

CONSUMERS IN NHS RESEARCH SUPPORT UNIT

NEWS

Spring 2001

Welcome to the spring newsletter of the *Consumers in NHS Research Support Unit*. In it, we update you on activities and projects aimed at involving consumers in research, and on page 4 you'll find a notice board providing "headline" news of developments and events connected with our work.

Thank you to all of you who have sent in information and articles. We are particularly pleased to include in this issue an article from Steve Lister offering a potent, practical consumer perspective of involvement in research. We are always delighted to receive articles on all aspects of consumer involvement in health research - so please don't hesitate to send us your contribution for a future newsletter!

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A Consumer's Perspective *by Steve Lister*

Steve Lister is a parent carer. The following is an extract from his presentation at a conference on "Involving Consumers in NHS Research" in Middlesbrough on the 29th November 2000.

My son Adam is five and a half years old. He suffers from quadriplegic cerebral palsy, is registered blind and has hydrocephalus. He is fed entirely by gastrostomy, can neither walk, talk or sit without support, and is completely incontinent.

In my capacity as a parent carer I have been involved with the Social Policy Research Unit based at the University of York for about three years. Informed by experience, my view is that a successful formula for research involving professionals and consumers needs careful thought and preparation.

The group needs to be small enough to allow reasonable debate and to develop a good working relationship throughout the members. Consumers almost certainly have other demands on their time and may sometimes be unavoidably absent or unpunctual. With these points in mind, a group might be between seven and ten, including professionals. In reality this might turn out to be four or five in a meeting.

Some thought should be given to distant participation using telephone, post or fax, etc. This would enable those consumer representatives who are unable to attend a particular meeting to contribute and maintain contact with the group. Many consumers are house bound and if we value both their right to equality and the significance of their contribution, every effort should be made to involve them. These people may be carers or have disabilities and be at the sharp end of experience in relation to both health and social services.

The venue should be neutral, free of interruptions, and chosen with reference to accessibility for all those in the group. If possible, successive meetings should be held at the same place. The timing of the meeting should be such that it does not clash with childcare or other commitments. The time and date should be set by negotiation between researchers and consumers several weeks in advance in order to maximize attendance; members could be telephoned a few days before the meeting as a reminder.

(“A Consumer’s Perspective” continued from page 1)

In my view it is important to avoid, if possible, the us/them split in meetings. Use first names, and provide refreshments. Exert no pressure; people must be allowed their own space and time to develop and then speak about their ideas. Seating arrangements need to avoid expressing a split between researchers and consumers. Such meetings can be alien and even frightening for many people, and every effort should be made to allay such anxieties.

Remember, researchers are paid to attend, but other group members often give their time free. This should be respected and every appreciation shown. Travel and childcare expenses should be paid, and childcare should be provided on site. These can be achieved within existing regimes; however, I feel strongly that in the present climate of increased involvement in both research and decision-making, new initiatives need to be developed. Serious thought should be given to financial incentives for consumer members of research groups.

Consideration should be given to consumer involvement in the choice of research topics and in the direction any investigations might take. It should be possible for researchers and consumer representatives to work as partners in this area.

Expectations of high consumer input must be complimented by regular feedback, and any final report should be copied to consumer representatives. It must acknowledge the contribution of all who took part in the research.

If consumers are to be involved, the result has to be a change for the better in their lives. The research must be done well, with the aim being to bring about service improvements, and it must not descend into a public relations exercise.



Regional News

Trent: As a follow up to the Conference last November, Trent Regional R&D Office have produced an A5 10-paged information leaflet called *Consumer Involvement in NHS Research and Development*. Congratulations in particular to Sarah Kent for her hard work on the leaflet and for keeping the momentum going since the conference. For a copy, please contact the office on Tel: 0114 282 0332/0302 or e-mail: Sarah.Kent@doh.gsi.gov.uk

North West: As a follow-up to the three one-day conferences that took place in the North West last year, the Regional R&D Office organised an excellent seminar called *Making it Happen: Action Learning for User Involvement in Research and Development*, which took place at Haigh Hall, Wigan on 23rd April. The seminar focussed on four themes from the conferences: Breaking Barriers; Contribution and Tokenism; Involvement at All Stages; and Training for Users. Action points were identified for each. The Regional R&D Office and other participants will now take these forward.

London: The region has recently begun a *Capacity Development Programme for Involving Consumer in NHS R&D* - a training programme provided by EQuIP (Effectiveness and Quality in Involving the Public) and aimed at developing a London Consumer Involvement Network. The training aims:

- to equip consumers, carers and their authorised representatives with the knowledge, skills and confidence needed to participate in research related decision-making, management, and practice.
- to ensure that health and research professionals also involved in these processes embrace consumer involvement in research and are able to work in effective partnership with consumers.

More details can be found in a recent paper *Capacity Development Programme for Involving Consumer in NHS R&D in London* by Nicola Woodward. This is available from the Regional Office - please call 020 7725 5300 to ask for a copy to be sent to you.

