

Welcome to the sixth and expanded edition of the *Consumers in NHS Research Support Unit Newsletter*, which now has a regular circulation of 2,250. This issue covers some exciting new developments, including our extended remit to work with the Department of Health Policy Research Programme in addition to our NHS work. This means we are now directly concerned with social care and public health research as well as health services.

There are also articles by Peter Beresford on research in social care and Clare Evans on involving people with disabilities in research. We welcome any articles on consumer involvement in NHS, social care and public health research, whether specific examples or more general pieces. Particularly welcome would be contributions from users of these service areas on their experiences of involvement in research, which may be helpful to readers.

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About the *Consumers in NHS Research Support Unit*

Taking on the Policy Research Programme - by *Bec Hanley*

There are two major research programmes within the Department of Health. The biggest one, the NHS R&D Programme, covers research which is of use to the NHS and the patients who use it. The second, much smaller programme - the Policy Research Programme (PRP) - aims to provide knowledge to inform health services policy, social services policy, and policies relating to the health of the population as a whole (for example about smoking, the environment etc.). Because the PRP aims to inform policy, the main 'customers' for the PRP's research are government ministers and the civil servants who support them, rather than the NHS.

Until recently, the remit of *Consumers in NHS Research* has been to promote the involvement of consumers in the NHS R&D Programme. This year, for the first time, we've been asked to extend our remit to cover the Policy Research Programme. This means that from now on we'll be promoting the involvement of consumers in social care and public health research, as well as health services research.

We'll be spending the next nine months talking with consumers, researchers and those working in the PRP about how

they think we could promote the effective involvement of consumers in social care and public health research. We'll also be changing the name of *Consumers in NHS Research* and looking at our membership to ensure we reflect the new areas we've taken on. We know that many people have done a lot of work to promote consumer involvement in public health and social care research, and we're looking forward to learning from them and working in partnership with them.

We'll keep you posted about our progress and our plans through this newsletter. In the meantime, please contact the Support Unit if you'd like more information about our new role. If you'd like to know more about the Policy Research programme, please look at the DOH website :
<http://www.doh.gov.uk/research/rd2/prpindex.htm>
If you don't have access to the internet, please contact the Support Unit.

Support Unit News

September launch for our internet database of consumer involvement

We are pleased to announce that the first release of the internet version of our database is scheduled to be live on our website by the middle of September 2001.

The database contains examples of research projects that have actively involved (or plan to actively involve) consumers in the research process. Examples on the database include various different levels of involvement by consumers - from research projects led by consumers, to consumers being involved in designing the research instruments, prioritising the topics for research, or being on a steering group of a project.

The database covers research projects in the field of health (including public health) and social care. All the project details have been written and submitted by the individual researchers. By providing us with details of their projects they disseminate their work and help others who are interested in similar work to identify and contact relevant projects.

The database can be searched by keyword, geographical region, research design, or stage of consumer involvement. If, however, you require a more detailed search, or if you do not have access to the internet, please contact Helen Hayes, Information Officer at the Support Unit, and we can search the database for any projects that might be of interest to you.



The database is still at the construction stage and is being constantly updated with new information and projects and reviewed for further development. We're continually looking to identify projects to include on the database, so if you are working on a research project that involves consumers, we would like to hear from you! You can phone or e-mail us to request a form for submitting details of projects for the database, or download it from the website. (Contact details are on the back page).

New Publication: 'Getting involved in research: A Guide for Consumers'

We aim to have this new guide published at the beginning of September as a spiral bound partner to the popular '*Briefing Notes for Researchers*'. The guide is for consumers who are either thinking about getting involved in research and development in the NHS, or who are still new to it. The guide is free of charge, and if you would like to reserve a copy in advance, we will send one out to you as

soon as it is published. Please contact Barbara Dawkins at the Support Unit if you would like to go on our waiting list. For all those who helped us with this guide - a copy will be sent out to you automatically when it is published, so there is no need for you to reserve a copy.

Primary Care Research Networks

The Support Unit has had a number of requests to attend, speak at, or run workshops for Primary Care research support network conferences and events in the last 6 months. Primary care staff such as GP's and Practice Nurses are expected to carry out research in addition to their heavy commitments to their practices. For many of these 'front line' practitioners, consumer involvement in their research can seem like an additional burden.

