

CONSUMERS IN NHS RESEARCH SUPPORT UNIT

NEWS

Summer 2002

Welcome to the summer edition of the newsletter, which continues to encourage the sharing of experiences and information about consumer involvement in research. This edition contains more examples of research projects that actively involve consumers, as well as details of a good practice guide to user involvement in Best Value Reviews. And we are sending some inserts with this newsletter for your summer reading, although this is not our normal practice.

Arrangements are well underway for our conference in November - we've been delighted by the level of enthusiasm and the number of contributions received. Hope to see you there!



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This newsletter is also available on tape. If you would like a taped version, please let us know.

New consumer group for palliative care research

Marie Curie's Palliative Care Research and Development Unit has set up a consumer group along with the Royal Free Hospital, London, and the Cancer Research UK Targeting Group. Most consumer members of the group are either cancer patients or their carers. Other members include representatives from a self-help group, a cancer support trust and a lay person with no cancer experience. Professional representatives on the group help and advise other members. The new group aims to add a consumer perspective to the development and implementation of clinical research. It advises the two departments on the best ways of involving patients and carers in research - including palliative care research and clinical trials of drugs and cancer treatments.

The group is consulted on the topics researchers plan to investigate and advises on their significance to patients and carers. Members also help draw up plans for how the research will be carried out. Consumers on the group will also advise on the design of leaflets for cancer patients explaining about medical research. The researchers hope that the results will be more user friendly and will help recruit more patients. The researchers also hope that the involvement of consumers in the total research process will enable research results to be disseminated more widely and increase the opportunity for care to be based on the latest research evidence.

For further information please contact: Margaret Goodman, Marie Curie Palliative Care R&D Unit, Royal Free Campus, Rowland Mill Street, London NW3 2PF
Telephone: 020 7435 3893
E-mail: m.goodman@rfc.ucl.ac.uk

Support Unit News

Consumer involvement in public health research

The 'Consumer involvement in public health research' seminar - held in London on 21st May 2002 at the Institute of Public Health - was a great success. In the morning, Don Nutbeam, Head of Public Health Division, Department of Health, spoke on the evidence base and consumer involvement and a commissioner, a researcher and consumers all gave their different perspectives of consumer involvement in public health.

Afternoon workshop presentations focused on projects that had involved consumers, with presentations from both the consumers and researchers involved. The discussions covered lessons learnt and how the learning could be applied to other research in public health. Workshop presentations were heard on the following projects:

- Survey of health and pesticide exposure (SHAPE Study): seeking the evidence
- Involving people in public health research: consumers or producers?
- Working together - the Watcombe Housing Project
- Developing substance misuse services - a peer led drugs research project

The seminar was oversubscribed and we were unfortunately unable to accommodate everybody who wanted to attend. A short report of the seminar will be produced. If you would like a copy please contact Helen Hayes at the Support Unit.

New Staff for the Support Unit

The Support Unit is looking forward to welcoming three new members of staff, we are in the process of recruiting a part time office co-ordinator assistant to support Barbara, a part time research programme co-ordinator and a full time liaison worker. Details of the appointments will follow in our next newsletter.

'Making a Difference' Our third national conference

Booking forms for our conference - on November 7th 2002 at Harrogate International Conference Centre - should be available from the end of July.

The conference is for anyone with an interest in consumer involvement in health, social care and/or public health research. Whether you are:

- a service user
- a carer
- a member of a voluntary organisation
- an interested member of the public
- a researcher
- a research commissioner
- a research manager
- a practitioner
- someone involved in community development
- or any combination of these...

this conference is for you!

The conference will look at how consumers can be and have been involved at different stages of the research process. In particular we hope to look at the impact consumers have had on the research as well as how it has changed the people who have been involved.

If you are on our mailing list, you will automatically be sent a booking form. For additional booking forms or further information please contact:

Professional Briefings, 120 Wilton Road,
London SW1V 1JZ

Telephone: 020 7233 8322

Fax: 020 7233 7779

Email: london@profbriefings.co.uk

Deadline for contributions for our next newsletter is September 30th 2002

We welcome contributions about any aspect of consumer involvement in health and social care research. Articles can be any length between 50 and 600 words. If you have any questions about submitting an article, please get in touch with Roger Steel at the Support Unit.

