

# CONSUMERS IN NHS RESEARCH SUPPORT UNIT

# NEWS

Autumn 2000

Welcome to the third edition of our newsletter. In it, we bring you news of seminars on consumer involvement in health research which will be taking place in the autumn. We have also included items about new initiatives to involve consumers in research at national and local levels. And there's information about some new publications, too.

Sarah Gorin, who edited the first two issues of our newsletter, has now left the *Consumers in NHS Research Support Unit*. (Thanks again to Sarah for all her hard work!) We are hoping her successor will be in post in December.

We hope you find this newsletter helpful. Don't forget to contact us if you'd like more information, help or advice about consumer involvement in health research. Contact details are on the back page.

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## Guidelines for consumers on getting involved in research

Following the very successful guide for researchers on how to involve consumers in research and development, the *Consumers in NHS Research Support Unit* is developing some guidelines for *consumers* on getting involved in health research. The guide is being developed from the consumer's point of view and in partnership with consumers.

Discussion groups have been held with consumers in Exeter and London, and telephone interviews have also been carried out. The consumers taking part have experience of involvement with local and regional research projects, and with national research programmes such as Cochrane and the Health Technology Assessment Programme.

Consumers have identified a wide range of issues to be addressed in the guide. These include:

- Definitions of research
- Why do consumers get involved in research?
- How are consumers involved in research?

- Good and not so good experiences of being involved in research
- The things consumers wish they had known before they became involved in research eg: where can you get support and training?
- Ethical issues
- What experience and skills do consumers need to get involved in research?
- Examples of what has happened as a result of consumers being involved in research

The first draft of the guidelines is currently being written. A draft copy will be circulated to all consumers involved in the discussion groups and interviews for comment. The guide will be made freely available and published on the website.

If you would like to contribute to the guidelines, please contact Bec Hanley at the Support Unit.

## New national consumer advisory group for cancer research

The UK Co-ordinating Committee for Cancer Research (UKCCCR), a forum for joint working and exchange of information amongst leading cancer charities, has set up a Consumer Liaison Group (CLG). The chair of this new group and the majority of its members have personal experience of cancer.

The Consumer Liaison Group will be advising the UKCCCR on appropriate ways to involve consumers in cancer research, and working with other UKCCCR groups to advise on recruitment of consumers to other committees and groups. The CLG is also a resource for the organisations funding the UKCCCR, which include the Cancer Research Campaign, the Imperial Cancer Research Fund, the Leukaemia Research Fund and the Medical Research Council. The CLG has also been advising those involved in taking cancer research forward at a national level in the NHS.

This is an exciting new group and we wish them the very best of luck in their work.

For more information about the UKCCCR CLG, visit the UKCCCR website (<http://ukcccr.icnet.uk/>), or telephone Julie Hearn on 020 7269 3548.



## Regional News

In our last issue, Sue Straughair (who is working with us on a part time basis until the end of this year) wrote about plans to hold a series of seminars in the four northern NHS regions on the theme of consumer involvement in health research.

Dates for these events have now been fixed. They are:

- Trent Region:  
10th November in Nottingham
- Northern and Yorkshire Region:  
29th November in Harrogate
- West Midlands region:  
5th December in Birmingham
- The North West Region:  
30th November in Manchester  
1st December in Preston  
7th December in Liverpool

If you live and/or work in one of these regions and you'd like to find out more about these events, please contact the Support Unit. We can also help you if you don't know which NHS Region you are in!

If you live in the southern half of England and you'd like to find out what is going on in your region to promote consumer involvement in NHS R&D, the following people have kindly agreed to act as contact points:

**Eastern Region:** Celia Richards  
Telephone: 01908 844539  
E-mail: [Celia.Richards@doh.gsi.gov.uk](mailto:Celia.Richards@doh.gsi.gov.uk)

**South West:** Jane Moore  
Telephone: 0117 984 1775  
E-mail: [jane.moore@doh.gsi.gov.uk](mailto:jane.moore@doh.gsi.gov.uk)

**London:** Nicola Woodward  
Telephone: 0207 725 5323  
E-mail: [Nicola.Woodward@doh.gsi.gov.uk](mailto:Nicola.Woodward@doh.gsi.gov.uk)

**South East:** Heather Hawkins  
Telephone: 0207 725 2705  
E-mail: [hhawkinu@doh.gsi.gov.uk](mailto:hhawkinu@doh.gsi.gov.uk)

# Examples of consumer involvement

## Involving consumers in randomised controlled trials

Randomised controlled trials (RCTs) are seen as one of the most reliable research methods within health. Thousands of RCTs have taken place around the world. Here's some information about two projects that are promoting the involvement of consumers in RCTs...

