

CONSUMERS IN NHS RESEARCH SUPPORT UNIT

NEWS

Autumn 2001

Welcome to the autumn newsletter of the *Consumers in NHS Research Support Unit*. Starting with news of exciting new changes in the Support Unit, we have a range of contributions, including more about our new work with the Department of Health's Policy Research Programme (PRP), as well as updates of work on consumer involvement going on in NHS R&D. Lisa Baxter reports back on the Related Fields research commissioned by the group, and we hear about new work about to be begun.

Support Unit on the move

Some of you will already know that the *Consumers in NHS Research Support Unit* will be moving in February next year. We're currently based at the Help for Health Trust in Winchester, but from February 2002 we'll come under the umbrella of the *National Cancer Research Network*. Our remit will remain as it is now, and we'll continue to provide all of the services we do at the moment. But expect to see some improvements, too! We'll be appointing an information officer on a permanent basis to enable us to provide answers to the many queries we receive more quickly and more fully. And we'll be drawing on advice from the Social Policy Research Unit at York University, where staff have a great deal of experience of social care research.

We'll continue to be based in the south of England, and are currently looking for offices in the Southampton or Winchester area. We'll provide full information about new contact details in the next edition of the newsletter. In the meantime, please bear with us - we'll be trying to set up a new office as well as dealing with an ever increasing interest in consumer involvement in research!



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Parents affected by research on their children

The Support Unit has recently had contact with two groups who are composed of or include parents of children who have been involved in clinical research, and whose concerns include issues of consent, tissue retention and access to information about their children.

Many readers will be aware of the DoH Research Governance Framework and the recently published Research Governance Implementation Programme, designed to avoid the repetition of incidents such as at Alder Hey in Liverpool. However, readers may not be aware that many of these parents are still having to fight for information about what happened to their children. These parents feel that the various Inquiries have not addressed many of the issues they were most concerned about, and wanted to see tighter legislation, not just more guidelines.

None of the parents we met were absolutely against research; indeed, some wanted to be more involved, but they were understandably mistrustful of the behaviour of research institutions. These parents are consumers who wish to influence the way future research in this country is carried out so that it is safe, of high quality, and respectful of individuals' needs, wishes and dignity.

Support Unit News

Scoping study to look at Randomised Controlled Trial (RCT) information from a consumer perspective

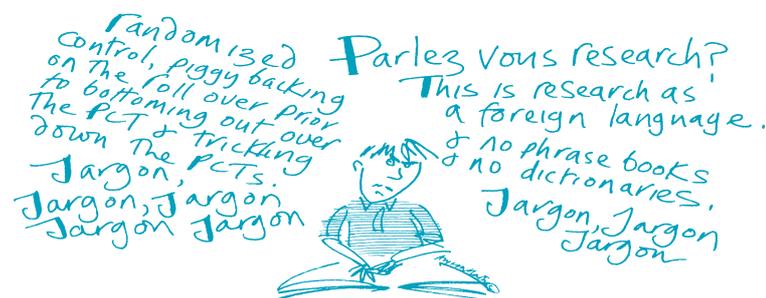
We are very pleased to let you know that a team has been selected to carry out a study exploring the most appropriate way to provide information on the quality of RCTs from a consumer perspective.

Working from the Health Services Research Unit at Aberdeen University, the team includes Marion Campbell, Vikki Entwistle and Adrian Grant. They will be carrying out a focused literature review as well as interviews with potential and current participants in ongoing trials, representatives of national consumer groups, and researchers involved in the design and conduct of clinical trials.

The main questions they will be addressing are: what issues are important to consumers when deciding whether or not to take part in a trial, and what is the feasibility and appropriateness of different ways of providing information from a consumer perspective, on the quality of RCTs?