Research into training for consumer involvement in research

We mentioned this project, which has been commissioned by the Empowerment Sub-group of *Consumers in NHS Research*, in the last newsletter. We are pleased to announce that the research will be carried out in collaboration between John Sitzia at Worthing and Southlands NHS Trust in Sussex, the CAPITAL Project Trust (Clients and Professionals in Training and Learning) and the Centre for Nursing and Midwifery Research, University of Brighton.

The capacity building phase of the research project began on 1st July, and the research itself will begin on or by 1st October. Rachael Lockey, one of the research partners is leading on the capacity building phase. The research will scope and evaluate existing training for consumer involvement in research across the country.

We hope this will lead to some clear recommendations on effective training for consumer involvement in research, particularly from the consumer perspective. For more information contact Rachael on 01903 284193 or e-mail her at Rachael.Lockey@wash.nhs.uk

Plans for a Young People in Research seminar

In collaboration with the Social Policy Research Unit (SPRU) in York, *Consumers in NHS Research* are planning a seminar on 'Young people's involvement in research' later this year. SPRU will be asking young people what they think should be discussed at the event and how it should be managed.



A good practice guide to user involvement in Best Value Reviews

In May, the Wiltshire and Swindon Users' Network launched their good practice guide to user involvement: *Users' Best Value*. This was published as a result of a user-led Best Value Review of 'Direct Payments' in Wiltshire, funded by the Joseph Rowntree Foundation.

All Best Value Reviews undertaken by local authorities are expected to consult with users of the services which are under review. In this groundbreaking piece of work, however, a project group of disabled people took a central role, both designing and undertaking the research based on the Best Value 4C's framework of challenge; compare; compete and consult. This involved survey work, user led interviews, diary work, cost analysis and literature reviews. The work was undertaken in collaboration with the University of Bath Research and Development Partnership, and had the full support of senior social services management at Wiltshire County Council.

'Direct Payments' is a scheme whereby local authorities hand over funds to disabled people to purchase services and equipment of their own choice. This is the alternative to services being 'prescribed' by social services departments where disabled people have little control. The findings of the Best Value Review showed that there was more work to do to ensure that care managers are knowledgeable and confident enough to inform service users about their choice about whether or not to have 'Direct Payments' - and to ensure that there are appropriate support and financial mechanisms for those who do choose them.

The experience gained in this innovative, user-led review has been used to produce the publication '*Users' Best Value: A guide to user involvement good practice in Best Value Reviews*' by Clare Evans, Angie Carmichael, and members of the Direct Payments Best Value Project Group of Wiltshire and Swindon User's Network.

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This should be an important guide for local authorities wishing to work alongside service users on Best Value, and it also contains information and guidance which could be helpful to any organisation wishing to work with service users as partners in service development.

For more information contact Clare Evans, c/o DPBVR, Wiltshire and Swindon Users Network, 7 Prince Maurice Court, Hamilton Avenue, Devizes, Wiltshire SN10 2RT. Telephone: 01249 815170. E-mail: clareevansuser@yahoo.co.uk.

The findings of the review are published on the Joseph Rowntree Foundation website: www.jrf.org.uk
A covering note of explanation and the executive summary report of the Direct Payments Review presented to Wiltshire County Council can be downloaded at: www.wiltshire.gov.uk/performance/html/best_value_reports.html

The full report, *User's Best Value: A guide to good practice in user involvement in Best Value Reviews* by Clare Evans and Angie Carmichael (ISBN 1 84263 075 X) is available from York Publishing Services Ltd at £13.95 plus £2.00 p&p per order. Contact: YPS Ltd, 64 Hallfield Road, Layerthorpe, York YO31 7ZQ. Telephone: 01904 430033 E-mail: orders@yps.ymn.co.uk.

A research advisory group for South Asian women with diabetes who do not speak English

By Penny Rhodes, Andrew Nocon and Aliya Darr. This is a follow up to 'A user's advisory group in practice' an article on diabetes research in Bradford that appeared in the Autumn 2001 newsletter.

In addition to lay representation on the steering group for this project, we decided to set up a Service Users' Advisory Group. We were aware that many people from minority ethnic communities were not fluent in English and that language difficulties tended to be greater for women. Therefore, in addition to the ethnically mixed English-speaking group, we decided to establish a separate group for South Asian women. The meetings were conducted in Punjabi by an Asian facilitator. (Due to limited resources a decision was taken to include speakers of other languages in the interviews with service users, but not in the group).