*Consumers in NHS Research* has worked with the London School of Hygiene and Tropical Medicine to identify where and how consumers have been actively involved in RCTs in the UK. The results of this study are available now, and we'll be sharing these, as well as looking at examples of good practice, at a seminar on consumer involvement in RCTs.

The seminar is being organised with colleagues at the Clinical Trials Unit at the Medical Research Council. It will take place in London on the 11th of December. Places are free, and there are bursaries (to cover travel and carer costs) available to consumers who have been actively involved in trials. *You can get more details from Barbara Dawkins at the Support Unit.*

It is often difficult for consumers, researchers and health professionals to find out about RCTs that are taking place around the world. To try to address this problem, Current Controlled Trials (part of the Current Science Group of science publishers) has developed the online metaRegister of Controlled Trials - an international database of ongoing (and some completed) RCTs in all areas of healthcare. The metaRegister is already available free of charge through the World Wide Web.

A working group has been set up to develop a scheme to try and give a unique number to every RCT, whether it is taking place, has finished, or is planned for the future. We hope that this will avoid duplication and save time and resources, as well as providing an easier way for consumers to access information about trials. Those involved in developing the numbering scheme (including the UK Cochrane Centre, the Medical Research Council, Current Controlled Trials and the *Consumers in NHS Research Support Unit*) are working hard to ensure that information is presented in a way that can be easily understood by consumers.

*Details are available from <http://controlled-trials.com> or from Bec Hanley at the Support Unit.*

## Interactive information on Parkinson's Disease

A partnership of researchers and consumers has developed a self-help manual and CD-ROM on Parkinson's Disease (PD).

The aim is to modernise health care and redress the balance of power between professionals and patients. Partners in the project included the NHS Executive West Midlands; Foundation September (a Dutch organisation dedicated to the development of patient information); the Parkinson's Disease Society (PDS) and the European Parkinson's Disease Society (EPDA).

The PD manual was translated from the Dutch manual and the CD-ROM was developed from this. The content includes medical, psychological and social information and the CD-ROM uses text, video, audio, animations and photography.

It provides comprehensive and objective information on PD, enabling people with PD to find out about and make use of existing services.

Evaluation of established self-care written manuals shows:

- they are well received by patients and carers
- they are used as reference material
- quality is high
- information is correct and practical
- material can be used to train professionals

The CD-ROM and manual will be available later this month. The project team believes that the manual and CD-ROM could be developed for other conditions, and that the strategies used could function as templates for future projects.

*More information is available from: Karen Saunders, NHS Executive West Midlands  
Tel: 0121 224 4674*

*E-mail: [karen.saunders@doh.gsi.gov.uk](mailto:karen.saunders@doh.gsi.gov.uk)*

# NOTICE BOARD

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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.

## Seminars:

*Seminar on Research, empowerment and agenda setting:*  
The Toronto Group (an alliance of researchers and consumers, committed to the involvement of consumers in social care research) is organising a seminar on research, empowerment and agenda setting. This will be held on the 20th of November at the London Voluntary Sector Resource Centre.

The Joseph Rowntree Foundation has supported the seminar, and places are free. Service users will be reimbursed their expenses for travel, personal assistance, and overnight accommodation, if required. A payment of £50 is available to people who are not in paid employment to enable them to attend this seminar.

The organisers hope that this event will encourage debate about user-led, empowering and inclusive approaches to research and enable an exchange of views between people with different perspectives on social care research. More information is available from Rose Freeman at the National Institute of Social Work, Tel: 020 7387 9681.

*Seminar on consumer involvement in randomised controlled trials:* See the article on RCTs on page 3 for more information

*Seminars in the north of England:* See the 'Regional News' article on page 2 for more information.

## Training

Are you interested in training about consumer involvement in health research? Some groups offer training for consumers and researchers on this theme. They include the College of Health, Folk.us and the Critical Appraisal Skills Programme. The Alzheimer's Society is also offering training for their members through their Quality Research in Dementia Programme. More details about all of these are available on our website, or in a leaflet which is available free of charge from the Support Unit. If you offer training in this area, we'd be very interested to hear from you. Please contact Bec Hanley at the Support Unit.

## Database

In our last issue, we asked you for information about any research projects in which consumers have been actively involved. Lots of examples are still coming in. We'll be using these to develop a database which will be available next year. If you'd like to add details of a research project, or if you'd like more information about the database, please contact Sarah Buckland at the Support Unit.

## Publications

Several new publications are now available from the Support Unit, free of charge. They can also be downloaded from our website:

- *Involving consumers in commissioning health research* - Report of a seminar held on 26th June 2000
- *Research: Who's Learning?* - Report of the second *Consumers in NHS Research* national conference held in January 2000
- *Working partnerships* - the third report of *Consumers in NHS Research* (will be sent to everyone on our mailing list)

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## 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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