

CONSUMERS IN NHS RESEARCH SUPPORT UNIT

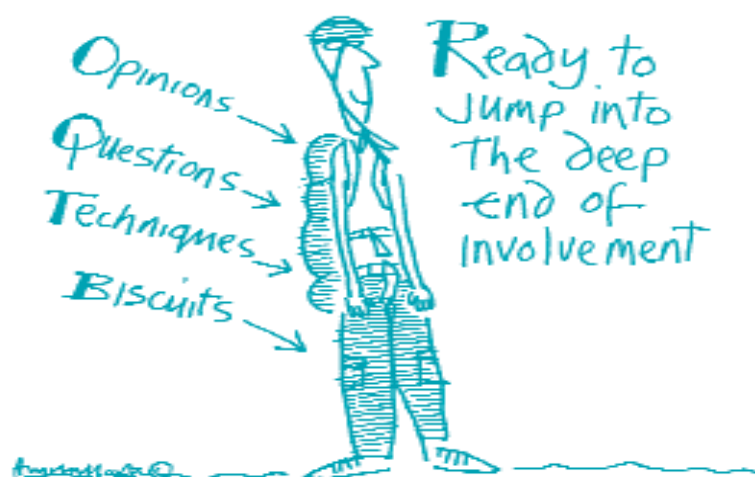
NEWS

Winter 2002/2003

Welcome to the winter edition of our newsletter. You'll find a training theme running through the articles and examples in this edition.

Our national conference in November demonstrated just how valuable it is to be able to network with people who have been working hard on a wide range of innovative projects involving, or being led by, consumers in a number of different ways. Our newsletter is one way to continue this exchange of ideas, so please keep sending in examples and experiences.

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



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Consumer involvement database now on website!

We are delighted to announce that a public version of our database of research projects in health and social care that actively involve consumers is now available on our website www.conres.co.uk

The project details have all been written by the individual researchers and the projects use a variety of research methods with different levels and stages of consumer involvement. The researchers have included their contact details for those wanting further information about their project.

The database currently holds 150 examples of projects that have actively involved consumers and we would like to develop and build on this in the forthcoming months. If you have been involved in any projects that have or plan to actively involve consumers then we would like to hear from you. Please contact Helen Hayes at the Support Unit by e-mail at hhayes@conres.co.uk or complete a questionnaire on the database section of our website.

To access the database, enter www.conres.co.uk and click on the database button. The database can search for projects in four ways:

- 1) By *browsing* through all the projects
- 2) By *keyword*
- 3) By *stage of consumer involvement*
e.g. prioritising topic area or undertaking the research
- 4) By *freetext*

If you would like any further information or assistance in searching the database please contact Helen Hayes at the Support Unit on hhayes@conres.co.uk

Support Unit News

Consumer involvement in public health research seminar 21st May 2002

The report summarising the presentations and discussions which took place at the public health seminar, held last May, is now available from the Support Unit.

The report includes different perspectives of consumer involvement in public health research, describing projects from the commissioner's, the researcher's and the consumer's perspective. The presentations summarised are from projects involving consumers in research into pesticide exposure, housing, public health research, and developing substance misuse services. The presenters discuss what they would do differently next time in relation to consumer involvement and how the lessons learnt from their research can be applied to other research in public health.

If you would like a copy of the report and have not already given your details to the Support Unit please contact Helen Hayes hhayes@conres.co.uk

Third national conference

Thank you to all of those who attended and participated in our conference "Making a Difference" on 7 November 2002. Your time, commitment and enthusiasm helped to make the day a success. 420 delegates, consumers, researchers and health and social care professionals attended the day in Harrogate, creating a vibrant atmosphere for networking and discussing consumer involvement in research.

A choice of thirteen morning and thirteen afternoon workshops covered involvement in the different stages of the research process and research around issues affecting different groups of people e.g. people affected by cancer, dementia, parents and older people. Discussion groups considered how representative consumers should be and if it mattered, as well as ethics and consumer involvement, cultural diversity and inclusion in research and 'hearing the unheard.'

If you were unable to attend the conference and would like a copy of the conference programme and abstracts we have a few spare copies (please contact Helen Hayes at the Support Unit on hhayes@conres.co.uk). There will be a postage and photocopying charge of £10 per copy.

A conference report will be published and we will provide details of this in the Spring newsletter.

Evaluation of consumer involvement in the London Primary Care Studies programme

The Support Unit will shortly be commissioning an evaluation of consumer involvement in the London Primary Care Studies programme. This programme consists of 11 primary care research projects funded by the former London regional office, in which active consumer involvement was a condition of funding. These research projects are very varied, and include, for example, a study promoting testicular self-examination and awareness amongst young men with learning disabilities, and a project looking at whether a lay-led self management programme for chronic illness can improve the health of Bengalis. As part of the research programme, money was set aside to provide training and support to the consumers and researchers on the projects.

