended up doing their training at a University but were held up for many months. The ethics committee also required permission from their care co-ordinator for the service users to take part. It was suggested that mental health service users may become unwell during the research and that the trust involved wanted to cover themselves.

Other members made the following comments:

- Elizabeth Clough advised that there was a mutual benefit from having a contract. The trust had to have a duty of care to patients etc and the contract offered liability cover to the service user. One suggestion to get around this problem would be to offer a honorary contract to the team head who would have responsibility for the conduct of each team member.
- It was suggested that we needed to get the message over at local level so that users are aware of the situation at the outset.
- Russell Hamilton advised that obtaining an honorary contract was the same as doing a risk assessment, to find out if you are at risk of

harming the people you come into contact with. He is not sure if this is discrimination, but felt that people should be advised at the outset if it is not going to be a swift process.

- It was suggested that personnel departments should have disability awareness training and that our organisation should be advising this.

It was discussed as to who actually needs influencing and the following list was drawn up:- human resources departments within NHS Trusts, ethics committees, occupational health, people who issue standards, people who work with mental health service users and researchers working with service users.

Action: Support unit to ask on website/newsletter if anybody else had experienced difficulties with honorary contracts.

Action: Sarah Buckland to approach Group members for help and support to find the best way to take this forward. Progress to be reported at next meeting.

5. Involving marginalized and vulnerable groups: consultation document – annex C

Roger reported that this paper was started two years ago and he had been asked by the Empowerment sub-group to put all the ideas together. The paper had since been developed and he hoped it could be used as a discussion document for those working with consumers. The paper had been written to develop discussion, and not as a definitive guide. He advised that he had been approached by Lesley Lowes of the University of Cardiff to condense the paper into a chapter for a book.

It was suggested that the paper could benefit from a bibliography to reference the sources and where the ideas came from. It was also thought that the paper was probably too long for some, and that it should also be condensed into an easy to read shorter summary. It was however felt that the paper was a good basis to start from.

The Group came up with other groups that they felt should be added to the list and they are as follows:-

- Service users who are facing or who have been bereaved.
- People suffering from a life limiting illness.
- Substance and alcohol misusers
- Lesbians, gays, bisexuals and transgendered
- People in prison
- People whose voices cannot be heard.

The Group suggested that the following amendments should be made to the list:-

- The word immigrants should be replaced by asylum seekers and refugees
- The word illiterate should be replaced by another word

Kay suggested that Roger could liaise with Katherine Harney of the Forensic Mental Health Programme, who could share ideas.

It was suggested that as there was a danger of the list getting too long that an alternative would be to define the meaning of vulnerable, marginalized and excluded, nearer the beginning of the paper, and either just give a couple of examples of each group, or put the list at the back of the document.

It was suggested that instead of a list, a diagram could be produced with all the names on the list just scattered randomly on a blank page, with space for those groups that had been missed.

Action: Roger to take on board the issues raised, and to make the paper available on the website.

6. Consumers in NHS Research Conference 2004

Elizabeth reported back from the Strategic Alliance sub-group after considering the feedback forms from the conference. Their conclusions were as follows:-

Positive

- The overall comments were positive
- Progress had been made in peoples thinking from the previous 2 years, in terms of maturity and acceptability of ideas.
- The soap box session was a great success

Negative

- Only a small percentage of evaluation forms were completed, she felt this might have been due to the fact that no reminders were given out during the day or at the end of the conference.
- There had been conflicting views regarding the venue, however it was felt that the location was not ideal in terms of rail and road links
- It was felt the whole day had been too busy, with people dashing around and not enough time for networking

Elizabeth reported that the sub-group had considered venues for 2004 and the two favourites were the Midlands (e.g. Nottingham) or London. London was favoured by the sub-group, because of accessibility, however it would be up to the main planning group to decide. The sub-group also felt that due to cost implications 1 day would be better than 2.

They felt that the planning group should include group members with backgrounds in social care and public health and consumers. They felt the chair should be a consumer and they hoped that Sarah Buckland, Barbara Dawkins and the Support team would also help in the planning. The sub-groups view was that November would be the best date for the conference.

