

## 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.

### The MetaRegister of Controlled Trials

Current Controlled Trials (CCT) now has a MetaRegister which aims to promote the availability and exchange of information about randomised controlled trials. It is accessible on the CCT Website (<http://contolled-trials.com>), which is dedicated to promoting the exchange of information about controlled trials in all areas of healthcare. This could be a useful source of information for consumers wanting to become involved in RCTs.

### DISCERN on the Web

The DISCERN website is an experimental site consisting of an online version of the DISCERN instrument and handbook. The handbook is designed to help you understand and use DISCERN effectively. It has been written from the perspective of a health consumer (or patient), but can be used by anyone interested in information about treatment choices. Visit the site at [www.discern.org.uk](http://www.discern.org.uk).

The DISCERN on the Internet Project is funded by the NHS Executive Research and Development Programme. More information about the Project can be found in an article which appeared in the He@lth Information on the Internet newsletter at <http://www.discern.org.uk/HOTI.htm>

### Guide for Consumers

The *Consumers in NHS Research* publication "Getting Involved in Research: A Guide for Consumers" is now in draft form. If you would like an opportunity to comment on the final draft, please contact Roger Steel at the Support Unit.

### Free Associate Membership

If you are interested in becoming more involved in *Consumers in NHS Research* activities, you can now become an Associate Member. It's free, and we'll keep in closer touch with you, letting you know about opportunities for involvement. Please contact us if you would like a Membership Form sent to you.

### Events to watch out for...

As part of a strategy to expand the remit of the group to include social care as well as public health research, *Consumers in NHS Research* will be hosting two "Expert Workshops" this year. The first will be about Social Care Users in research and will be held in June, and the second will focus on Public Health Service Consumers in research and will be held in October. These workshops will be followed by a combined event in November/December. Another National Conference will be held in 2002.

### We are interested in your experiences as a consumer in research!

Have you as a consumer collaborated in health research? What was it like? We would like to hear from anyone interested in writing a piece about their experience for a future newsletter, so that consumers considering getting involved can get an idea of what it might be like. Contact Roger Steel if you would like to chat about it, or just send in your article.

**Copy date for articles for the Spring Newsletter is the 2nd of April.**

### 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.

**Consumers in NHS Research Support Unit  
The Help for Health Trust  
Highcroft  
Romsey Road  
Winchester SO22 5DH**

**Telephone: 01962 872247  
Fax: 01962 849079  
E-mail: [conres@hfht.org](mailto:conres@hfht.org)**

**Website:  
[www.hfht.org/ConsumersinNHSResearch](http://www.hfht.org/ConsumersinNHSResearch)**



## CONSUMERS IN NHS RESEARCH SUPPORT UNIT

# NEWS

Winter 2001

Welcome to the fourth edition of the *Consumers in NHS Research Support Unit* newsletter.

In it, we'll be updating you on the work of *Consumers in NHS Research*, the Group that advises the NHS R&D Programme on how best to involve consumers in research within the NHS.

We'll also be informing you about other projects that are successfully working to involve consumers in health research, so that ideas and information can be spread. There's news, too, about upcoming seminars and training opportunities.

Roger Steel - recently appointed Development Worker at the *Consumers in NHS Research Support Unit* - will be editing the newsletter, and welcomes ideas, suggestions, and contributions for future articles.

### Involving Consumers in Randomised Controlled Trials: *The Seminar*

The seminar was organised by *Consumers in NHS Research* and the Medical Research Council Clinical Trials Unit, and held on the 11th of December 2000 at the MRC Clinical Trials Unit in London. Over 70 people attended, including consumers, researchers and health professionals.

The morning presentation covered the results of a survey done on consumer involvement in the design, conduct and interpretation of RCTs - one of the first to provide some hard data about the extent and impact of that involvement. It was found that in spite of some difficulties, "all of those co-ordination centres who experienced involvement reported benefits" and that further research of this kind was called for.

In the afternoon, examples of consumer involvement in RCTs in the fields of HIV/AIDS, maternity and cancer were presented and discussed. Smaller groups then addressed the following questions: How can consumer involvement in trials be promoted and encouraged? Is there any merit in developing a guide on how to involve consumers in trials? If so, what should it cover, and how could it be evaluated?

### In this issue:

Involving Consumers in RCTs 1

CASP training; IMPACT workshops;  
Are you providing training? 2

Regional News 2

Examples of consumer involvement 3

- West Lancashire Association for Disabled People (WLAD)
- Users' Voices

Notice Board 4

About the *Consumers in NHS Research Support Unit* 4



The final presentation of the day covered the MetaRegister of Controlled Trials (see the Notice Board on the back page for more about this), and the introduction of the ISRCTN (International Standard Randomised Controlled Trial Number), which aims to clearly identify different trials.

It was an enjoyable and thought provoking day. Many thanks to all who organised and participated. A detailed report of the seminar is available on request from *Consumers in NHS Research*.

## CASP Training

The Critical Appraisal Skills Program (CASP) aims to “enable decision makers and those who seek to influence them” to “acquire skills to make sense of, and act on, the evidence.”

CASP’s core work involves half-day workshops, which introduce the key skills needed to find and make sense of the evidence about effective health care. CASP’s work is not only with those that purchase and provide the services but also with those in research and development, clinical audit and consumer groups.