Examples of consumer involvement

Involving a user and a carer on a steering group

In 1999, a pilot study was carried out at Stepping Hill Hospital in Stockport to trial a new service for people with alcohol-related liver disease. The pilot study demonstrated some benefits, and a steering group - consisting of NHS staff from Stockport and Tameside and University staff from Salford - was formed to develop a research proposal to gain funding for a full study. Once the study outline had been agreed, the group decided to invite some service users to join, to help with identifying the questions that should be asked to measure the "success" of the service.

A job description was developed and people working in the community alcohol team approached a user and a carer. The user and carer met with the alcohol liaison nurse and the research development co-ordinator to discuss the pilot study and the practical issues of being involved. The user and carer agreed to join the steering group for a trial period of 3 months. They were paid an hourly rate for their time spent reading papers and attending meetings, in addition to receiving travel expenses.

The contribution of the user and carer was very valuable in identifying practical issues on how to approach and recruit people onto the study, what questions to ask about their experiences of various services and what to write in the information sheets. They integrated easily into the steering group and were happy to be giving something back to the service they had received.

If the application for funding is successful, the user and carer will continue to work on the steering group throughout the study. The researchers will also consider including users and carers at an earlier stage in any future research proposals. For further information please contact Dr Joanne Foster on 0161 419 5814.

The Consumer Audit Project

The Consumer Audit Project was set up in 1997 to develop a method to enable consumers to have a real influence on the quality of community care services, supporting the development of needs-led rather than resource-led services. It is managed by Southampton Centre for Independent Living. *Consumer Audit* trains disabled people to evaluate community care services for disabled people. Consumers are seen as the experts on the effectiveness of services, and

auditors are trained to help consumers identify key areas of concern about the outcomes and impact of services they use.

Consumer Audit is based on the social model of disability, which perceives barriers as being created by society rather than by a person's impairment. So far, the Southampton Centre for Independent Living has trained disabled people to work on audits on social care provision, but sees this model applying equally well in health care.

For more information please contact Neil Luckett, Consumer Audit Co-ordinator, on: Tel: 023 8033 0982

E-mail: Neil@SouthamptonCIL.demon.co.uk



NOTICE BOARD

This is a regular column which can be used to advertise events, initiatives and publications about consumer involvement in R&D. If you would like to put an article on our notice board please contact the Support Unit.

CNHSR Remit to be Extended

Consumers in NHS Research will soon be broadening its remit to include the DoH-funded Policy Research Programme which does research to provide policy advice to ministers, and includes public health and social care. This exciting new development means that we will no longer be covering only NHS research. The group is organising three small “expert” workshops over the next few months in order to ensure members are up to date with the consumer issues involved in this kind of research. It also means that *Consumers in NHS Research* will have to review its title.

Consumers’ Guide

Thank you to all of you who fed back on the consultation draft of “Getting Involved in Research: A Consumers Guide.” There is further work to do on the guide in order to get it right, but if you would like to be put on a waiting list to receive a copy as soon as it is published, please contact Barbara Dawkins at the Support Unit.

Training Information and Research

Thank you to all who responded to our request for information on training relevant to consumers who become involved in research. This will help us update our records. Over the next few months we hope to be commissioning some research to evaluate training relevant to consumer involvement in research.

Hub & Spokespeople

Alan Boyd of the “Hub & Spokespeople” project - part of the *Health for All Network* - is currently involved with some local level pilot projects to support consumer involvement in health service provision in general. This may be of interest to consumers involved in research. For further information, contact Alan on Tel: 0151 231 4283 or e-mail: A.Boyd@livjm.ac.uk or visit the website: <http://independent.livjm.ac.uk/healthforall/hubspoke/main.htm>

Reports Now Available

- The full report of the *Consumers in NHS Research* Randomised Controlled Trials Seminar which took place in December is now available on our website under “news.”
- *Involving Consumers? An exploration of consumer involvement in NHS Research & Development managed by the Department of Health Regional Offices* can now be downloaded from the Publications page of our website.

If you do not have access to the internet, please contact us for a printed copies of these reports.

Associate Membership and Mailing List Update

Thank you to everyone who expressed interest in becoming more involved with our work by becoming an Associate Member. The information you sent us will be used as a guide when we are looking for extra help, expertise or experience in a particular area.

The general mailing list will be updated for the next newsletter, so if your details are still incorrect please bear with us; they will be changed if you sent us a correction sheet in response to our last mailing.

About the Support Unit...

The *Consumers in NHS Research Support Unit* is based at the Help for Health Trust in Winchester. Our role is to:

- Provide information, advice and support to consumers, researchers and those working in the NHS on consumer involvement in health research
- Commission and undertake research about the involvement of consumers in health research
- Produce publications and reports
- Organise seminars, conferences and workshops on consumer involvement in health research

Please contact us if you’d like to know more or wish to contribute to our next newsletter.

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