

**Notes of the Twenty Seventh Meeting of Consumers in NHS Research held
at The Commonwealth Club, London on 10th December 2002.**

Present: Nick Partridge
John Gabbay
Elizabeth Clough
Kate Sainsbury
Russell Hamilton
Derek Stewart

In Attendance: Catherine Law (Policy Research Programme)
Carol Lupton (Policy Research Programme)
Morton Phillips (Dept of Health)
Jane Durham (NCRN)

Mary Nettle (Observer)
Vinod Kumar (Observer)
Deborah Tallis (Observer)

Sarah Buckland (Support unit)
Helen Hayes (Support Unit)
Roger Steel (Support Unit)
Paul Jones (Support Unit)
Fran Christopher (Support Unit)
Jane Royle (Support Unit)
Sarah Bayliss (Support Unit)
Achara Western (Support Unit)

1. Welcome, introductions and apologies

Nick informed the Group that unfortunately Professor Mike Oliver was unable to attend the meeting but that he would be invited to attend one of our meetings early in the next year.

Apologies were also received from Peter Beresford, Mike Fisher, Kay Pattison, and John Sitzia. For future meetings Sarah Carr will deputise for Mike Fisher on behalf of SCIE (Social Care Institute for Excellence) when he is unable to attend.

Nick welcomed Jane Royle in her new role as a member of the Support Unit.

Nick suggested that in future the group minutes should be available on the Consumers in NHS Research website. Morton also requested that they were

made available on the Department of Health Research and Development website.

Action: Support Unit to ensure minutes placed on website

2. Notes of the away day 16th / 17th October 2002

The notes of the away day were agreed subject to one correction. Page 1 under the heading Public Health. The sentence should read: 'Catherine started by giving an accepted definition of public health ...'

It was requested for the sake of clarity that where acronyms are used these should also be written in full.

Action: Support Unit to check for acronyms in all papers produced

Nick informed the Group that the next step after the away day was to develop the strategic plan for the group. Each of the sub groups had discussed priorities for a strategic plan, informed by the discussions which had taken place at the away day. They were asked to report back the thoughts from their sub-group.

Nick, said that along with the vice chair, the chairs of the sub-groups, Kay Pattison, Carol Lupton and Sarah Buckland he was going to develop a draft strategic plan which they would then bring to the next meeting in March for discussion.

In relation to developing the strategic plan, the sub-groups raised the following points:

Empowerment

- Kate reported that her group felt that 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. They suggested that Kay should discuss her report to the group, with the Support Unit, to assist in highlighting relevant issues and for Kay to highlight areas where the work of the group was having some impact within the Department.
- Other suggestions were for the need to promote the work of the group within the Department of Health and ensuring that the Group was meeting the needs of the Department.
- The need to set a standard about consultations to ensure that the views of the community are adequately reflected.
- Accessibility was an important part of the development work of the Group and the empowerment sub-group valued task focused association with user groups.

Strategic alliances

The Strategic Alliances sub-group raised the following main discussion points:

- The need for a 3-year strategic plan with focused objectives for one year.
- Consideration to be given regarding whether the Group should be commissioning research or not.
- To what extent should the Group focus on policy, and where should most influence be placed? This sub-group felt that the Group could be more innovative and seek big impact with relatively modest effort. This raises questions for the Support Unit as to whether there are things they should do differently.
- The need for a marketing strategy that targeted the strategic direction and focused priorities of the Group.

It was felt to be important to learn from others and not aim to do everything ourselves. It was also felt that ministers needed to know about who we are and what we are doing. Nick reflected on the importance of working with the big institutions as well as with grass root links. It was important to consider how to keep both areas of work appropriately resourced.

Monitoring and evaluation

The following were the main points raised by the monitoring and evaluation sub-group.

- The importance of maintaining monitoring and evaluation as part of the Group's remit.
- Whether we should be evaluating the work of the Group as well as consumer involvement more widely.
- Need to develop a broad and balanced portfolio of public health, health and social care.

Nick drew these points together as follows: -

- The need to consolidate and build on work already done while expanding further into the fields of public health and social care without forgetting health.
- The need to look at the way we communicate, who we wish to target and why.
- What role the group has in influencing policy and how we engage in consultation.
- How we continue to widen the group's membership to reflect diversity.
- The need for an audit of existing group member's skills and experience and to provide training and support to members.

Nick said that these discussions provided the framework for developing the strategic plan, within limited resources.