Anyone who is interested in attending a standard CASP workshop, or the Training for Trainers, please contact the CASP office: Tel: 01865 226968 Fax: 01865 226959 Email: rowan.williams@phru.anglox.nhs.uk Website: <http://www.phru.org>

## IMPACT Workshops

IMPACT workshops are two-day events that enable participants to develop skills and confidence to make and influence healthcare decisions. All sessions are interactive, with many practical elements, and are supported by an information pack. For further information call Claire Spittlehouse on 01865 226968 or Elisabeth Buggins on 01922 629687, or e-mail: [claire.spittlehouse@phru.anglox.nhs.uk](mailto:claire.spittlehouse@phru.anglox.nhs.uk)

## Are you providing training?

In the last newsletter we asked for anyone out there providing training to contact us. This would help us “map out” available training across the country, and enable us to disseminate information about training opportunities through this newsletter. If you are involved in providing training, please contact Roger Steel at the Support Unit.



## Regional News

Congratulations to all in the four Northern Regions who were involved or took part in the joint *Consumers in NHS Research/Regional Office* events. Six events were held across the four regions. Thanks must go to all the staff in regional offices who put so much work into making the events so successful. Bec Hanley gave a keynote speech at all of the six events and over 500 people in total, took part. Discussions will now be held to consider how the momentum built up can be maintained and progressed.

The Trent event and the Central Manchester Trust Annual Research Exhibition both held poster competitions, and the Central Manchester Trust competition included a category for the best consumer involvement poster. The winning project - “Access to Primary Care and Accident and Emergency Departments for Deaf People in the North West” - was a team effort involving The Manchester Deaf Centre, the British Deaf Association (BDA) and the Trust. As part of the project, a tool is now being developed which managers can use to evaluate access in their departments. Deaf people were involved in every aspect of the research.

Many other events have been taking place in all regions in the past six months and some of you have been kind enough to invite the Support Unit staff to take part. The events demonstrate how the active involvement of consumers in research is developing at a local level. What are your local trust, research community, or university doing? Some of the voluntary organisations are also involved in research at all levels. How much do you know about what is going on in your location? It might be worth finding out!

Some of the voluntary organisations are also involved in research at all levels. How much do you know about what is going on in your location? It might be worth finding out!

- Sue Straughair,  
Northern Development  
Manager

## Examples of consumer involvement

### West Lancashire Association for Disabled People (WLAD)

West Lancashire is a semi-rural district with a population of about 110,000 people. WLAD (West Lancashire Association for Disabled People) is a voluntary organisation and a registered charity, run by a management committee consisting mainly of disabled people.

Early in the 1990’s, the committee identified a need to establish the role of WLAD and consider whether it was serving a useful function. They received Joint Finance money to fund a three year research project into the lives of disabled people living in West Lancashire, and “The People Factor” research project was initiated in 1993 in cooperation with Edge Hill University College. A full-time worker, then later a part-time worker, were both assisted on occasions by students from the college.

The main aims of the research were:

- to make contact with the maximum number of people in the district who identified themselves as disabled;
- to obtain qualitative and quantitative data about them to help in planning and purchasing services;
- to carry out qualitative in-depth research on a number of people;
- to provide WLAD with valuable data about the needs of local disabled people which could be fed into the planning and purchasing processes.

WLAD designed and sent out 470 questionnaires to people who expressed a willingness to take part, and 219 were returned. Approximately 70 taped interviews covering about 90 hours were obtained and transcribed. A report was produced in two parts: the first part, entitled “The Voice of the People” contained selected extracts of the tapes and commentary; the second part - “The Lives of the People” - included statistical information, commentary, conclusions and 63 recommendations.

The report was launched at Edge Hill College, with over 500 disabled people in attendance, and WLAD sent a mail shot to every house in the district. As a result of this work, over 1,000 people are now members of WLAD and a worker has been employed to create a Network of Disabled People.

Copies of the report are available at cost price (£15 for two volumes). E-mail [Ken@WLAD.co.uk](mailto:Ken@WLAD.co.uk). Tel: 01704 895486. This article was contributed by George Weeks.

### Users’ Voices

“Users’ Voices” is a report launched by the Sainsbury Centre for Mental Health on 23rd January. It is the result of research carried out using a User Focussed Monitoring (UFM) model on the views of Mental Health Service Users about their experience of the services they receive at a number of sites in England. UFM was developed and pioneered by the Sainsbury Centre in 1997 with a pilot user-run project in the London Borough of Kensington, Chelsea and Westminster.

The report is groundbreaking in that it may be the first time that people with severe and enduring mental health problems have created, carried out and analysed such a major piece of research. 61 service users, many of them previously isolated and lacking confidence, were trained as interviewers and carried out the work in eight different projects. In all, they interviewed about 500 service users living in the community and in hospital across the country. The fact that the questions were developed and asked by user interviewers clearly affected the interviewees who, it is reported, felt able to open up once they knew their interviewer had also “been through the system” and understood their situation.

The UFM model is user focussed in at least five different ways. 1) Most of the people working centrally to co-ordinate research and evaluation are users or former users of psychiatric services. 2) The instruments used are constructed by groups of local service users. Whilst those working centrally also have professional qualifications, the local service users are in touch with grass roots services. 3) The research is carried out by local service users (interviewing, etc). 4) Informants are people who make heavy use of psychiatric services and who often do not have “a voice.” 5) Results are interpreted and reports are written from the service users’ perspective.

“Users’ Voices” - written by Dr Diana Rose, a service user - is available from the Sainsbury Centre for Mental Health. Tel: 020 7403 8790.