The Support Unit has been keen to get the message across that it can also be important and helpful.

Consumer involvement in primary care research can help assure the relevance and increase the quality of the research that is done. In addition, consumers involved in research work can often also be 'allies' to the researchers.

Consumers and public health research – by Jane Royle

Consumers in NHS Research has recently extended its remit to include public health research. On the 1st of June 2001 I took on the role of Public Health Development Worker with the Support Unit on a secondment from the Wessex Institute for Health Research and Development, University of Southampton, for one day a week. 2001/2002 will be a year to develop alliances and agree a strategic plan with the Department of Health's Policy Research Programme (PRP).

My role will be:

- To develop an effective working relationship with liaison officers working on public health issues within the Policy Research Programme
- To identify and build links with key individuals and agencies within public health research, to listen to their views and priorities with regard to consumer involvement and to tell them about the work of *Consumers in NHS Research*
- To organise a consumer involvement public health research seminar.

Catherine Law, who coordinated the development of the R&D Strategy for Public Health and is assisting the Department of Health with its implementation, has agreed to offer support on public health issues.

I have already met with some of the Policy Research Programme Liaison Officers to find out what public health research the PRP is funding; what consumer involvement is already happening; and what help is required from *Consumers in NHS Research*.

I have also started contacting key stakeholders in public health research and have plans to make contact with the following agencies:

- UK Public Health Alliance (UKPHA)
- Health Development Agency (HDA)
- Association of Public Health Observatories
- Modernisation Agency,
- Food Standards Agency,
- Society of Health Education and Health Promotion Specialists (SHEPS),
- National Consumer Council
- Community Practitioners' and Health Visitors' Association

Please do contact me if you would like more information or wish to discuss any aspect of this work with me.
Telephone: 023 80 595660 E-mail: j.royle@soton.ac.uk

Regional News

South East Region

During July, the South East Regional NHS R&D Office, in partnership with the Help for Health Trust, hosted three day-long seminars on consumer involvement in research in Tunbridge Wells, Southampton, and Slough. Each seminar was attended by a mix of researchers, NHS R&D staff, Community Health Council staff and members, and lay people from across the region. There were a number of presentations about research, the organisation of NHS R&D and the different ways in which consumers could be involved. The South East Regional R&D office are keen to involve consumers at a variety of levels within the R&D structure in future. If you are from the region and interested in getting involved, contact Heather Hawkins on 020 7725 2500.



User involvement and social care research

by Peter Beresford

Peter Beresford is director of the Centre for Citizen Participation, and Professor of Social Policy at Brunel University. He is a long-term user of mental health services and is actively involved in the user/survivor movement.

To make sense of differences there may be between social care and health research, it is most helpful to start with social care itself. It is worth looking at three particular features of social care. Each of these has implications for both the nature of social care research and the role that service users have played in it.

First, social care is associated with social approaches to understanding and practice. These are concerned with the wider circumstances and material conditions which affect people, as well as people's individual nature. This is in some contrast to mainstream health approaches, which have largely been based on a medical model whose focus is in the individual, their physical and mental state.

Second, interest in user involvement in social care was greatly accelerated in the early 1990s by legislative requirements for participation in both child and community care.

Third, and perhaps most important, social care is probably the policy area which has been most influenced by the emergence of social movements of service users, including those of disabled people, mental health service users/survivors, looked after young people, older people and so on. These movements, particularly that of disabled people, have developed their own organisations, ideas, ways of working, knowledge, services and proposals. They are now having a growing impact on policy and practice. The social models of disability and distress they have developed have encouraged new ways of interpreting and addressing people's needs, highlighting the traditionally oppressive and discriminatory social responses to impairment and distress and framing issues in terms of human and civil rights.

These three developments have provided a supportive context to advance thinking and practice on user involvement in social care research and evaluation. Social care has become a focus for pioneering work. This has gone far beyond the satisfaction surveys and consultations which reflect an early interest in user involvement in research. It also extends beyond involving service users solely in existing research methods and paradigms. The disabled people's movement, for example, has developed its own new research methodology – 'emancipatory' research - and raised debates about the role of the disabled and non-disabled researcher and the purpose of research.