The meetings were held in the local hospital: members commented that this venue helped to make them feel their views were valued. The women were offered lifts to and

from the meetings: this meant they did not have to walk into the room on their own and could chat with the facilitator and other women in the car. The provision of transport and offer of token payments of £20 for each attendance were important factors in ensuring initial acceptance and continued commitment. With participants' agreement, meetings were taped, partially transcribed and translated.

The benefits of the groups for the researchers included:

- helpful comments on research design and suggestions about recruitment of the interview sample, payment of interviewees, how to approach people, how to access 'hard to reach' groups, how to conduct interviews, and the content of interviews;
- access to a range of service users' views and experiences;
- potential publicity and the promotion of goodwill towards the project in the wider community;
- promotion of greater understanding of research within the wider community;
- practical help with the research, e.g. useful contacts and offers of help with interpreting and translation.

For the women who participated, membership of the group provided an opportunity to:

- share information about services and treatments;
- give each other advice;
- learn about the research process;
- offer and receive mutual support - which is particularly important for people living with a disease which can be both isolating and debilitating.

This last benefit was especially appreciated and, when the research ended, the women said they would like to continue meeting as a support group. This possibility is currently being explored with the local Health Promotion Team.

For more information, please contact Penny Rhodes by telephone on 01274 365904 or e-mail: penny.rhodes@bradfordhospitals.nhs.uk

A longer version of this article is available on the *Consumers in NHS Research* website.

Journey to Independence: doing research as self-advocates

By Natasha Snelham, Gordon McBride and Stacey Gramlich, with Brian Myers (Swindon People First), Val Williams and Ken Simons (Norah Fry Research Centre)

We are a team of three self-advocate researchers who worked for *Swindon People First* on a project about direct payments, in partnership with *Norah Fry Research Centre*. This article is about what research means to us, and how we did it.

What does research mean to us?

Research is about people and about power. You have to be really active to do research, and do lots of work to find things out. But that's good. People believe in research, and that's why they listen to us.

Research is about changing things from the norm. People's attitudes have been set for a long time, but our research can change things. It may be by creating new things, or proving something wrong.

Why should we be doing the research ourselves?

We want to do our own research because it's first-hand, and then we don't have to learn from second-hand research. It's first-hand because it's our own. Other research is clouded by the fact that it's done by professionals, it's from their point of view, and they're effectively only guessing how we feel. Also, other research is very hard for us to understand.

Researchers often try to include people with learning difficulties, but the real power lies with other people. People don't always believe that research can be done by self-advocates, but we have found our way of doing it, and it's worked for us.

Our way of doing research

In our research, we went to different parts of the country, to look at all the different ways people were supporting direct payments. Some people may think that people with learning difficulties just sit there and do research about themselves, but we've also been out finding out what other people think. In all, we interviewed 88 people on our research visits!

When we first started doing research, we were all new to it. So we had to learn. That's why we had a researcher and a supporter to help us. Our research supporter is now going to write a bit about the way we did research together.

Supporting self-advocates to do research

Being a research supporter is different from being a researcher. It is both challenging and rewarding, and I was continually learning about my own role as I helped them to work out theirs. During the first part of the project, I felt I was very much the planner and occasionally the tutor. Although I wanted the team to have power as researchers, people did need to learn skills for research, and I was there to make sure this happened. One of the things we tried was a short course about research, when we made videos of each other doing interviewing. We also had to learn about the subject we were researching: direct payments - a big part of my job throughout has been to help make things easier for them to understand. As my colleagues say,

'We soon found out that direct payments can mean freedom and control for people just like us. That is why it is so important!'

The best way of learning how to do research is to get out there and do it. For instance, getting consent from people was hard, as we felt that other people were answering for them. So we had to find other ways to make sure we could tell people first about the project, and then let them decide whether to talk with us or not. These are the sort of problems that lots of researchers have, and it was no different for this team. Instead of deciding on all these issues myself, I made sure that we shared all the decisions and dilemmas.