The proposed evaluation will consist of two parts: 1) evaluation of the impact of the training programme on consumer involvement in the 11 primary care research projects, and 2) evaluation of the impact of consumer involvement on the quality of those 11 primary care projects.

The Support Unit will shortly be advertising to invite tenders for the proposed evaluation. We intend to advertise in the national press and will also be circulating the invitation to tender to all those on our mailing list. If you are not on our mailing list and wish to be sent further details at the time of the advert, please contact Fran Christopher at the Unit on 023 8062 6231 or fchristopher@conres.co.uk

Ethics in social care research consultation workshop

In November, at the request of the Department of Health, the Support Unit facilitated a workshop to enable social care service users and carers to feed in to the development of a Research Governance Framework for Social Care. Although this consultation was considered by participants to have come very late in the process, it was nevertheless a lively day from

which emerged some clear themes and issues which have been taken forward to the Research Governance working group in the Department of Health. We hope to make a report on the day generally available in the near future.

Social care follow-up workshop

In the autumn of 2001 we held a social care workshop facilitated by Shaping Our Lives, a user controlled organisation, in order that *Consumers in NHS Research* could be advised by expert service users on how best to include the views and wishes of service users in the work of the group. A report was produced and one of the recommendations was for a follow-up workshop. Participants will be meeting again in February to review what has happened so far and give further advice. A report will be written, and we hope to be able to report back on the workshop in the Spring newsletter.

Research Programmes Liaison Manager

My name is Jane Royle. I am the Support Unit's Research Programmes Liaison Manager. This is a new half-time post and I joined the Support Unit team on the 1st of December 2002. For the last 4 years I have worked as the Consumer Liaison Manager for the NHS R&D Health Technology Assessment Programme. My new role will focus on promoting and supporting consumer involvement in the commissioning of research funded by the NHS R&D National Programmes and the Department of Health Policy Research Programme. I can be contacted by e-mail at Jroyle@conres.co.uk or by phone on 023 8065 1088.

Would you be interested in becoming a member of our Readers Panel ?

Consumers in NHS Research is beginning to work towards making sure that its new publications are more accessible and readable. To help us do this we need to bring together a small "Readers Panel" to work with us to make sure we get our message across in a clear format, using appropriate language.

Members of the panel will receive a small payment for each publication read and all expenses will be met. Panel members can choose to read as many or as few publications as they wish. The work can be done from home and will take no more than a few hours each month.

We are in the early stages of what should be an interesting and rewarding piece of work which we hope will make a real difference. If you would like to know more please contact Paul Jones on 023 8062 6234 or at pjones@conres.co.uk

TRUE = Training in Research for service users: Evaluation. We are coming to the end of the first 5 months of this project, funded by *Consumers in NHS Research* and being undertaken jointly by The CAPITAL Project, University of Brighton, and Worthing Hospital (see Summer and Autumn Newsletter 2002). The involvement of team members has gone from strength to strength, with seven service-users/researchers actively involved in the project, one research supporter and three project managers.

We are still collecting information about training available nationally and designed to facilitate service user involvement. Tina, Rachael and Jan have all been doing telephone interviews with providers of training. We will shortly begin analysing all the data collected. In January 2003 we will have our first 'data analysis day' where the whole TRUE Project team will begin the data analysis process. There will be six case sites undertaken during the project and we have done the first of these.

Because we are a large team we have found it extremely helpful to meet regularly for check-ins to see how each other are getting on. It also provides a useful space to try out new skills such as chairing meetings and doing presentations, and has helped us to develop as a team and offer each other support.

- Rachael Lockey, Research Co-ordinator
Telephone: 01903 205111 ext 4193
E-mail: Rachael.Lockey@wash.nhs.uk

"The TRUE Project has brought a lot of meaning to me. It has empowered me to work well alongside a team. I have met some really nice people. I have learnt a lot of new skills including how to work with others. I've travelled a lot more than I have done in my life so far."

- Tina, service-user/researcher

"The interviews I have conducted have been interesting and sometimes very enlightening. The essence of these are input into an EXCEL spreadsheet and we also write a short summary of the interview."

- Jan, service-user/researcher

Planning and designing an evaluation of an electroconvulsive therapy (ECT) service

By Virginia Minogue, Una Parker

In July 2001, an evaluation of service users' perspectives of the ECT service at Fieldhead Hospital, Wakefield, was commissioned. This would involve interviewing patients some time after they had completed a course of ECT. The focus of the evaluation was on the quality of the service and was not intended to replicate other research by asking for people's views on ECT treatment.