Disabled researchers argue that research should be based on changed, more equal research relationships and its aim should be the empowerment of research participants.

In social care there are now examples of service users as research commissioners, funding advisers, managers, researchers, research trainers and interviewers, as well as, of course, active research participants. Disabled and service user researchers and their organisations have now established a growing and significant body of emancipatory and 'user controlled' research and a body of evidence to increase understanding of these new research paradigms. Supported by innovative funders like the Joseph Rowntree Foundation and National Lottery Charities Board, there is also social care research which involves a wide range of service users, including those most liable to be marginalised, in many different ways.

There is, however, still much work to be done. There need to be more opportunities to develop user-controlled research and to evaluate it. We need to have more systematic data about the gains to be got from user involvement in research; the strengths and weaknesses of different approaches; how such research can most effectively impact on policy and practice, and how service users can most helpfully be supported to be involved. But existing experience of user involvement in social care research now provides a crucial base to build on.



Practicalities of the involvement of disabled people in research

by Clare Evans

The following is taken from a section by Claire Evans in the forthcoming Support Unit publication 'Getting involved in research: A Guide for Consumers.' Clare is manager of the Leonard Cheshire Disabled People's Forum.

The term 'disabled person' applies to a large number of people who may have a variety of impairments. There are disabled people who have physical impairments, sensory impairments, cognitive impairment or learning difficulty, and people who use the mental health services. In order for research to be empowering for disabled people a lot of planning and sensitivity is needed when considering practicalities.

- **Access:** This is not just about physical access to enable people with a physical impairment to gain access to the same room as others to discuss research. Comprehensive access is about considering all kinds of impairments so that the venue is prepared for people with sensory impairments, and everyone has adequate support to understand and join in what is being discussed. This includes appropriate refreshments and breaks in meetings.
- **Variety of formats:** A range of formats needs to be considered to make the information advertising the meeting, and the meeting papers themselves, accessible. These might include audiotape, easy English, large print, or BSL sign language, for example. Provision of these needs to be arranged sensitively, and as a matter of course, rather than people having to request particular formats retrospectively.
- **Times of meetings:** Many disabled people are governed by others in the times they can get up or get transport to reach venues, so no assumptions should be made when arranging meetings. Rather, participants should be consulted about acceptable times.
- **Payment:** In addition to automatically covering the cost of transport, including taxi fares if necessary, it is usual for disabled peoples' expertise to be recognised by a small payment if they participate. Some people may not wish to claim such a fee because of rules affecting their Benefits, but it is important that organisers do not fall into the trap of prejudging this. Disabled people should be given a choice in the matter.
- **Support worker arrangements:** This will vary from person to person depending on their situation. Some people will wish to bring personal assistants with them and have their costs reimbursed while others may wish the organisers to arrange assistance as appropriate. Usually people prefer to meet together alone with personal assistants accommodated in

another room provided nearby. The workers can then join them at breaks and mealtimes. However, sometimes people may require their support worker to assist them to participate in the meeting e.g. sign interpreters.

• **Role of allies:** Disabled people can expect able-bodied allies to work in an enabling and empowering way when involving them in research. They should aim to share as much power as possible and enable disabled people to remain in control.

• **Value of disabled people's involvement in research:** In general, disabled people are a minority group, discriminated against in society. They therefore experience oppression and disempowerment. This means that they have the expertise to understand large numbers of people within the minority group and to interpret to others what the key issues are for them, such as how they should be asked questions and how to analyse the results of research from a disabled people's perspective. Research can also be given more credibility by disabled people carrying out interviews. Research recipients may respond more honestly to such interviewers, rather than give the answers they think able-bodied people want.

Disabled people can also advise on the dissemination of research results. They may know how best to reach other groups of disabled people and the format needs of wider groups. They have often been excluded from the opportunity to learn and make use of research because traditional means of dissemination do not reach them.

