

# CONSUMERS IN NHS RESEARCH SUPPORT UNIT

# NEWS

Spring 2002

Welcome to the spring edition of the newsletter. There's lots of news from the Support Unit, including a request for feedback to help us with plans for our website and reviewing one of our publications. And as usual, this issue offers a range of articles and examples of consumer involvement in research.

Thank you to everyone who has contributed to the newsletter since it was launched two years ago in spring 2000. Short articles about experiences and insights into consumer involvement in research are always welcome, so do write in, whether you're a consumer, service user, researcher, research commissioner, or any combination of these!



## New training research

Research into training for consumer involvement in research has recently been commissioned by the Empowerment sub-group of *Consumers in NHS Research*. It will explore what training for consumer involvement in research is/has been going on across the UK and examine what is actually effective, particularly from the consumer perspective.

Hopefully, this research will help inform us about what sort of training programmes are needed for effective involvement and capacity building nationally. There will be more about this project in the next newsletter.

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## *And it's hello from me...*

I have been working for the *Consumers in NHS Research Support Unit* as R&D Co-ordinator for the last 3 years, and have been Acting Director since Bec Hanley left at the end of January. I am delighted to tell you that after a recruitment process, I have been offered the post of Director.

We were all very sad to see Bec leave and it is a big responsibility to take over from her. However, I am looking forward to the new role, and am hoping to take forward some of the initiatives that Bec started, as well as looking to see how we can further improve the support we provide.

I am also really pleased to let you know that Helen Hayes (who has been working for us on a temporary contract) has been appointed as our Information Officer. Amongst other things, Helen will be jointly editing this newsletter with Roger Steel and maintaining and improving the information provided on our website.

- Sarah Buckland

## New guide to paying consumers

The first edition of the *Guide to Paying Consumers* is now available on our website. The guide is intended primarily for the use of researchers, and should also be helpful to research commissioners and funders. It includes guidance on the factors to consider when deciding on payments for expenses as well as for time and expertise. There are some examples of rates paid by different groups and organisations at the end of the guide.

The document is not prescriptive about payment levels, but sets out some principles of good practice. Almost every new situation where consumers are involved in research is different in some respect to previous situations. We therefore welcome feedback which will help keep the guide as relevant, inclusive and as up to date as possible. If you do not have access to our website then we would be happy to send you a hard copy.

## Induction pack

An induction pack has been produced for new members of the *Consumers in NHS Research* group and its sub-groups. Although this is specifically designed to help new members settle into the group, we think that it also provides a useful insight for those who are interested in how the group operates and who is involved. We have therefore put the pack onto our website. Again, if you would like a hard copy, do contact us.

## 'Small Voices, Big Noises'

Hard bound copies of this report of research - commissioned by *Consumers in NHS Research* and carried out by Lisa Baxter, Lisa Thorne, and Annie Mitchell in association with the University of Exeter and Folk.us - are now available directly from the *Support Unit*. The research, described in our Autumn 2001 newsletter, explores how consumers have been involved in fields of research other than health and what can be learned from it by health researchers.

## 'Making a Difference' national conference 7th November 2002

Those of you who are on our mailing list should have already received separate information about this conference with an invitation to contribute. If you are not on our mailing list but would be interested in making a contribution, please contact Professional Briefings (details below). Contributions might be for workshop presentations, poster presentations, 'soapbox' presentations or discussion topics - but you need to register your interest by Friday 14th June.

If you do not wish to make a contribution, but would like to participate in the conference, registration forms will be mailed



out in July. If you are not on our mailing list and want to make sure you receive a registration form in July, contact Professional Briefings with your details. In the meantime, make sure you've put the 7th of November 2002 in your diary!

Registration fees have not yet been set, but they will be on a sliding scale as at our last national conference. Bursaries and some free places will be available.

Contact: Professional Briefings, 120 Wilton Road, London SW1V 1JZ.

Telephone: 020 7233 8322

E-mail: london@profbriefings.co.uk

## Scoping study: information about RCT quality

*Scoping study to explore the most appropriate way to produce and disseminate information on the quality of randomised controlled trials for potential participants* - Marion Campbell, Vikki Entwistle, Anne Langston and Zoe Skea at the Health Services Research Unit, University of Aberdeen, 2002.

