

CONSUMERS IN NHS RESEARCH SUPPORT UNIT

NEWS

Spring 2000

Welcome to this, the first edition of the *Consumers in NHS Research Support Unit* newsletter. Every three months, this newsletter will bring you information about what is happening to promote consumer involvement in research within the NHS.



We'll tell you about the work of *Consumers in NHS Research*, the Group that advises the NHS R&D Programme on how best to involve consumers (patients, carers, long term users of services, organisations representing consumers' interests, etc).

We'll also tell you about other projects that are successfully working to involve consumers in health research, so that ideas and information can be spread.

Research: Who's learning?

On the 28th of January we held our second national conference on consumer involvement in health research. Entitled *Research: Who's Learning?*, the conference aimed to promote consumer involvement in health research, build alliances and share learning. Over 300 consumers, researchers and research managers attended the conference, and a further 50 were turned away due to lack of space.

Lord Hunt of Kings Heath, the Parliamentary Under Secretary of State for Health, gave the keynote speech, and offered strong support for the involvement of consumers in NHS R&D. This was echoed later in the day by Professor Sir John Pattison, director of R&D for the NHS. There were workshops on a variety of subjects, including different techniques for involving consumers, user led research, consumer involvement in randomised controlled trials, ethics and many others.

Thanks to everyone who came along, led workshops, offered posters or made other contributions.

Feedback from participants was very good, with 95% of participants stating they enjoyed the conference a great deal or quite a lot, and 70% of participants saying they learned a great deal or quite a lot about consumer involvement in health research.

A copy of the abstract book for the conference is available from the Support Unit for £10.00. We will be publishing a conference report later this year, which will be sent to all participants. We will also be giving details about how to order this free publication in the next edition of this newsletter.

We hope this publication will be useful - please let us know what you think of it. We welcome suggestions for future articles as well as contributions from you. To find out more about the *Consumers in NHS Research Support Unit*, our publications and how to contact us, please turn to the back page.

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How do you involve consumers in R&D?

We have recently published a booklet of briefing notes designed to help researchers think about how they can involve consumers in research and development.

The booklet was developed by a group of consumers and researchers who have a commitment to, and experience of, consumer involvement in health research. Seven people took part in a workshop to develop the booklet and then made comments on drafts. A draft of the booklet was also circulated to other consumers and researchers for comment.

The booklet combines practical advice with examples of how consumers have been involved in current or completed research initiatives. The examples illustrate that consumers can be involved at different stages of the research process, from identifying topics for research through to disseminating and evaluating research outcomes. The booklet also provides examples of consumer involvement in different types of research, including clinical trials.

Although written primarily for researchers receiving funding from the NHS, we believe that this booklet will also be of use to other health researchers. To obtain your free copy please see the back page for details.



Consumer involvement in work managed by the regional NHS R&D offices

The *Consumers in NHS Research Support Unit* is currently undertaking a research study that aims to examine the nature and extent of consumer involvement in work managed by the eight NHS Regional R&D offices. The study aims to:

- provide an understanding of the ways in which consumers are involved
- identify the obstacles and opportunities for effective consumer involvement.

The study is organised in two phases - the first of which is now complete. It involved a combination of interviews with representatives in the regions and analysis of documentary information on consumer involvement by NHS Providers receiving support funding.

The second phase will involve visits to a number of Providers (e.g. NHS Trusts) that receive NHS R&D support funding and will include visiting R&D co-ordinators and consumers involved in research.

The study is ongoing and we will keep you updated on its progress. For further information, please contact Sarah Buckland or Sarah Gorin at the Support Unit.

Regional News

Regional R&D offices know about the strengths and interests of their R&D communities and provide a link with national R&D policy as well as supporting research in all parts of the NHS. The *Consumers in NHS Research Support Unit* is therefore keen to work with regional R&D offices to encourage strategic alliances in regions and the development of regional collaborations of consumers and researchers.

Sue Straughair has been seconded to the Support Unit from Northern and Yorkshire Regional R&D office and will be a resource to the four Northern regions of Trent, West Midlands, North West and Northern and Yorkshire. Sue's work will help to strengthen current links in these regions and develop new networks of people interested in consumer involvement in R&D. The shape and scope of regionally based fora will depend on local circumstances and the plans of regional R&D Directorates.

Please contact Sue if you are interested in this work or have any ideas you'd like to share.

