

Welcome to the second edition of our newsletter. We had lots of very positive feedback about the first issue, and we hope you find this one equally interesting and helpful.

As you'll see, it contains a questionnaire asking about research projects that have actively involved consumers. If you have undertaken any research as a consumer or with consumers, we'd be grateful if you could complete and return this to us in the pre-paid envelope. We are interested in research projects involving consumers in health and other related fields.



Our aim is to compile a database providing a useful resource to disseminate information about research involving consumers. Look out for more news about the database in future editions.

If you'd like more information about the **Consumers in NHS Research Support Unit** and how you can contact us, please turn to the back page.

## In this issue:

Seminar for research commissioners and funders 1

Regional News 2

MRC Consumer Liaison Group makes a start 2

Examples of consumer involvement 3

- South London & Maudsley NHS Trust
- The Cochrane Skin Group

Notice Board 4

- Forthcoming events
- Interesting publications

About **Consumers in NHS Research Support Unit** 4

## Seminar for research commissioners and funders

On the 26th of June *Consumers in NHS Research* held a seminar for research commissioners and funders. Around 50 research commissioners (from voluntary organisations, National NHS R&D Programmes and NHS Executive regional offices) attended the event. Our aim was to facilitate the sharing of information and experience about involving consumers in the research commissioning process.

The morning session provided an opportunity for discussion about the definition of 'consumer' and the stages of the research process in which consumers can be involved. Most people felt that quite a broad definition is necessary (ie: including patients, carers and representatives from patient organisations) and that consumers could be involved at all stages of the research, though it could be harder to involve consumers at some stages and with some types of research.

During the afternoon, the National Lottery Charities Board, the Joseph Rowntree Foundation, The Alzheimer's Society, The Health Technology Assessment Programme and the UK Coordinating Committee on Cancer Research all shared their experiences of involving consumers in their work.

*A seminar report will be available soon. To get a copy, please contact the Support Unit.*



## Regional News

- In June, the South East NHS Executive held a seminar on consumer involvement for Local Research and Development Officers. The seminar aimed to provide a forum for discussion about how consumers can be involved in R&D.

Representatives from NHS Trusts, voluntary organisations and social service departments in the region led discussions with small groups about their experiences of involving consumers. This highlighted a number of key issues including how to identify consumers, training and support for consumers and professionals, and the need for additional resources.

The regional office intends to run a series of seminars in the Autumn/Winter on consumer involvement in R&D, clinical governance and patient partnership.

*Further information: Heather Hawkins, South East Regional NHS Executive Tel: 020 7725 2705 E-mail: [hhawkinu@doh.gov.uk](mailto:hhawkinu@doh.gov.uk)*

- Plans are underway for joint *Consumers in NHS Research* and NHS Executive one-day workshops to take place in the northern regions. The workshops will aim to bring together those with an interest in involving consumers in

NHS research. The events will focus on addressing the practical and methodological issues around involving consumers and will create opportunities for like-minded people to network and explore the formation of collaborations.

The workshops will take place in October/November and details will be announced on our web site and through regional offices in the very near future. If you're in a northern region and want to find out more about consumer involvement in R&D, contact names are below.

North West: Catherine Verrill  
Tel: 01925 704278  
E-mail: [Catherine.Verrill@doh.gsi.gov.uk](mailto:Catherine.Verrill@doh.gsi.gov.uk)

Northern and Yorkshire: Victoria Cave  
Tel: 0191 301 1455  
E-mail: [Victoria.Cave@doh.gsi.gov.uk](mailto:Victoria.Cave@doh.gsi.gov.uk)

Trent: Elizabeth Clough  
Tel: 0114 282 0430  
E-mail: [Elizabeth.Clough@doh.gsi.gov.uk](mailto:Elizabeth.Clough@doh.gsi.gov.uk)

West Midlands: Frances Howie  
Tel: 0121 224 4600  
E-mail: [Frances.Howie@doh.gsi.gov.uk](mailto:Frances.Howie@doh.gsi.gov.uk)

## MRC Consumer Liaison Group makes a start

The MRC consumer liaison group met for the first time in May. The thirteen members of the group were selected from 150 people who applied in response to advertisements in national newspapers and through other networks. The group has members from a wide range of backgrounds. One of the criteria for selection was evidence of active participation in consumer involvement. Professor Ray Fitzpatrick chairs the group.

The first meeting aimed to balance items relating to how the group would work, information items, and items for detailed discussion. The group met in time to contribute to consultation on the Draft Guidelines for Tissue Collection which raised considerations about confidentiality, ownership and consent. Also discussed was the UK Biomedical Collections project, which the MRC and the Wellcome Trust are jointly developing. The project proposes recruiting 500,000 people aged 45-64 to donate DNA. CLG members discussed ways in which the public could be consulted and accurate information could be disseminated. This will be a topic for further discussion as the project progresses.

Feedback from members about the process so far has been positive but it is early days in terms of identifying the impact it will have. Look out for further reports from members of the group in this newsletter.