If you would like to be able to contribute your views to the study, please contact Marion Campbell on 01224 554480 or e-mail: mkc@hsru.abdn.ac.uk

For more background information about the study, contact Sarah Buckland at the Support Unit. Tel: 01962 872213/210, e-mail: sbuckland@hfht.org



Internet Database of Consumer Involvement

Due to technical difficulties, we were unable to link our database - which contains examples of consumer involvement in research projects - to our website during September. We are now working on correcting these problems and we are still actively collecting projects for the database. If you would like us to search the database for you, please contact Helen Hayes, Information Officer, at the Support Unit.

Guide for Consumers out now!

We are delighted to announce that the *Guide for Consumers* arrived from the printers in the first week in October. We have already sent out a large number of them, but don't worry, there are plenty left, so do contact us for a copy, and we will send one to you completely free. Alternatively, you can download it from our website.

Associate Membership

After reviewing the first few months of this scheme, we have decided we need to clarify what Associate Membership entails.

Associate Membership is for people who are interested in being more actively involved with the work of *Consumers in NHS Research* and the Support Unit. For example, to help us review research proposals; to comment on drafts of new publications; to be part of a steering group for a project we are undertaking; or to help with talks or workshops.

We will be changing the Associate Membership form so that those who are interested have more opportunity to say what they want to get out of being an Associate Member. This will help us to know whom to approach as tasks and opportunities come up. It is likely that in future *Consumers in NHS Research* will look to the Associate Membership for potential members of the main group and its subgroups when vacancies arise.

Details of the membership of *Consumers in NHS Research* and its sub groups are made publicly available, but Associate Membership is not made public - it is kept confidential to the Support Unit and to *Consumers in NHS Research* members.

If you just want to be kept informed about our work, there is no need to be an Associate Member - you can simply be on our mailing list.

Introducing Brigid Morris...

Now that *Consumers in NHS Research* has become involved with the Policy Research Programme (PRP), I have been employed for 2 days a week as an additional member of the Support Unit to develop links with those involved in all aspects of Social Care Research funded by the PRP.

I will be talking to both those who fund the research and those who receive funds to carry it out. I will be exploring the current level and range of consumer involvement in this work and will be asking service users, researchers and commissioners about the types of support they feel are needed to continue to develop this involvement.

I also plan to talk with people carrying out social care research not funded by the PRP. This will be important in enabling the Support Unit to build up a clearer picture of the diversity of consumer involvement within social care research and to gather and publicise examples of innovative practice. We are aware that many groups and organisations already involve service users in the research process, and have done so for a long time, and that this continuum of involvement ranges from consultation to collaboration to user-control.

My experience of consumer involvement in research is in the field of mental health. For 3 years I was involved in a national project supporting and enabling groups of people with mental health problems to design and carry out their own local service evaluations. More recently I have been supporting mental health service users to become involved in collaborative research with mental health workers and researchers.

I will be working for the Support Unit on a freelance basis until early next year. Please get in touch if you have any questions or would like any further information. We are extremely keen to hear about any research that you have undertaken or know about that has involved social care service users. Not only would we like to hear about your experiences, but we would also like the opportunity to publicise your project via our internet database.

You can reach me by phone on 07939 147089 or e-mail brigidm@morrisb.fslife.co.uk

I look forward to hearing from you.

Brigid Morris
Social Care Liaison Officer

NW workshop on themes

The North West Regional NHS R&D Office held a facilitated workshop in April 2001 to develop an action plan around four main themes that emerged from conferences held in the North West late last year.

The four themes are 1) *Breaking Barriers* - the interaction between health professionals and users; 2) *Involving Users at all Stages of the Research Process* - ensuring that involvement occurs at all stages of the research process; 3) *Contribution and Tokenism* - ensuring that the user's input is valued and rewarded; and 4) *Training* - empowering users to become involved in R&D.

The workgroups involved in this event are currently developing time-limited programmes of work around these themes. A workshop report has been produced and is available by contacting Catherine Adams on 01925 704278 or from the website: www.doh.gov.uk/nwro/rddnwro.htm or

Restructuring Regional NHS R&D

Many of you will be aware that there is to be a reorganisation of the NHS Regions - there will be fewer of them by the end of 2003. The changes will of course affect the Regional NHS R&D Offices.