There were mixed views amongst Group members as to the location of the Conference and the length of the event.

Some felt that 2 days would be better than one, to allow more time to network and meet people and to relieve the burden on some people attending. Others felt that it was important to keep the costs down by keeping the event to one day and that some people would not be able to commit to a 2 day event.

It was suggested that having an evening event could be an opportunity for informal events and networking. It was pointed out however, that if the event was to involve an evening, then London might not be the most suitable location as accommodation costs were higher. One suggestion for assisting people in identifying people to talk to, might be to organise some form of introduction service, although this would work best with a two day event.

Nick asked Kate Sainsbury if she would agree to chair the planning group and she agreed. Kay offered Morton's help in his absence.

Action: Kate to approach members of the group to volunteer to join the conference planning group.

7. Strategic Plan – annex D

Nick advised that the key points to focus on today were to clarify and draw out the working principles, the strategic objectives and future direction of the Group. (pages seven and eight)

If people had comments on the other sections they should feed them back to Sarah.

Introduction

Peter commented that he felt that the word 'Public' in the strap-line needed to be made more clear and explicit in the document. He felt the word

'Public' needed to be reflected in the document to be clear that we are being inclusive not exclusive. This needed to be explained more in the introduction.

Action: Sarah Buckland to change the introduction.

Working principles

Everyone agreed that they were happy with the content of the working principles.

Strategic objectives

The strategic objectives need to be completed. The sub-groups were working on these.

It was suggested that there was a need to ensure that the work carried out by one sub-group was then followed through and implemented. Systems needed to be put in place to ensure that this occurred.

It was also suggested that a system should be put in place to compile a list of activities of the Group. This would monitor year on year how many workshops had taken place, how many had attended etc.

Action: Helen Hayes to take forward the development of a system to monitor the activities of the Group.

There was a discussion about the detail of the Plan and whether it should include more specific objectives. It was agreed that there was a need to find a balance between setting detailed objectives, and indicating a direction of travel for the group. Nick agreed to look at this in revising the Plan.

It was felt that if we could define who our audiences are for the work of the Group, it would be easier to clarify our objectives and strategic aims. Nick replied that we needed to be clearer about the remarkable multi-disciplinary nature of the Group. The richness of the Group had enabled us to do what we have done, especially as we don't just have one single customer and we don't wish to have just one single customer.

The issue was raised of who was addressing consumer involvement in private funded health research. There was some discussion as to whether the Group should get more involved in the private sector.

Action: Sarah Buckland to discuss with Sally Davies the appropriate relationship we should take up with the private sector.

Action: Sarah Buckland and Nick to develop the last 2 pages of the plan and bring back to the next meeting for discussion.

8. Priorities for 2003/2004 and agreement of Group's Plan.

The following priorities were proposed by the sub groups for 2003 / 2004, with suggested budgets.

PRIORITIES FOR 2003 /2004

Strategic Alliances	Approx budget
Conference 2004	£10,000
Social Care (building on previous meetings)	£10,000
Public Health (building on previous workshop)	£5,000
Research commissioning workshop	£15,000
Research ethics	£10,000
Disability awareness workshop	£3,000
<hr/>	
Sub total	£53,000

Empowerment

Decisions based on strategic plan and strategic objectives: accessibility; addressing barriers to involvement; information; dissemination of good practice; promoting the value of involvement; and ensuring involvement leads to meaningful results.

TRUE research project	£20,000
TRUE process report	£8,000
Pity II workshop	£10,000
Guide for young people	£5,000
Research Governance leaflet	£500
Accessible materials	£10,000
Toronto seminar	£2,000
Public health work	£2,000
Follow-on training workshop	£5,000
<hr/>	
Sub total	£62,500

Monitoring and Evaluation

RCT Booklet	£5,000
Toronto seminar – peer review	£5,000
Primary care projects evaluation	-
Definitions of user controlled research	£15,000
Evaluation of Folk.Us	£20,000
Monitoring NHS R&D	
National programmes	Support Unit

NHS Trusts R&D Support funding	Support Unit
Documenting work of Support Unit	Support Unit

Sub total	£45,000
-----------	---------

John Sitzia raised an issue about the London Primary Care projects, where much of the support for the projects has dissolved because of changes to the London Regional Office. He suggested whether the London Regional Office should be approached re the Support Unit being able to provide some of that support. He also suggested that agreement should be sought to allow some flexibility in the timing of the contract, to enable the evaluation to be extended.