*Consumers in NHS Research* commissioned the Health Services Research Unit to carry out this study because it has been suggested that a centralised resource could help potential participants of randomised controlled trials (RCTs)

to identify which trials are ongoing, and find information about the quality of these trials. The study involved academic and lay literature searching, interviews, focus groups and e-mail discussion. It looked at what information would be important to people considering participating in RCTs and how information could be provided to enable consumers to assess the quality of an RCT.

The Executive Summary of the findings of the study is now available. You can download it from the publications page of our website or contact Helen Hayes, Information Officer, at the *Support Unit* if you would like a copy sent to you.

### London support for consumer involvement

The Department of Health and Social Care's Research and Development Office in London is funding 11 research projects in primary care in which active consumer involvement was a condition of funding. These research projects are very varied and include, for example, a study promoting testicular self-examination and awareness amongst young men with learning disabilities, and a project looking at whether a lay-led self-management programme for chronic illness can improve the health of Bengalis.

As part of this research programme, money was set aside to provide training and support to the consumers and researchers on the projects. Further funding was made available to support consumer involvement in the commissioning of research in the London region, as well as for two evaluations of the impact of the training and consumer involvement on this programme of work.

The *Support Unit* are pleased to have the opportunity to support this initiative, and we will shortly be recruiting someone to commission and manage the evaluation studies and training contract. If you would like to know more, please contact Sarah Buckland at the *Support Unit*.

### Feedback please...

Over the next few months we will be revising and updating our publication *'Involving Consumers in Research and Development in the NHS: Briefing Notes for Researchers.'* We hope to have a new edition ready for the National Conference on 7th November. Further on down the line, we plan to produce a separate supplement which may be in the form of a resource pack to complement the Briefing Notes.

This might include, for example:

- expanded links for further reading
- links to relevant organisations and networks

- an abridged version of the *Guide to Paying Consumers*
- guidance on working with disabled people and with traditionally marginalized groups
- Research Ethics Committees and consumer involvement
- a section expanding on the meaning of effective involvement and how to check you have it
- more about training
- more on user controlled research
- further samples of paperwork such as job descriptions and person specifications for consumer involvement.

To help us decide on the content of the revised guide and, later, its supplement, it would be very useful to have feedback from those of you who have used the current *'Briefing Notes for Researcher.'* What do you think could usefully be expanded, removed, redefined or added? Please contact Roger Steel at the *Support Unit*.

### And web users - we need your views!

Later in the year we hope to further develop our website and in order to ensure that it's as helpful and relevant to you as possible, we need your help.

We'd be grateful for your views, ideas on how we could improve the site, and any suggestions you might have. Simply use the Feedback Form in the Contact Us section of the site at: <http://www.conres.co.uk/feedback.htm>

### Support Unit core staff:

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- Helen Hayes, Information Officer  
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## Training Workshops for consumers in the North West

'Health R&D NoW' is a collaborative venture between the Universities of Lancaster, Liverpool and Salford and is funded from the North West Regional Office of the Department of Health. The unit run a series of workshops and short courses addressing various aspects of research. It is planned that a user 'strand' be developed as part of these workshops to encourage researchers to involve users at all stages of the research process.

The Unit will also be piloting 3 training workshops for users in the North West. The workshops are geared to non-health professionals who are actively involved in a research project, or about to be involved, or have some other active role in R&D in an NHS Trust. For further details, e-mail HRDN@lancaster.ac.uk or refer to the 'Health R&D NoW' website: [www.lancaster.ac.uk/users/IHR/HRDN](http://www.lancaster.ac.uk/users/IHR/HRDN)

## Cardiovascular Disease (CVD) R&D Strategy Group Event

Coronary heart disease is one of the Government's three national priority areas as outlined in the National Plan. A North West Cardiovascular Disease R&D Strategy is being developed to help achieve NHS R&D objectives for CVD. An event was recently held in the North West to develop a framework for the strategy. One of the objectives of the day was to ensure the framework promoted meaningful carer and user involvement. Several users contributed to the group discussions and the following suggestions were raised:

- Researchers need to listen to users - their priorities are often very different from those of clinicians/researchers.
- Incorporate the user/carer perspective at each stage of the patient's journey.
- Obtain the patient's views from satisfaction surveys and patient forums.
- Establish a website for user's 'frequently asked questions' for users to ask researchers research questions and for researchers to ask users what questions are important to them.
- Establish mixed training sessions that are flexible to the needs of the users.
- Ensure users are paid for their contribution to research projects and Committees.
- Provide feedback on outcomes (even if the user's views are not taken on board, explain the reasons why they weren't).