Nick then suggested that Kate Sainsbury might like to feed back on the SCIE (Social Care Institute for Excellence) conference that she had recently attended. Kate reported that they had discussed how SCIE could work more effectively with consumers. The conference highlighted to Kate the overlaps and importance of working together. She also described how the minister appeared unaware of the work of Consumers in NHS Research in relation to payments to consumers.

Action: Sarah to write to the minister explaining about the work of the Group and to send a copy of the paper on paying consumers.

3. Notes of actions taken since the away day and matters arising

Carol Lupton reported that she was pleased with the proposal for further work on user-controlled research. She clarified her concerns about the original paper written by Peter Beresford and Roger Steel, which were over the implications for good quality research where any one stakeholder had control over the research. She felt that there was a need for checks and balances and was therefore concerned about the implications of user controlled, rather than user led research. She said that she would find it valuable if the clarification paper to be commissioned could concentrate on this aspect.

4. Presentation by Mike Oliver, British Council of Disabled People.

Mike Oliver was unable to attend due to ill health.

5. Harrogate Conference

Firstly Nick wanted to thank all who contributed to the conference especially the Support Unit and the Group members, who both facilitated and chaired the conference.

He gave special thanks to Harry Cayton for chairing the Planning Group and also to Peter Beresford for the way he rounded up the conference.

Nick made the following points regarding his thoughts of the conference: He thought that everybody involved in the conference had made it very successful. He said that since the last conference the debate had moved forward yet again and different questions were being asked. He felt the starting point of the conference was different to the last one, and he found it rare to be able to mark a shift in approach. He described the conference as being hugely impressive, which he felt we should be proud of.

Sarah reported on the evaluation received from the conference organisers. Half of the people attending were from the statutory sector and half were from the voluntary sector and/or service users. Out of 400 attending approximately 30 service users received bursaries towards the costs of attending the conference.

Only a small percentage of those attending completed evaluation forms (85). Sarah summarised the information from the forms, reporting that the comments were largely positive, but there were some negative views expressed. Some of these are detailed below:

Positive

- Over 70% said Nick and Peter's speech were good or very good.
- Some commented that there was good provision made for everyone's needs.
- People enjoyed networking and enjoyed the experience and discussion.
- There were lots of interesting presentations.

Negative

- Respondents felt that the content of Hazel Blear's video was good, but it was let down by her not being able to be present on the day.
- A few were critical of the content and the organisation of the conference.
- A few commented that there was too much to cram in one day, with a busy lunch and no time to reflect or network. It was suggested that it may have been better over 2 days.
- Some wanted fewer sessions but more discussion in the workshops.
- There were few negative comments about access, although some had difficulty finding their way around the venue.
- Some people commented that there was no facility set up to pay their expenses in advance.

Sarah summed up by saying that they were aware that there might have been too much for one day but at the same time they had tried to facilitate a wide range of presentations. She felt that more consumers were presenting this time and that there was a lot more active involvement being reported.

The Group then discussed their own experiences and views of the Conference. The following are some of the issues raised:

- The venue was felt to be too large
- The conference might have benefited from a stronger theme linking the sessions
- Appreciation of Peter Beresford's closing speech
- The difficulty of meeting everybody's needs and expectations

- The shift in emphasis from the previous conference, with more sophisticated questions being discussed, and more partnership working
- Suggestion that in future there might be more liaisons between the Planning Group and the Main Group.
- The need to learn from the Conference to ensure that future conferences were even more accessible and inclusive
- To advise other conference organisers of the lessons learnt

Nick felt that most of the negative comments were singular compared to a large amount of positive comments. He felt that although there were 400 people there it was not too packed but it felt busy. He advised that he had limited the opening plenary as the minister was originally going to be there and there was then no chance for questions. He reported that he felt there was a culture change, as at the last conference, questions were being asked as to our value and purpose; however he felt we had moved on to “how do we do it best and measure it”. He felt there was a greater involvement and desire to share than ever before.

Action; Sarah to take forward comments for planning the next conference.

John felt that the conference was one way in which the progress of the work of the group could be monitored. He felt we needed to measure progress and decide, “What is progress?”

The following points sum up everyone’s thoughts: -

- The debate on consumer involvement has moved forward since the previous conference.
- Various concerns were raised regarding the venue.
- There had been a move from questioning the value and purpose of consumer involvement to the need for practical help and support in order to make consumer involvement a reality.
- Evaluation of the conference will enable the group both to look at potential changes and improvement for next time and the opportunity to measure how far we have progressed in meeting our aims and objectives.