In many regions, useful experience has been gained in consumer involvement in NHS R&D and it is clearly important not to lose all that has been achieved to date. We are currently looking at ways to avoid this.

In the meantime, Regional NHS R&D offices and the consumers who have been involved with them are invited to use this section to write about their work so that it can inform future development in consumer involvement in the new structures when they are set up. We will be reporting on the new regional structures for NHS R&D in future newsletters as we hear more about what is planned.

Small Voices, Big Noises

Lay involvement in health research: lessons from other fields

By Lisa Baxter, Lisa Thorne & Annie Mitchell.

Consumers in NHS Research commissioned us to undertake a scoping study to find out the extent and nature of the involvement of lay people (consumers, service users, local people, carers and others) in research in fields other than health. We were also asked to highlight lessons that can be transferred to health research.

We use the term 'lay people' because it includes all the different people who get involved across the fields we investigated. We consider 'lay involvement' to be 'becoming involved using expert 'life experience' rather than specialist professional or academic knowledge.'

We worked in association with Folk.us members on this project, holding two workshops and also obtaining feedback at a forum meeting. As a result of the work with Folk.us, we produced a booklet - *Knowing How* - aimed at lay people interested in getting involved in research.

We found participatory research projects and information about approaches to involving lay people in research in a number of fields: Social Care, Education, Public Health and Health Promotion, Community Development UK, Housing and Regeneration, Agriculture and Environment, and Development Overseas. We also visited eight research projects and talked with the lay people, professionals and, where possible, funders and/or commissioners involved, in order to find out more about their experiences.

We learned many lessons about lay people getting involved in research from the case studies and other projects identified. One interesting lesson was that lay people were more likely to get involved if the research was meaningful and enjoyable. Other major lessons focused on the need to make the research process more flexible and responsive to the changes which often occur when lay people are actively involved. We also learned about many innovative, often visual, research techniques that can cross language barriers and do not rely on literacy skills, again making it more likely that people from all backgrounds get involved.

We make recommendations based on these lessons in our report to the Department of Health and other research funders, *Consumers in NHS Research*, service providers and professional and lay researchers. A key finding of the report is the common desire of lay people to get involved in projects

that will make a real difference and that findings will be acted upon. We hope that our recommendations will be taken up by the relevant people and acted upon too, so that this report will also have made a difference.

The full report is due for publication in October. If you would like a copy of the executive summary, the full report, or the booklet, please contact Katharine Gomme at: Folk.us, The School of Psychology, Washington Singer Building, University of Exeter, Perry Road, Exeter EX4 4QG
Telephone: 01392 264660
E-mail: folk.us@ex.ac.uk.

Alternatively, you can download the report from the *Consumers in NHS Research* website.



Practical advice for involving consumers

The College of Health has recently published the *Voices in Action Resource Book*, a practical manual on training and support for user representatives in the health service. By Gillian Fletcher and Jane Bradburn, it is available for £25.

Training and Support for Lay Representatives in the Health Service is a research report written by Jane Bradburn, Gillian Fletcher, and Catherine Kennelly. Published in 1999, it is also available at £10.

Both publications can be obtained from:
College of Health, St Margarets House, 21 Old Ford Road, London E2 9PL
Telephone: 020 8983 1225
E-mail: info@collegeofhealth.org.uk

HTA Update:

An update on consumer involvement in the Health Technology Assessment (HTA) programme

Health Technology Assessment (HTA) is a national programme of medical research established and funded by the Department of Health's Research and Development Programme. It is managed by the *National Coordinating Centre for Health Technology Assessment (NCCHTA)*. Since 1998, the NCCHTA has actively involved consumers at all key stages, developing resources, providing support and obtaining feedback.

There are two consumer panel members on each of the three HTA advisory panels. Induction/training days and ongoing support are available and feedback is obtained for the purpose of further development. A job description and person specification has been developed for consumer panel members, and there is a mentoring scheme.