The following is an account of some of the issues that arose during this period and is written from the perspective of the Research and Development Manager and a member of the Project Board and Project Team who is also a former service user.

Setting up the Project

Representatives of the Service User Forum were involved on the Project Board from the outset. However, the Board were initially uncertain whether service user representatives should be involved in the Project Team who would carry out the interviews. It was felt that ECT was an emotive subject and the possibility of introducing bias into the study would be increased. The issue was revisited and a decision taken to interview in pairs, with one half of the pair being a research assistant and the other a service user representative. The service user representatives were volunteers and were recruited from the Service User Forum and the Trust service user and carer research group, Direct Impact.

Experience of research and interviewing varied within the group of seven interviewers. We held a series of 4 half-day events focusing on interviews and interviewing, including de-escalation training.

We found that training was an important stage in the team understanding and owning the project, in building confidence, building trust and confidence in colleagues, and gaining familiarity with the questionnaire. Other benefits were that participants learnt more about the design of interviews and interview skills.

An unanticipated advantage was that this pre-pilot test of the questionnaire revealed problems with format and layout that could be resolved before going 'live.' We were also able to develop some 'prompt cards' to help the interviewers and interviewees work through some of the more complex questions.

A Board and Team Member's Perspective

I have taken an active interest in issues to do with ECT since my own experience of the treatment in 1972, so when the Service User Forum was approached for two volunteers to join the Project Board I put my name forward.

Because of my own experience and knowledge of research into the effects of ECT, I regard it as a treatment which can be hazardous. Issues of information and consent are therefore very important, even vital. I wanted to see how the delivery of ECT could be improved. This proposed research looked as if it could bring about positive change, even though it was made very clear from the outset that the investigation was to be limited to issues of information about ECT treatment and attitudes of staff, and would not consider patient perception of its effectiveness.

I felt that service users should be actively involved in the research and surprised myself by being assertive about this when opinion on the Board was rather against it. The group worked on the draft questionnaire for a structured interview, with what seemed like endless revision of the questions, but doing this was particularly relevant for the two service users.

The group also refined the patient information leaflet and consent form for the research. The consent process for people taking part in this project needs a complex three-stage process in order to keep patient details confidential. After considerable thought, because of my concern about compulsory treatment and doubts about truly informed consent, I decided I would volunteer as an interviewer.

The planned training session for the volunteer interviewers were enjoyable and allowed us to understand the different types of question and the structure of the questionnaire.

The project is now proceeding to the interview stage and we hope to provide a further report at the end of the study.

If you would like more information, please contact:

Dr Virginia Minogue on 01924 327431, or Una Parker c/o Direct Impact, The PALS Office, on 01924 328656.

PEER REVIEWING

By Tina Coldham

I was involved in reviewing the proposals put forward for a research project to be commissioned by *Consumers in NHS Research*. This is something I haven't done before and coming from a mental health user background and only recently an academic one, I didn't think that I would be up to the job. No problem, I received lots of encouragement and guidance from Roger Steel at the Support Unit and Jane Royle at Southampton University.

There were five proposals in all, and when the big envelope plopped through my letterbox, I did wonder what I had let myself in for. But undeterred I set about my task. I found it was best to flick through each proposal first to get an idea of what I was to look at. Then, I worked systematically through each proposal one at a time, leaving myself breathing space in between. This way I would approach each proposal with a fresh mind, and not get muddled up! I did this over the course of a week. The task was therefore quite time consuming, but when you consider you are having a say in someone's future employment, and the hopes of fruitful research, it's important to get it right.

Some of the research language was off-putting, but allowing myself time to think, I understood what was being said. It was good for me to use this as a learning opportunity. The first thing to look at was the Applicant and Project details to get an overall picture of what was to come. Then it was really interesting to read the CVs of the applicants. This gave me background to people's previous research efforts and a base to work from when deciding whether they would be able to do this piece of research. Next came some

ethical questions around the research, important in proving no tendering advantages or possible exploitation from the work. Gosh, I was feeling rather important at this stage!

The next thing to check was the breakdown of finances for their proposal - back down to earth again as this is not my strongest suit. But from my perspective as a user of services I felt it important to look for realistic contributions to include consumers in the process.

Then to the nitty-gritty - reading through the detailed project description. I was interested to see what justification and methods for these were being proposed for the research. But as a user researcher myself I was also keen to see how consumers can be involved throughout the whole process of managing and controlling the work, let alone doing some of the important leg work. I was also looking for an awareness of consumers' needs from being involved in research to being the subject of research (especially confidentiality here). It was helpful to place myself in those consumers' shoes when considering these points. I really do think good user involvement has a strong bearing on possible outcomes of this type of research.