Examples of consumer involvement

Consumer involvement in the HTA programme

The Health Technology Assessment (HTA) programme is learning how to involve consumers in its work and is developing support for staff and consumers to work together. Consumers are members of the HTA advisory panels which are responsible for prioritising topics for commissioned research within the programme. In addition, consumers:

- suggest research questions;
- peer review brief summaries of research needed (vignettes), comment on the relevance of the research questions and highlight any areas that require changes or more information;
- peer review research proposals in the light of their understanding of the subject from the perspective of patients or service users. They are asked to consider what questions patients or service users may ask about the treatment, the possible outcomes and the proposed study and how important these issues may be to them;
- peer review draft final reports and comment on whether the report has addressed the areas they think are important and ways that the report could be improved.

HTA has recently explored consumers' experiences of peer reviewing research proposals. The aim was to find out consumers' views on the process; what further guidance would be useful and what the important issues are for consumers. Initial findings include the following comments made by consumers: they valued the experience; they would have felt more comfortable if the referees' assessment form had been designed for consumers; they would have valued feedback on their contribution and they would value support and training.

For further information please contact: Jane Royle, Consumer Liaison Manager, NCCHTA, Wessex Institute for Health Research and Development, University of Southampton, Mailpoint 728, Southampton SO16 7PX. E-mail: j.royle@soton.ac.uk Telephone: 023 8059 5757 Fax: 023 8059 5639.



Folk.us

Successful collaboration between consumers and researchers

The Forum for Collaboration with Users in Research (Folk.us) is a unique and innovative partnership between users, lay people, academics, clinicians and managers that promotes and supports collaborative and participatory research in the fields of health and social care.

People connected with Folk.us are keen to find ways to build mutually respectful relationships between professionals and ordinary folk who are concerned with research in health and social care.

Folk.us aims to:

- Promote research that is relevant to the real concerns and priorities of people who use health and social services
- Encourage a research/ practice culture influenced by users, carers and professionals in which research findings are actively put into practice
- Ensure that those who are frightened to speak are encouraged to do so and listened to.

Folk.us has organised a successful regional conference, run training events and supported the development of a number of successful research projects. They have recently received a project grant from the South West NHS R&D Regional Office to develop their work. This has enabled them to recruit a member of staff to support their work, and to plan a second regional conference.

Folk.us have also successfully bid for a grant from *Consumers in NHS Research* to conduct a scoping study of contexts, concepts and methods for consumer involvement in health and other related fields, such as social care.

For more information about Folk.us please contact Annie Mitchell, Department of Psychology, Washington Singer Building, Perry Road, University of Exeter, EX4 4QG.

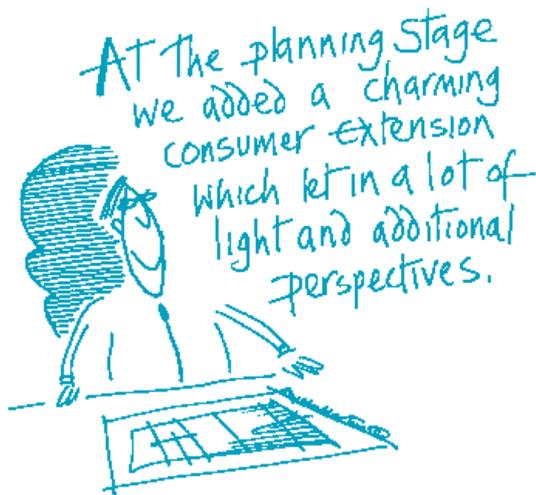
More about the *Consumers in NHS Research Support Unit...*

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.

We have five members of staff, almost all of whom are part time. They are:

- Bec Hanley, director
- Barbara Dawkins, administrator
- Sarah Buckland, research co-ordinator
- Sarah Gorin, action researcher
- Sue Straughair, northern development manager



We can be contacted at:

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Website

The *Consumers in NHS Research Support Unit* now has a website, which includes information about both the Support Unit and the Group. The website also answers questions that are frequently asked about involving consumers in research, and provides information on other websites that might be useful.

Copies of this newsletter and other publications written by *Consumers in NHS Research* can be downloaded from the website at:

www.hfht.org/ConsumersinNHSResearch

Publications

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 the publications listed below by contacting the Support Unit or downloading them from our website.

Research: What's in it for consumers?

The first report of the Standing Advisory Group on Consumer Involvement in the NHS R&D Programme (now *Consumers in NHS Research*).

Research: What's in it for me?

A report on the first national conference held by the Standing Advisory Group on Consumer Involvement in the NHS R&D Programme.

Involvement Works

The second report of *Consumers in NHS Research*.

Research and development in the NHS: How can you make a difference?

Provides information about how R&D in the NHS works, and how consumers can get involved.

Involving consumers in research and development in the NHS: Briefing notes for researchers

Offers guidelines to researchers on how to effectively involve consumers in health research.

Please don't hesitate to contact us if you have any questions, require further information, or would like to offer a contribution to our next newsletter, to be published in the summer.