- Encourage funding bodies to support user-led research.
- Link with user networks groups creating a joint website to bring users and researchers together. Establish a mixed group to develop this website.
- Professionals should have respect for the abilities and capabilities of users - they may be lay in the professional's field, but in their own field they may be experts.

## User involvement publications

The North West Regional Office, R&D Directorate are due to publish several user involvement documents summarising conferences and workshops held over the past 18 months. These are as follows:

- 1) *How can we involve users in research?*  
A report of the three conferences held in Winter 2000
- 2) *Making It Happen: Action Planning for User Involvement in R&D*  
A report of the facilitated action planning workshop in April 2001 addressing the main themes that emerged from the conference
- 3) *User Involvement in NHS Provider Organisations*  
A report summarising the user involvement activity of Trusts in receipt of support funding
- 4) *Training for Service User Involvement in NHS Research and Development*  
A summary of the training focus group workshops held to develop a training programme for users. This workshop has informed the content of the training workshops to be piloted by 'Health R&D NoW'

To be added to the mailing list for these publications please contact Catherine Adams  
Telephone: 01925 704278  
E-mail: [Catherine.adams@doh.gsi.gov.uk](mailto:Catherine.adams@doh.gsi.gov.uk)

For further details of user involvement in the North West please refer to the North West Regional Office website:  
[www.doh.gov.uk/nwro/rddnwro.htm](http://www.doh.gov.uk/nwro/rddnwro.htm)

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## *A collaborative review of autism research*

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*In March 2001, the Medical Research Council (MRC) was commissioned by the Department of Health to provide it with a clear picture of what scientific research has revealed about the epidemiology and the causes of autism. Three groups of scientists examined the research evidence, and importantly - for the first time in an MRC research review - questions and other extensive input from lay people were incorporated from the outset. This article represents the views of Helen Millar, one of the two MRC Consumer Liaison Group members of the lay group.*

The Autism Lay Group was set up by the MRC to work with the scientists reviewing the existing research on autism with a view to identifying areas of future research. The group consisted of representatives of autism charities, parents of autistic children and two members of the MRC Consumer Liaison Group - Jon Sussex and myself - both without special knowledge or personal interest in autism. One member of the group has autism.

The members of the lay group, in consultation with their networks, formulated a set of questions which they wanted, if possible, to be answered by research. The independent scientists were tasked with reviewing all research, attempting to answer the questions and identifying future research priorities. A final report, agreed by both the lay group and the scientists, would go to the Department of Health.

There were some difficulties and tensions during the process. Initially the lay group members were unsure about the independence of the scientists but were reassured by being enabled to suggest names of people to serve on the scientific panels, by guidelines on declarations of interest issued by the MRC and by serving on the review groups, where they could act as 'watchdogs' on the review process. A major issue was that of 'grey' science. Many group members had strong beliefs in small-scale, un peer reviewed research which they felt might be neglected by the reviewers.

A major step forward came when the scientists agreed to look at such research submitted to them. Towards the end of the process there seemed to be a much clearer understanding by both the lay and the scientific members of the purpose of the review and each others' roles.

As the 'disinterested' member of the group I felt I had a useful role, acting as a bridge between the MRC, the scientists and the lay group members. I had no vested interest other than wanting this innovative experiment in consumer involvement to succeed.

I tried to ensure that the lay group members understood the attitudes and values of the scientists and how reviews were conducted, while at the same time attempting to make the scientists understand not only the concerns of the lay group but also that there was a public interest in the review. As a member of the general public, with no personal involvement in autism, all that was important to me was that the review was as thorough and professional as it could possibly be, that the lay group trusted the work which was done and that future priorities for research into this distressing condition were jointly agreed by everyone involved.

It was, at times, a rough ride for everyone concerned but I believe a great deal was achieved and a real level of understanding reached. I think that by being a detached public interest representative I may have played a small part in the final success of this challenging, but exceedingly worthwhile exercise, which should certainly be repeated.

*- Helen Millar*



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## *A service user/researcher's experience with an ethics committee*

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A recent recommendation made in the National Framework for Mental Health called for greater user-involvement in all aspects of mental health care. This includes current or ex-service users participating in research and development, strategic planning of future services, and involvement in these processes from conception through to implementation.

The validity and importance of such input has been recognised and utilised by the private sector, charitable organisations and other Non-Governmental Organisations (NGO's) for some time. It is now not uncommon for a service user to be part of the interviewing process for prospective employees involved in their care. While unfortunately the impact this has on improving services is almost impossible to quantify, never-the-less it is a welcome advance for those who use them.