Who did I go for? Well that would be telling, but the process felt really worthwhile and I received helpful feedback from Roger on my efforts. Have a go yourself - I learned a lot about research from doing this and felt the user view was valued in being asked to do this in the first place.

Interesting recent reports and journal articles

A service users' research advisory group from the perspectives of both service users and researchers

Rhodes, Penny, et al.

Health and Social Care in the Community 2002 10 (5): 402-409 (September 2002)

Systematic review of involving patients in the planning and development of health care

Crawford, Mike J., et al.

British Medical Journal 2002

325 (7375): 1263-1265 (30 November 2002)

Involving users in the delivery and evaluation of mental health services : systematic review

Simpson, Emma L. and House, Allan O.

British Medical Journal 2002

325 (7375): 1263-1268 (30 November 2002)

User control in a Best Value review of direct payments project : a case study

Evans, Clare

MCC: building knowledge for integrated care 2002

10 (5): 39-44 (October 2002)

Helping older people to share the research journey

By Mary Leamy, Vince Miller and Roger Clough (Lancaster University)

This article introduces a 3 year research study, due to end in January 2003, called “Housing Decisions in Old Age” (HDOA). It has been carried out by Lancaster University (Roger Clough, Mary Leamy, Vince Miller) and Counsel and Care, a registered charity which gives advice to older people (Les Bright, Liz Brooks).

As part of the research design, the research team developed a “Certificate in Social Research Methods” that was taught at undergraduate level to people aged 60 and above, over two academic terms. The original idea behind the development of a course stemmed from a desire to find a way of being able to relate to older people differently, as research colleagues rather than as advisors or research subjects.

The course was set up to provide older people with a grounding in social research interview methods, an awareness of research issues and full supervision to enable them to conduct nearly 200 in-depth interviews. Two courses - one in Lancaster and another in London - have now been successfully run by the Department of Continuing Education (DCE). As a result of adopting the DCE’s policy of open access, the students came from extremely diverse social, economic and educational backgrounds. To be considered for the course, they needed to supply two character references and complete an application form describing their relevant education, work or life experience and reasons for wanting to participate in the research.

The two course tutors (ML and VM) were academic researchers working within the department of Applied Social Science in Lancaster University. Funding for the course was built into the HDOA research bid to the Community Fund (previously known as the National Lotteries Charities Board). This enabled the research students to receive payment for their fieldwork and for their course fees to be heavily subsidised.

In the first term, students attended ten two-hour afternoon weekly sessions consisting of lectures on research methods and issues, workshops on practical interviewing skills and sessions on designing the HDOA interview guide. In the second term, students conducted up to ten in-depth interviews each and attended fortnightly group supervision sessions so they could receive both peer and tutor support and encouragement.

At the end of each module, they completed assessments in order to satisfy the criteria for receiving the certificate, which was formally validated and worth 30 credits. To ensure that all students were competent, sensitive interviewers, they were advised that they needed to successfully pass the module one assessments before they would be considered eligible to conduct HDOA interviews. Their assessments included:

Module one

- An interviewing skills audiotape where they interviewed a fellow student on their own housing decisions, using the interview guide
- A 1000 word assessment - lessons learnt on practical interviewing skills workshops

Module two

- Data analysis of two HDOA interviews
- A 2000 word assessment - lessons learnt during fieldwork



The students have been so enthused by their experiences of undertaking research interviews that they have set themselves up as a research consultancy to market their skills and have worked with our Research Director, Professor Roger Clough to put together research bids for further funding.

*For further information, please contact:
Dr Mary Leamy, Senior Research Associate,
Lancaster University
Home e-mail: Mary@mleamy.fsnet.co.uk*

SURESearch: Developing user expertise in research and education

SURESearch, a West Midlands mental health service user network, has been developing its contribution to mental health research and education for the past two years. SURESearch provides information support and skill development to service users involved in training and research in this field. Through its association with the Department of Social Policy and Social Work, The University of Birmingham, it also offers the potential for developing collaborative research and training with academics and mental health professionals, service providers and policy makers.

From the outset SURESearch members have been motivated by their concerns to work for the improvement of mental health services. Their use of services as well as their experiences in user and advocacy organisations have provided them with considerable expert knowledge about mental health. Forming SURESearch was seen as a way of using and developing training and research skills. The SURESearch network offers a resource for policy makers, practitioners and academics working in the mental health field. It also offers a way of ensuring quality and standards to those organisations who are seeking user led training and research.