• **Research controlled by disabled people:** A growing amount of research, particularly in social care, is being commissioned, carried out and published by disabled people who see its role as to enable them to press for society to remove barriers. Such research is often referred to as 'grey literature' not fully accepted as valid by those traditionally responsible for research.

The gap between this kind of research and traditional methods of research may well be met by the growth of collaborative research.

Examples of consumer involvement

The East Loan leavers questionnaire

The East Loan leavers questionnaire is a partnership initiative between East Loan, Psychology, Clinical Governance and Northumberland User Voice which looks at client satisfaction in an In-Patient Rehabilitation Unit. It set out to break down some of the barriers and myths in involving service users in evaluating services.

The development of the partnership and subsequently the involvement of service users in the designing of the questionnaire and interviewing of those leaving the East Loan Unit is covered in a report published in June 2000 - '*Partnership Can Be More Than a Word*' by Sandra Hutton and Michael Lavelle of Northumberland User Voice.

The report describes some of the complications and challenges of this development work, what it meant to be working in partnership, and how eventually it led to a formal Service Agreement between the East Loan Rehabilitation Services (Northumberland Mental Health (NHS) Trust) and Northumberland User Voice to provide a consultancy service about leavers satisfaction with the Rehabilitation service. This agreement, which continues to work, includes Northumberland User Voice interviewing up to 10 leavers per year and training and paying user interviewers to carry out the work.

For further information, please contact:

*Sandra Hutton, Project Worker, Northumberland User Voice,
St Georges Hospital, Morpeth, Northumberland, NE61 2NU.*

Telephone: 01670 512121 ext. 3694, 3655, or 3698.

Website: <http://uservoice.tripod.com>



Warwick Diabetes Care User Group

On July 4th 2001, the warmest evening of the summer to date, with Tim Henman in the middle of his quarter-finals at Wimbledon, Warwick Diabetes Care (WDC) held its first meeting for local people living with diabetes. Over 35 members of the public attended this event which had attracted both local radio and newspaper attention.

WDC has been keen to engage with users to ensure that the educational programmes and research activity are relevant to people who are living with diabetes. User involvement is an NHS priority and is being actively promoted by the West Midlands NHS R&D office and by charities who fund health related research.

The evening began with a post-it note exercise where people were asked to write down their own ideas about what diabetes research needs to be carried out. 26 research questions came out of this exercise, which a small workshop group later arranged into themes. Example of the research priorities for this user group were:

- variations in care
- medication and daily life
- continuity of care.

The chair of a local Diabetes UK group was asked to present some of her ideas about why she wanted to be involved with this initiative. She told us what her questions and concerns were and participants were then asked to talk to someone they did not know and answer some of these questions in relation to themselves.

Dr Hilary Hearnshaw and Professor Jeremy Dale each gave a short presentation about WDC, its role and its current research. Some questions from the floor raised issues relating to use of terminology by health professionals, for example when we talk about type 1 or type 2 diabetes, is it not more relevant to people living with diabetes to have it referred to as

Insulin dependant or non-Insulin dependant irrespective of the type?

Participants chose one of four workshops for the remainder of the evening, covering:

- the development of a job description for user involvement
- receiving training
- the role of users in the delivery of diabetes educational programmes
- patient information leaflets for studies in development (this offered an experience of the real work that continued participation in the WDC user group would bring).

At the close of the evening, participants were asked to consider whether they would like to continue their association with the user group. They were asked to indicate the nature of their interest from a list including:

- receiving a newsletter
- engaging by post/telephone
- forming a committee to discuss current research proposals
- work with WDC to identify research priorities

26 forms were received, most indicating a desire for active involvement in one or more ways. The evening was felt to have been a great success. Everyone worked hard, both user and WDC participants, to begin developing relationships with each other based upon trust and sincerity.

As Professor Dale pointed out, the stakes are high when engaging in this type of initiative. The WDC research and education team exposed their work to the very people they could least afford to disappoint. The rewards were manifold on this occasion and the user group views have already resulted in changes to three research proposals being submitted for funding or ethical approval.

We are presently putting together our first newsletter to distribute widely. We believe this is the beginning of the process and wish to be an inclusive organisation to those who feel they have the time and interest to work with us. We will be engaging formally with participants in their preferred way early in the autumn.