Actions: Nick to write to Hazel Blears and Sir John Pattison, giving an overview of the conference.

- Sarah to take account of feedback in looking at what has been learnt from the conference.

- Consideration to be given to ways and means of making future conferences more accessible. Feedback should be shared with other conference organisers.

6. Consideration of the name for Consumers in NHS Research.

Nick advised this had not been an easy process however there were now some possible suggestions that the group could adopt. The key points to consider in this choice was the need to encapsulate the scope of our remit into one easy phrase, and how easy it would be for the Support Unit to answer the telephone.

The main suggestion was to adopt the name 'INVOLVE' with the strap line "Promoting Public Involvement in NHS, Social Care, Research and Development" or 'INVOLVE' with the strap line "Promoting Public Involvement in NHS and Social Care Research and Development"

It was felt by the group that the strap line was important, however the word "Health" should replace "NHS", and that "Development" should be dropped.

Discussions also took place regarding whether the word "Public" should be included. It was decided that it should.

Nick's preference was the name 'INVOLVE' with the strap line "Promoting public involvement in health and social care research".

This was endorsed by the group and viewed as an indication to the public at large that we are taking on a wider remit. Before proceeding it will be necessary to obtain Sir John Pattison's approval.

Action: Nick

It would then be necessary to obtain a new design for stationary and publications while ensuring that the change of name is publicised appropriately.

Action: Support Unit

7. Budget update

Morton Phillips reported that he thought the group would be under spent in the current financial year. However, he had not yet received the invoice from the conference organisers Professional Briefings.

8. Reports from Sub Groups

The following key points were reported from Sub Group meetings.

Empowerment

Kate Sainsbury reported the following points: -

- Work with young people: although slightly delayed, progress has been made. It is hoped that a good practice guide will be produced at the end of this project.
- Training Research: This is a good piece of research. An additional £750 has been requested to provide funding to support staff on the project.
- Pity II: A planning/information exchange meeting will take place on 16th January 2003 involving the Department of Health, Pity II parents and Consumers in NHS Research.
- Toronto Group: Work is proceeding regarding the Racial Equality workshop.
- Involving vulnerable people. The 'think piece' will be sent out again to members, with a view to using this document as a position statement.
- User Involvement in Research: Difficulties and uncertainties have arisen regarding the need for service users to be given honorary contracts. It was agreed that this issue would be discussed as a main item at the next group meeting.

***Actions: Honorary contracts to be an item on next agenda.
Elizabeth Clough to raise with Research Governance, difficulties with honorary contracts.***

Strategic Alliances

Elizabeth Clough reported the following:

- It was noted that the group will be organising a Research Commissioners round table early in 2003. Jane Royle will be taking this forward in her new role.
- COREC (Central Office for Research Ethics Committees): Links with this organisation to be discussed as a main agenda item at the next group meeting. Meanwhile Harry, Kate, Elizabeth, and Sarah will seek to meet with COREC.
- Social Care and Research Governance framework: This is being revised to take account of new legislation. The consultation, which was facilitated by the Support Unit, was felt to be very useful.
- Disability Awareness Training: This was due to take place on the 11th December, which some of the Group and Support Unit staff would be attending.

Action: Roger to email group to remind them of Social care workshop 12th February.

***Harry, Kate, Elizabeth and Sarah to meet with COREC
COREC to be a main agenda item for next meeting.***

Monitoring and Evaluation

Derek Stewart reported the following:

- Randomised controlled trials summary booklet: This will be produced in a number of formats to meet the needs and requirements of a diverse readership.
- Forum for those involved in Research: Sarah was asked to take this forward in partnership with Strategic Alliances Sub Group.
- Monitoring Consumer Involvement In NHS R&D: The Support Unit will be looking at Research Governance data being collected by the Research Directorates to explore the value and feasibility of using this information to monitor trends in consumer involvement.
- Increasing the membership of the M&E sub-group was discussed.
- A draft research brief on User Controlled research was discussed

Action: Sarah to discuss forum with Strategic Alliances

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

A paper from Kay Pattison and Carol Lupton (Annex D) was included in the papers. No further comments were made.

10. Directors Report

Members noted that the report was attached as Annex E. There were no further comments made.

11. Any other urgent business not included on the agenda.

There was no other business

12. Date of next meeting

The meetings for the next year are as follows: -

6th March 2003

4th June 2003

4th December 2003

Away day

1st/2nd October 2003