All of the above however, seems to have escaped the attention of a local ethics committee which was approached by a University that wanted to train service users to carry out research for the Trust to help improve local services offered. The research project was commissioned by the local NHS Trust to involve users to interview people who had been recently discharged into the community from a psychiatric admission. The user-researchers were keen to carry out this work in the hope that the local services provided by the Trust be improved. However, the requirements stipulated by Local Research Ethics Committee made the project very difficult to carry out.

The advantages of users interviewing other users are manifold. Knowing that the interviewer has had similar experiences and been through the same system as themselves is key. Knowing that the researcher will respect their views, whatever they are and understand implicitly the question of confidentiality and anonymity is equally important. It enables people to 'open-up' and be less reticent regarding their true feelings about the treatment and services they have received.

So, how was it that this Local Research Ethic's Committee made this so difficult? Firstly, as user-researchers we were told that our care co-ordinators would be informed of our involvement in the project. As a group we were unhappy about this as we felt we were competent enough to decide what therapeutic work to undertake - after all, we were members of the community and not inpatients. We felt that this decision would not have been made about people who

had not experienced a mental health problem. The situation deteriorated even further when we were also told that our care co-ordinators would be asked for their approval regarding our participation in the project. The idea that a mental health professional would make a decision on our competency as intelligent informed adults is demeaning and a breach of our fundamental human rights. It also flies in the face of every recent report and recommendation regarding empowering services users.

The fact that many of us hadn't even seen our 'care co-ordinators' for months, so they were in no position to comment on our ability to do anything, let alone something as important as help shape the very services they were providing, also seemed particularly ironic.

Secondly, the ethics committee decided that only members of the NHS Trust could encourage or even approach potentially interested service users to take part. We would have to go through ward managers or care co-ordinators to recruit 'volunteers' for the study. This meant that hundreds of information packs had to be sent to scores of NHS staff, not only stretching an already tight project budget but also creating more paper-work and administration for overworked NHS employees. The committee conceded that we could put up posters advertising the project, only on the condition that it was done on Trust paper and that first contact would be with the ward managers or care co-ordinators. This seemed to imply that service users themselves are in no position to judge whether they are well enough to participate!

The end result seems to have turned a valuable, well overdue and relatively simple project into a convoluted, and unnecessarily complicated piece of research. It will be one that will only be completed due to the determination and resolve of those of us who genuinely believe that future services will improve by listening to user voices.

We wonder if this situation could have happened if it had been a Randomised Controlled Trial!

We realise that safety and risk needs to be

assessed for all concerned in any research. The fact that ethics research committees are vital to protect vulnerable people and ensure that research carried out is morally correct and proper is unquestionable. In our view it is also unquestionable that our research project has been all of these from the very start. We, as service users or ex-service users, have been unwell or are unwell for periods in our lives, but we are not stupid.

- Mick Burke

*In the next Newsletter we hope to include an article about the changed arrangements that are being put in place for the remit, composition and management of NHS research ethics committees. These changes are designed to achieve national consistency, make processing of proposals more efficient and speedy and broaden the expertise of the committees (for details published so far see [www.corec.org.uk](http://www.corec.org.uk))*

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## *‘A voice for older Londoners in the doctor’s surgery’*

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This Lottery-funded action research project was commissioned by Age Concern, London. The aims of the project were to work with six GP practices to undertake older patient involvement and evaluate its impact. The findings reflect issues which arose in setting up and running the project and views expressed in interviews by the researcher, Barbara Sheppard, with the participants - patients, doctors and each practice’s designated project lead. They cover practical issues in recruiting participants and running meetings, alongside wider policy issues about age discrimination and bringing about change.

The action research approach reveals the reality behind much of the rhetoric around user involvement in health care planning, research, and service evaluation. The report shows how everyday events like building work in the surgery, or staff turnover, affect the practice’s commitment to involving older people. It confronts the ‘fear factor’ - whereby staff at the outset of the project showed their apprehension that the main outcome of involvement would be expressions of dissatisfaction. And it reveals the impact of largely unintended age discrimination in the National Health Service.

In the context of new Primary Care Trusts and the National Service Framework for Older People, this report is a valuable resource to primary care planners and practitioners wanting to tackle the necessary task of achieving more meaningful involvement of older people in their work. The report is accompanied by a leaflet, *‘Making a Start. Involving older*

*people in the doctor’s surgery.’* This practical leaflet is based on the experiences of those who took part in the project.