- by Jackie Sturt,
Researcher and Co-ordinator, Warwick Diabetes Care.

For more information, you can contact Jackie at WDC at the Centre for Primary Health Care Studies, University of Warwick, Coventry CV4 7AL

E-mail: mesbs@dredd.csv.warwick.ac.uk

NOTICE BOARD

Folk.us

The Forum for Collaboration with Users in Research (Folk.us) are a group of consumers and researchers in the South West who meet regularly in Exeter, publish a newsletter, and run a training programme. They recently welcomed Rachael Purtell as their new programme co-ordinator.

The group has produced an annual report which reviews the last year and describes some important targets for the year ending April 2002. These include: reviewing the strategic aims of Folk.us, developing the group's work, supporting the development of collaborative research involving users, forming links with national and regional organisations, promoting mutual learning, and disseminating the group's outputs.

The group has also recently produced a leaflet called '*Understanding Users as Trainers: Users Voices*' compiled by Sylvia Downs. Mainly by and for service users, this leaflet will be followed up in due course with one aimed at service providers. Both the annual report and the leaflet are available from Katherine Gomme, Folk.us administrator, telephone 01392 264660.

Research Governance and Consumer Involvement

As many readers will be aware, the new *Research Governance Framework* from the Department of Health includes a statement about the importance of having consumer involvement in research. The research governance assessment form, which local NHS Trusts use to monitor their progress in research governance, includes at least two questions relating to consumer involvement in research being commissioned or carried out locally.

Congratulations!

The Alzheimer's Society have won the '*Best Healthcare Medical Research Charity*' award in the Charity Awards 2001, partly because of their pioneering work on consumer involvement.

For details, please contact Julia Cream on 0207 306 0606.

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.

Strategies for Living Phase 2

The Mental Health Foundation (MHF) is running a lottery-funded project called '*Strategies for Living*' which aims to document and disseminate people's ways of coping with mental distress. Recently they have been seeking people with experience of mental distress or users of mental health services to undertake research projects to investigate the strategies people use to cope with mental distress, and to develop accessible information for users/survivors. The researcher(s) will be supported by a worker from MHF who can provide training and practical and emotional support relating to the research. Grants will cover researchers' expenses. *For more information, contact Sarah Wright on 020 7535 7431.*

Cancer Research Open Day

The Academic Palliative Medicine Unit of the University of Sheffield will be hosting a Cancer Research Open Day on Wednesday 21st November 2001. The event, which will be free to patients and carers, will be an opportunity to hear about and understand some of the latest research, meet other patients, carers, researchers and medical staff, and to have your say and perhaps influence future research. Spaces are limited, so early booking is advised. Contact: Tony Stevens or Elizabeth Pinney on 0114 271 1707/1706. Fax: 0114 271 3991, or Email: t.stevens@sheffield.ac.uk.

Cochrane 'Hot Topic'

The Cochrane Consumer Network have a new information product - the *Cochrane Consumer Hot Topic* on their website at www.cochraneconsumer.com

They need people who would like to be in the pool of people they can ask to comment on drafts. There is usually at least two weeks to do this, and they then circulate back to you all the comments everyone has made. You would get a copy of the final version which would include an acknowledgement of your help. This would be an e-mail exercise.

If you're willing to be called on from time to time, let them know. If there are particular areas that you are interested in, or you are only interested in some areas, let them know that too. Contact Hilda Bastian, Convenor of the Cochrane Consumer Network, on e-mail: Hilda.bastian@cochraneconsumer.com

Ceres Leaflet

Consumers for Ethics in Research (CERES) have produced a new leaflet - '*Genetic Research and You*'. Genetic research undertaken by the NHS on patients is rapidly expanding, so anyone might be invited to be involved in genetic research

trials. The leaflet is designed to help individuals decide whether or not they want to be involved by giving information on what it is all about, and on the implications for families and individuals.

Single leaflets can be obtained free from: CERES, PO Box 1365, London, N16 0BW. Packs of leaflets are also available at £5 for 10 copies; £15 for 50 copies; and £25 for 100 copies.

**Copy deadline for next issue -
21st of September 2001**

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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