Procedures have also been set up for identifying and contacting consumer experts to inform short scientific research summaries of possible research areas (vignettes). To date, over 60 consumer experts have commented on vignettes.

Procedures for identifying and contacting consumers to referee research proposals have been established, and more than 35 consumers have so far been involved. One-to-one telephone interviews with consumers on their experience of refereeing research proposals have been undertaken and feedback on consumer comments has been obtained from HTA Commissioning Board members.

Procedures for identifying and contacting consumers to referee draft final reports for the HTA monograph series have been established, and at least 17 consumers have been involved in refereeing these. Feedback has been obtained on consumer comments obtained from the HTA monograph series editors of draft final reports.

The NCCHTA have published a report - *Needs and feasibility study for developing consumer involvement in the HTA programme* - and a web page (www.ncchta.org) on consumer involvement in the HTA programme has been set up. This includes a section on 'frequently asked questions' about the role of consumers in the HTA programme.

In the future, the NCCHTA plan to gather consumers' ideas for new research topics, produce guidelines to help consumers referee research proposals and reports, develop new routes for identifying more consumers, and publicise progress at conferences and in journals.

To find out more about the HTA programme, please contact:
Jane Royle
NCCHTA Consumer Liaison Manager
Tel: 023 8059 5757
Fax: 023 8059 5639
Email: j.royle@soton.ac.uk

The Toronto Group

The Toronto Group was set up following the 4th International Empowerment Conference at the University of Toronto in September 1997. It seeks to:

- promote research as an empowering process
- provide a forum promoting open and critical debate on the nature and measuring of evidence in social care research, including social work, health and social policy
- enhance the role of service users, carers research participants and other citizens in research.

Membership includes service users, user and non-user researchers, practitioners and managers and other interested citizens. Anyone with an interest in promoting the aims of the group is welcome to join.

In November 2000, the group held a seminar, supported by the Joseph Rowntree Foundation, which brought together a

wide range of participants with different perspectives on research. The aim was to share experiences, explore some of the difficulties of undertaking more empowering and inclusive research and start to identify ways of overcoming them. We hope to use the issues identified by participants to structure further debate in a proposed series of seminars, and have produced a report on the event which will shortly be published electronically.

For more information, please contact:
Martin Stevens, Hampshire County Council,
Southside Offices, Trafalgar House, The Castle,
Winchester, SO23 8UQ.
Telephone: 01962 847121
E-mail: martin.stevens@hants.gov.uk

Examples of consumer involvement

A user's advisory group in practice

Penny Rhodes, Andrew Nocon, Michael Booth, M.Y. Chowdrey, Anne Fabian, Neville Lambert, Faqir Mohammed, Teresa Walgrove.

In 1998, a new service comprising a number of specialist primary care diabetes clinics was established as part of the Bradford Health Action Zone. An evaluation of the service, funded by Diabetes UK with support from Bradford Health Authority, is currently being undertaken.

In addition to user representation on the Project Steering Group, a separate Service Users' Research Advisory Group was established. Members were recruited through a variety of professional and community channels.

For pragmatic reasons and on advice from Asian informants, it was decided that meetings would be in English and that interpreters would not be used as this would inhibit discussion and could cause misunderstandings and confusion. Since language difficulties tended to be greater for women than men, a second group for Asian women who did not speak English was established, facilitated by an Asian researcher.

Group members valued the opportunity to share information; some were able to pass on their knowledge to others outside the group. They also noted that the discussions had enabled them to better understand the needs and circumstances of people from other cultural groups. Not least, they expressed satisfaction in feeling that they had been able to make a worthwhile contribution to the research process and that, through the research, their contribution would benefit other people:

“If what you've learnt, to pass on to others, and our experience in talking together, if it benefits other people, well then it's something worthwhile.”

At times, the group functioned more as a mutual support group: this was an important aspect of the group experience and necessary for group cohesion.