SURESearch welcomes as members users and survivors of mental health services and their allies who have experience and/or an interest in mental health research and education. SURESearch is an independent organisation and is based in the Department of Social Policy and Social Work, The University of Birmingham.

The aims of SURESearch are to:

- Increase the involvement of mental health service users in research and education
- Provide opportunities for its members to work in partnership with each other to share and develop skills and knowledge
- Develop and provide programmes of education and training for its members
- Respond to, and take up opportunities for research, consultancy and education
- Influence the quality, ethics and values of mental health research and education
- Link with other local, regional and national partnerships in mental health

SURESearch meets bi-monthly and meetings are open to anyone with an interest in mental health research and education. People can attend as many meetings as they wish and new members are always welcome. The meetings provide an

opportunity to update on work in progress, share information and ideas, provide and gain support.

The portfolio of SUREsearch research projects includes work on the experience of compulsory admission; poverty, social exclusion and mental health; employment and mental health; mental health training needs; user experiences of mental health services and women and mental health. All of this work has been characterised by a collaborative, user-focussed approach. In addition members are involved in training initiatives with a wide range of professional and user organisations.

SURESearch members make regular presentations at local and national conference and training events on all aspects of their work. This year they were invited to address the AGM of the Royal College of Psychiatrists. Since SURESearch was established, a number of members have moved into employment, taking up opportunities in the research, training and advocacy fields.

The most recent commission that SURESearch has been offered combines expertise in research and training. The South Birmingham Mental Health Trust has asked the network to develop a user contribution to clinical governance in the Trust. This initiative, which will be collaboratively undertaken with The Department of Social Policy and Social Work, builds on research undertaken by SURESearch on users experiences of mental health services in the City of Birmingham.

*For more information, please contact Amanda Owen-Meehan, SURESearch Administrator, Department of Social Policy and Social Work, University of Birmingham, Birmingham B15 2TT
E-mail: A.OwenMeehan@bham.ac.uk
Tel: 0121 414 8089*

Deadline for contributions for our next newsletter: Friday 14th March

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

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.

Research in complementary and alternative medicine: user views

I am investigating the involvement of consumers in research into complementary and alternative medicine, in both NHS and private settings. I am doing a literature review, writing to organisations and groups, and talking to people with relevant experience. If anyone knows of any projects, large or small, or of any publications in this field I would be really grateful for information. My aim is to produce a report that will facilitate and encourage more user involvement in this type of research. Please contact:

Dr Charlotte Paterson, MRC Research Fellow, Dept of Social Medicine, Canynge Hall, Whiteladies Road, Bristol BS8 2PR
Tel: 0117 331 3901 E-mail: c.paterson@bristol.ac.uk

New guide

In order to set up successful user and carer involvement projects, there are a number of stages to consider. These include deciding on the main aim of the project, identifying potential hindrances and evaluating the project, so that user and carer involvement can be made effective. Researchers at the University of Leeds, have produced a guidebook, aimed primarily at service providers, which discusses the stages involved in developing and monitoring user and carer involvement projects. It is now available to download from: www.leeds.ac.uk/medicine/divisions/psychiatry/research/guidebook.htm

Alternatively, print copies can be ordered from Emma Simpson, Academic Unit of Psychiatry, University of Leeds, 15 Hyde Terrace, Leeds LS2 9LT or E-mail: medelsi@leeds.ac.uk

'Asking the Experts - A Guide to Involving People in Shaping Health and Social Care Services'

Produced by the Community Care Needs Assessment Project (CCNAP), a three year project in the Humber region which started in 1998, this guide looks at the context for 'involving' people and the thinking needed to develop practice that routinely involves service users, as well as others who may come to use services in the future. It considers the strengths and weaknesses of different approaches and includes examples from best practice, as well as research evidence of 'what works' where this is available. It covers practical approaches to involving people in shaping community care services.

Although this project is finished, the guide is still available on the CCNAP website: www.ccnap.org.uk

Reports and journal articles

If you have details of any articles or have published any research that might be of interest to readers of the newsletter, please let me know. I can be contacted in the Support Unit on telephone number 023 80 626235 or by e-mail at hhayes@conres.co.uk

- *Helen Hayes, Information Officer.*

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 workshops 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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Friendly disclaimer: The views expressed in this newsletter and in any enclosures are those of the authors and not necessarily those of The Standing Group on *Consumers in NHS Research*, the *Support Unit* or The Department of Health. Publication of research in this newsletter should not be taken as implicit support for the recommendations for policy. Articles are selected for the sole purpose of stimulating ideas and debate on consumer involvement in research.