At the start...

- Neither GPs nor group leads (nor, indeed, some of the older participants), expected older people to have much to contribute, but all the practices involved were sufficiently concerned about the needs of older people to make a commitment to the project and its aims.

- GPs and group leads were nervous about what the older patients might say, fearing complaints and criticism.

- Older people generally feared discrimination in health care because of their age. They wanted to be treated as individuals, rather than ‘older patients’ by GPs and practice staff.

During the project...

- Practice leads learned from early experience and changed both the organisation and style of the meetings, for instance the layout of rooms and the way meetings were run.

- Older people’s lack of information about primary care services was revealed, and they were able to find out more through the meetings.

- The GPs and practice staff became more aware of the specific needs of older people, including the need for more support in combating isolation.

- Between meetings, practice staff met to consider the issues the older patients had raised and what they could do about them.

- As the meetings went on, the older patients gained confidence both in the practice and in their own ability to raise more complex issues, such as health care rationing.

- Barbara Meredith

The project report, written and researched by Barbara Sheppard, with additional material by Barbara Meredith, is available from Age Concern London. The price of £10 includes the leaflet *‘Making a Start: Involving older people in the Doctor’s Surgery.’* For details of how to order, see the Age Concern London website: [www.aclondon.org.uk](http://www.aclondon.org.uk) or contact Vicky Duncan on 020 7346 5968 or at Age Concern London, 54 Knatchbull Road, London SE5 9QY.

# 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.

## Folk.us conference

Folk Us, who earlier this year were awarded further funding from the South West Regional Office to continue their work until 2004, will be holding their Annual Conference on Monday 23 September 2002 at the Peter Chalk Centre at the University of Exeter. The conference will explore some of the remaining barriers to meaningful consumer involvement in research and how they might be overcome. Further details from Folk.us, School of Psychology, Washington Singer Building, Perry Road, University of Exeter, Exeter EX4 4QG Telephone: 01392 264660. E-mail folk.us@exeter.ac.uk

## Understanding users as trainers

Folk.us have recently produced two leaflets entitled 'Understanding Users as Trainers.' The first, based on the experience of service users who have done training, is subtitled 'Users Voices.' The second, based on the experience of facilitators and trainers who have engaged users as trainers, is subtitled 'Facilitators & Trainers' Voices.' Both should be of interest to individuals and organisations undertaking training for consumer involvement in research. For further details, contact Folk.us (contact details above).

## Consumers for Ethics in Research (CERES) initiative for Clinical Trials

CERES receives a growing number of enquiries from people seeking independent advice on research and also from researchers who would like to comply with the International Conference on Harmonisation (ICH) guidelines and direct people to an appropriate independent agency. The ICH guidelines require that people taking part in research have an independent contact with whom they can discuss any concerns. However, as far as CERES have been able to establish, no one in the UK - or elsewhere - has yet worked out how this information and advice might be provided.

CERES are keen to do some focused work on developing an independent information and advice service for people who are either in or considering participating in clinical trials. One approach, for example, might be to pilot a telephone helpline. Initially however, the group want to make links with other organisations and individuals who are interested in taking these ideas forward. If you would like to find out more, contact Christine Hogg on 020 7226 5522 or e-mail: info@ceres.org.uk or write to CERES, PO Box 1365, London, N16 0BW. More info on the ICH can be found on [www.doh.uk/ich.htm](http://www.doh.uk/ich.htm)

## Newsletter on tape

We are pleased to have this and future newsletters available on tape cassette. If you would prefer a tape version on a regular basis, or if you know of anyone who cannot access the written copy but would be interested in a tape, we would be delighted to send one.

## Deadline for contributions for our next newsletter is the 5th of July

Articles can be any length between 50 and 600 words. If you have any questions about submitting an article, please get in touch with Roger Steel at the Support Unit.

## ABOUT THE SUPPORT UNIT...

The *Consumers in NHS Research Support Unit* is based in Eastleigh near Southampton. 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, would like to be on our mailing list, are interested in becoming an Associate Member, or wish to contribute to our next newsletter.

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*Friendly disclaimer:* The views expressed in this newsletter are those of the authors and not necessarily those of *Consumers in NHS Research* or The Department of Health. Publication of research in this newsletter should not be taken as implicit support for the recommendations for policy. Articles are selected for the sole purpose of stimulating ideas and debate on consumer involvement in research.