Handing over and sharing the decisions meant that the team members were soon involved in planning for themselves. For instance, they phoned up to fix up research visits, they planned their own interview questions, and they did all the interviews themselves. All this needed support, but the most important thing they had to learn was that this was their project, and that their own identity as self-advocates was important. My task was to support them in taking control, without taking over their agenda.

What came out of our research?

At the end of our project, we were all determined that the self-advocates should be fully involved in analysing their data. The whole

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purpose of the research was that it was their point of view.

This stage was hard work, but it was worth it. We tried out many different ways of analysing together, including picture charts and stories. I helped them go through the data, but it was the self-advocate researchers who said what they thought was important in it. Having your own voice in a report does not mean doing it all yourself. Self-advocate researchers can learn the skills to work together, and to be in control of their own support. They have since given their messages in conferences and presentations all over the country, and our final report (and an information pack for people with learning difficulties) will be published by BILD (British Institute of Learning Disabilities) this autumn.

A final message from the team

People First and self-advocacy groups all over the country are getting involved in projects like this now, and we would like to have more chances to share with them what we have learnt. People who fund research, as well as other researchers, need to listen to us too. We hope there is a



future for self-advocates to do more work like this, and to help to change things for others as well as for themselves.

Journey to Independence (report and information pack) to be published by BILD, 2002.

For more information, please contact:

Val Williams, Norah Fry Centre, 3 Priory Road, Bristol BS8 1TX Telephone: 0117 923 8137 E-mail: val.williams@bristol.ac.uk

A qualitative study to explore positive and negative aspects of long-term care settings as experienced by residents with dementia, their family and statutory carers

The Alzheimer's Society Quality Research in Dementia (QRD) Consumer Network programme has now won two major awards for its pioneering work in coming up with a truly successful model of consumer involvement in research. Its 140-strong UK-wide network of carers and users are involved in every stage of the research process from strategy setting, commissioning, grant application review, grant awards, project monitoring, and are now working on effective ways to promote dissemination and implementation of research findings.

I am a member of that network and privileged to be the first carer to be awarded a Research Grant by the Alzheimer's Society. The study originates from my personal experiences of caring for my husband who developed Alzheimer's some 15 years ago when in his 'fifties and our

three children then in their 'teens. He is now in long-term care but this has not offered the relief I had been lead to believe it would and for a variety of reasons the situation has proved extremely stressful.

With the help of a consultant psychiatrist and two researchers in the Dept. of Psychiatry & Behavioural Sciences at University College London, the project is nearing the writing-up stage. A paper will be sent to one of the leading journals on ageing and mental health for peer review.

Aware of the complex nature of the triangular relationship between residents, relatives and staff and the potential for conflict between parties, this study aims to explore differences in the experiences of the three groups and to identify contributory factors affecting positive or negative outcomes. We hope to make new information available on the factors which promote or hinder positive partnerships between parties and to make recommendations on what seems to promote good relationships and quality of life.

Apart from being involved in writing the protocol and planning and managing the research, I did several of the 68 interviews, analysed the research by hand, and attempted to help (not very successfully!) with entering data on NUD*ist software, which is specially designed for analysing qualitative data. Interim results have been disseminated at conferences and recently I gave a presentation and workshops at The Journal of Dementia Care conference in London.

There has been extensive input from members of the QRD consumer network who reviewed the initial application and made suggestions. Long-term care is a very emotive subject for carers and good care for people with dementia is in short supply. Three consumers were on the awards panel and two members are on the steering committee and have advised on protocol and the interview guide and offered ideas for dissemination of results.

The experience of leading a project based on a subject on which I have personal experience every day of my life at

present, has proved fascinating. I have not been surprised by some of the negative comments that came up during interviews, although the researchers working with me have been very surprised and sometimes shocked.

The input from the QRD consumers network has been invaluable and I hope the recommendations we make could lead to changes which in some small way could help to alleviate the stress of those carers who will face placing their loved-ones in long-term care in the future.

- Shirley Nurock

*For more information please contact:
Alzheimers Society, Gordon House, 10 Greencoat
Place, London SW1P 1PH
Telephone: 0207 306 0606
E-mail enquiries@alzheimers.org.uk*

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.

Valuing People? Improving Services for People with Learning Disabilities

The University of Birmingham's Health Services Management Centre is running a four-seminar programme focusing on specific aspects of learning disability services. With contributions from service users, practitioners, policy makers and researchers, the seminar series aims to support managers from health and social care seeking to improve learning disability services.