Action: Support unit to take both these points forward.

Kate felt that changes in emphasis and content of previous conferences should be analysed. She felt that this would make it easier in planning for the 4th conference.

Sarah replied to this and requested that funding could be found to pay for a consultant to do this work to ensure we learn from previous conferences.

Secondly Kate felt that the Empowerment sub-group and other groups should tackle the issue of benefits, which was a barrier to consumer involvement. She advised that Harry would be meeting with Malcolm Wicks the Parliamentary Under Secretary for Work, to discuss this issue. The problem that consumers face is that they can't get payment for consumer involvement without losing their benefits. Robert also felt that this was an issue we should lobby about as good work was being prevented from happening.

Action: Support Unit to ensure that the issue of benefits is put on the agenda for the next meeting.

9. Budget update (annex E)

Kay tabled the current budget update at the meeting. She said that the budget was on target this financial year.

10. Reports from sub-groups

The following key points were reported from the Sub Group meetings.

Monitoring and Evaluation

John Sitzia reported the following: -

- The sub-group were doing ongoing work to try and encourage information on consumer involvement to be included on research databases (e.g. the National Research Register).
- The sub-group were concerned at the low membership of the sub-group and were looking at various avenues to recruit new members.

Empowerment

Kate Sainsbury reported the following: -

- Kate explained that the sub-group had been discussing transferability. This meant ensuring that information gathered was passed on to other situations, which satisfied strategic objectives for accessibility etc.

Strategic-Alliances

Elizabeth Clough reported: -

- Many members of the Group had missed the excellent Disability Awareness training. This sub-group wanted the support unit to assess if another day was needed.

Action: Support Unit

- The Social Care workshop was held in January. Peter with the support of Roger was producing a paper, which will go back to the participants and be discussed at the next Group meeting.
- Jane Royle has been leading plans for a Research Commissioners Round Table; this meeting has been provisionally booked for the 2nd July 2003 at the Kings Fund, London. The round table will be made up of commissioners and consumers who have experience in this area.
- A suggestion of the Monitoring and Evaluation sub-group, and discussed by Strategic Alliances was to build up an evidence base of those researchers involved in evaluation of programmes involving consumers. It was suggested that a website JISMAIL might be used, which is a dictionary of discussion groups. It was suggested that this should now be taken further by the monitoring and evaluation group and managed by Helen Hayes.

Action: Helen Hayes/M&E sub-group

- The sub-group also felt that their membership should be increased.

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

At the last meeting Kate raised how they would like Kay to:

- Highlight areas where work of the Group was having some impact within the Department of Health
- How best to promote the work of the Group within the Department of Health
- How best to ensure the Group meets the needs of the Department of Health

Kay gave a presentation about the impact of the Group on the HTA Programme. The slides from this are attached.

Kay advised that at the next meeting she would discuss the Methodology programme.

12. Director's Report - annex F

Sarah reported that Roger is currently updating the Briefing Notes and they should be ready in the next few months. She also advised the Group that Paul had been contacting Primary Care Trusts (PCTs) in order to encourage consumer involvement in their research programmes.

13. Any other urgent business not included on agenda

Elizabeth Mitchell reported that there would be some changes to the Medical Research Council Consumer Liaison Group (CLG) as a result of a recent impact evaluation of the CLG. A small core group would concentrate on advising the MRC on how to involve consumers. A wider network would carry on doing the work of being involved in some of the strategic planning for research. This wider network will be tied into the MRC Units so that it has a regional focus.

14. Date of the next meeting

The next meeting is planned for the 4th June 2003.