For the researchers, the value of the group included opportunities to assess the appropriateness of research instruments, obtain advice on research strategies, gain useful background information, and assess the validity of interpretations. Service users were able to suggest new topics and lines of enquiry and to challenge the background assumptions of the research process.

Representation at the main Steering Group was extended to include all group members. They appreciated being able to attend the Steering Group in order to express their views and concerns directly to service providers and to gain further insight into the research process.

However, all agreed that it was beneficial to hold meetings separately from the main Steering Group. The more relaxed and informal atmosphere enabled participants to feel more at ease, discuss matters freely and in more detail, and be more critical.

A longer version of this article will be published in the near future. Please contact Penny Rhodes for more details:

Telephone: 01274 365904 or 364474

E-mail: penny.rhodes@bradfordhospitals.nhs.uk

Consumers inform the MS Society of their research priorities

The Multiple Sclerosis (MS) Society has commissioned a study to obtain the views of people affected by MS on priorities for the society's research programme. The study - by Sarah Chilvers, Rory McCrea, Gill Green and Karen Reed - has now been published in a 50 page report called *What Matters? An insight into the views of people living with MS in relation to research priorities in the MS Society.*

33 MS Society members contributed to the study by taking part in one of four focus groups (London, Belfast, Birmingham, and Glasgow) and completing survey questionnaires. They were also asked to indicate any personal interest in taking part in any future research. The study was presented to the MS Society Policy Development Group on the 20th of September.

Further details are available from:

Sharon Haffenden, Research Director, The MS Society, 372 Edgware Road, Staples Corner, London NW2 6ND.

Telephone: 020 8438 0700

E-mail: info@mssociety.org.uk

Consumer involvement in cancer research

There are now a number of new organisations and structures for Cancer Research. They include a National Cancer Research Institute (NCRI), chaired by Sir George Radda, and a National Cancer Research Network (NCRN), led by Professor Peter Selby.

The Consumer Liaison Group, chaired by Derek C Stewart, was formerly part of the UKCCCR but is now part of the NCRI Study Groups.

Further details can be obtained from: Julie Hearn, NCRN, PO Box 123, Lincoln's Inn Fields, London, WC2A 3PX.

Young people taking the initiative

Taking the Initiative: Live! - a conference on promoting young people's involvement in public decision making in the UK - took place in London on 2nd November. The conference, which was led by and involved young people from all over the UK, had the central message that young people are not citizens in waiting, but have an active and full part to play in society.

The conference was based on *Taking the Initiative*, a report on research undertaken by David Cutler and Roger Frost, published by the Carnegie Young People Initiative. The report includes a useful model for the different degrees of participation for children and young people, and includes recommendations on their involvement in, amongst many other areas, the health sector. From this it seems clear that there is a strong case for involving young people in many areas of health research and development to help shape the services and technologies of the future.

For more details, contact: Carnegie Young People Initiative, Elizabeth House, 39 York Road, London SE1 7NQ
E-mail: Carnegieypinitiative@rmpic.org.uk
Website: www.carnegie.youth.org.uk

Speaking...

Patient consumer
Waiting.

User, representing
Awaiting patients.
Patients weighted
Cancer burdened
Wanting journey
Quicker Better
Through the stages
Proving outcomes
Physical and Psycho-social.

Quantitive targets
Keep you going.