The first seminar on 30th October is: 'Nothing about us without us? User involvement and people with learning disabilities.' For further information on this seminar and the other three in the series, which are all to be held in November 2002, please see the leaflet enclosed with this newsletter or contact Jon Glasby on e-mail j.glasby@bham.ac.uk or telephone 0121 414 7050.

'Try it Our Way'

The Leonard Cheshire Disabled People's Forum are offering user participation and empowerment learning opportunities based on the experience of their work to implement user-led user involvement in organisations. They offer seminars, training, individual consultancy and mentoring, and a Briefing Pack.

For more information, contact Clare Evans, Forum Manager, Leonard Cheshire Disabled People's Forum, St George's, Semington, Trowbridge, Wiltshire BA14 6JQ Telephone: 01380 870777 E-mail: c.evans@forum.leonard-cheshire.org.uk

Catch Up on Cancer Research - Consumer's Open Day

The 4th annual Cancer Research conference of the Academic Palliative Medicine Unit of University of Sheffield will aim to increase awareness and the participation of consumers in cancer research. Entitled 'Catch Up on Cancer Research - Consumer's Open Day' this year's conference will be held at Stephenson Hall, Sheffield on Wednesday 27 November 2002. The event will be free to consumers, and there will be a limited number of places for fee-paying professionals. The conference will be co-chaired by Professor Sam H Ahmedzai from the Academic Palliative Medicine Unit who chairs the North Trent Cancer Network Consumer Research Panel. There will be four main themes:

- Advances in Surgery (incorporating the surgeons, nursing and patient perspectives)
- The Provision of Lymphoedema Services
- Audiotaping of Consultations
- Local and National Funding for Cancer Research.

For further information and an application pack please ring the Academic Palliative Medicine Unit on 0114 271 1707 or 0114 271 1706 or Trent Palliative Care Centre on 0114 262 0174.

Notice board

Measuring Success with the Multiple Sclerosis (MS) Society

The Measuring Success Awards were introduced in 1998 to reward those services which achieved the standards of healthcare developed by the MS Society and National Hospital for Neurology. Services were required to audit themselves against standards and then were visited by two assessors. Assessors were either people with MS or carers, trained by the MS Society to carry out the interviews. The Measuring Success Awards have recently been relaunched, together with a booklet and workbook 'Developing MS Healthcare Standards' for assessors and healthcare professionals. This publication, to which users of MS services contributed includes guidelines on involving people affected by MS in service quality improvement activities. For more information contact Barbara Poole, MS Society, 372 Edgware Road, London, NW2 6ND Telephone: 020 8438 0700 E-mail: info@mssociety.org.uk

BUPA Foundation funding

The Foundation wishes to advance thinking and practice in innovative and critical projects which address consumer (patient) involvement in healthcare, particularly where that involvement ensures better outcomes with available resources. Funding of up to £500,000 is available for one or more projects over one, two or three years. The closing date for applications is 6 September 2002. More details can be found on the internet at <http://www.rdinfo.org.uk> or <http://www.bupafoundation.com/html/funding/applying.html>

Successful user involvement - examples wanted

Do you know of an example of service users or user groups that successfully contributed to changes in the organisation of healthcare? The NHS SDO Programme has funded a research project to draw together examples of initiatives that have worked well in order to assist others involved in the development of new initiatives aimed at promoting user involvement. If you have details of reports or other information that has been written up please contact Deborah Rutter on 0207 886 6609 or send an e-mail to deborah.rutter@ic.ac.uk. They will pay for postage or other expenses involved in sending them copies of the reports.

An interesting journal article

Consumer Involvement in Health Research: Fact or Fiction? by R. Telford, C.A. Beverley, C.L.Cooper and J.D. Boote. British Journal of Clinical Governance, Vol.7 No.2, 2002.

ABOUT THE SUPPORT UNIT...

The *Consumers in NHS Research Support Unit* is based in Eastleigh near Southampton. Our role is to:

- Provide information, advice and support to consumers, researchers and those working in the NHS on consumer involvement in health and social care research
- Commission and undertake research about the involvement of consumers in health and social care research
- Produce publications and reports
- Organise seminars, conferences and work shops on consumer involvement in health and social care 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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