*Further information: Elizabeth Mitchell, External Communications Manager, MRC, 20 Park Crescent, London, W1N 4AL. Tel: 0171 636 5422 x 6190 E-mail: [elizabeth.mitchell@headoffice.mrc.ac.uk](mailto:elizabeth.mitchell@headoffice.mrc.ac.uk)*



## Consumer involvement at South London & Maudsley NHS Trust

In April 1999 three NHS Trusts (Bethlem and Maudsley, Guys and Lewisham Mental Health Trust and Lambeth Healthcare Trust) merged to form South London and Maudsley NHS Trust. The eleven existing user groups formed a Federation of South London User Groups (SLUG). During May 2000 the Trust convened a meeting of local users to find out their views on research priorities and to consider how users might be more involved in research.

There are a number of examples within the Trust of successful consumer involvement at different stages of the research process and with a variety of different client groups. Consumers have been involved in designing, planning, managing, undertaking, and disseminating research.

For example, the Centre for Rehabilitation in Severe Psychosis (CRISP) has a broad range of research projects aimed at improving the quality of life for people with severe and enduring mental illness, particularly psychosis. Users are involved on the steering committee for CRISP and have been essential in changing outcome measures, from specific outcomes such as symptom reduction to more general functioning outcomes like social functioning levels and quality of life measures.

Within the Disorders of Childhood Activity Area, users have also been involved in the planning of several research programmes.

*Further information: Dr Gill Dale, R&D Manager, South London & Maudsley NHS Trust, Institute of Psychiatry, De Crespigny Park, London SE5 8AF. E-mail: g.dale@iop.kcl.ac.uk*



## Consumer involvement in the Cochrane Skin Group

The Cochrane Skin Group (CSG) is an international network of health professionals and consumers who are committed to providing reliable evidence on the best possible ways to treat skin conditions.

A rigorous process has to be undertaken in order to establish the evidence. First, a question is formulated (eg: What are the effects of interventions for acne?) A protocol is then written, describing the methods to be used and stating which clinical outcomes will be considered. A comprehensive search is undertaken for all clinical trials, published and unpublished. The trials are then assessed and only those satisfying stringent quality criteria are used. Before the review can be published it is critically assessed by the editorial board of the Skin Group, as well as two 'external' subject experts and a consumer.

The CSG is one of about 50 'Collaborative Review Groups' (covering most medical specialities) which make up the Cochrane Collaboration. This international organisation exists to help people make well-informed decisions about healthcare. It publishes the systematic reviews prepared by the review groups in an electronic library. Consumer participation ensures that the language used is accessible and meaningful to non-technical people and that the outcomes studied are relevant to patients and their families.

The Skin Group has always encouraged consumer involvement at all stages of the review process. Consumers also participate in conferences, write articles, present papers and are members of the consumer network.

*Further information: Nicola Thornton, UK Cochrane Centre, Summertown Pavilion, Middle Way, Oxford OX2 7LG  
Tel: +44 1865 516300 Fax: +44 1865 516311  
Email: nthornton@cochrane.co.uk  
Website: <http://www.cochrane.org/cochrane/consumer.htm>*

# NOTICE BOARD

*In response to feedback about our first newsletter, we intend to include a regular notice board column. This can be used to advertise forthcoming events or initiatives about consumer involvement in R&D and let others know about interesting publications. If you would like to put an article on our notice board please contact Sarah Gorin at the Support Unit.*

## Forthcoming events:

- On 15th November the Department of Palliative Medicine at Royal Hallamshire Hospital is hosting a conference about user involvement in policy and service development (morning session) and the involvement of users in cancer research (afternoon session). The morning session will have a regional perspective and will focus on the feedback to user groups of a study of user involvement in cancer services in Trent. The afternoon will address the broader issues of involving users in cancer research. The conference will be held at the Quaker Meeting House, Sheffield from 10.30am-4.30pm.

*Further information and booking form: Tony Stevens, Department of Palliative Medicine, K Floor, Royal Hallamshire Hospital, Sheffield S10 2JF.*

*Tel: 0114 271 1707 E-mail: t.stevens@sheffield.ac.uk*

- The Toronto Group (Research as Empowerment) is an alliance of social care and health service users and researchers that meet regularly at the National Institute of Social Work in London. The group formed following a conference on Empowerment held in Toronto in 1997. The group's specific aims are to enhance the role of service users in research and to promote research as an empowering process. The Group has recently secured funding from the Joseph Rowntree Foundation to hold a seminar on

research, empowerment and agenda setting in the autumn/winter in London. Further details will be given in the next edition. In the meantime if you would like to come along to a meeting of the Toronto Group or register your interest in the seminar please contact Sarah Gorin at the Support Unit.

## Interesting publications:

- DeKoning, D. and Martin, M. (1996) *Participatory Research in Health*. London: Zed Books.

- Truman, C. Mertens, D.M. and Humphries, B. (2000) *Research and Inequality*. London: UCL Press.

- *Consumers in NHS Research* and the *Consumers in NHS Research Support Unit* have produced a number of publications. You can obtain free copies of all of them by contacting the Support Unit or downloading them from our website.

## 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 require further information, or would like 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

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