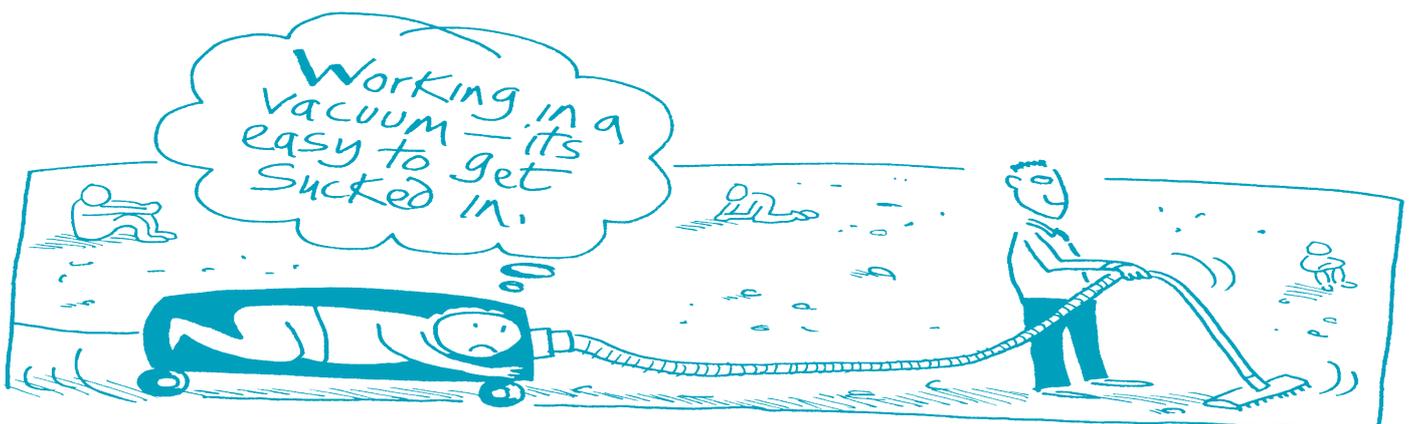
Qualitative feelings
Keep us hoping.

Can I represent
The views of others?
Am I still
A patient patient?

Talking at me
I'll be impatient.
Talking to me
I might be patient.

Now, talking together...

- by Derek Stewart



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.

Input needed for physiotherapy research

The Chartered Society of Physiotherapy is seeking the advice of different consumers on the question: Where do we need to focus our research? This is part of a project that aims to establish where evidence is lacking in our profession, and therefore where we should target funding for research.

If you would be interested in giving us your ideas for research questions or topics, either visit our web-site (www.csp.org.uk) and look under “what’s new” for more information and a standard form, or contact Marion Attew by phone on 020 7306 6617 or e-mail attewm@csphysio.org.uk

Research Governance Implementation Plan

Published in October, the Implementation Plan is a timetable of actions and key targets arising from Research Governance Framework. Section 3.13 specifically mentions consumer involvement in the ‘development and execution of research projects.’ The document can be downloaded from www.doh.gov.uk/research

Making Research Count - National Conference

Making Research Count is a national initiative providing a bridge between social work and social care practice and research. This year’s conference, entitled *The Rules of Evidence - Whose Rules and Whose Evidence?* takes place in London on the 30th of November and includes speakers and a workshop on user-led research. Contact Sue Bailey, Telephone: 01603 593557. E-mail: s.e.bailey@uea.ac.uk

Doing Research Ourselves

This report from the Mental Health Foundation’s *Strategies for Living* project, is an account of the development and implementation of six user-led research projects concerned with alternative approaches to mental health. It costs £10 (or £7 for users and survivors) and can be obtained from: The Mental Health Foundation, 20/21 Cornwall Terrace, London NW1 4QL. Telephone: 020 7535 7441. The first two reports from the supported research project - *An Investigation into Drop-ins* and *An Investigation into Massage* - are now also available at £5 each from the same address.

Call for Consumers

The Cochrane Skin Group is seeking consumers as co-reviewers for their new project review teams. This is important so that they can ensure the background is written

in language that is accessible to lay people, and that outcomes are consumer focused. Contact Tina Leonard, Review Group Co-ordinator, Cochrane Skin Group. Tel: 0115 919 4415. Email: tina.leonard@nottingham.ac.uk

The Cochrane Pregnancy and Childbirth Group’s Consumer Panel

A report on the first two years of activity of this group is now available. Contact Claire Winterbottom on 0151 702 4026 or e-mail claire@liverpool.ac.uk

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, 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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