

CONSUMERS IN NHS RESEARCH SUPPORT UNIT

NEWS

Spring 2003

Well, spring is here again and we have a collection of news items and articles for you which we hope you will find interesting. Consumer involvement in research is quickly becoming a widespread activity bringing with it innovation, improved research practice, and challenges too. Do write in and tell us about your experiences.



Announcing a new name... and a new look!

Consumers in NHS Research is about to change its name! In view of the widened remit of the group, which now includes involvement in public health and social care research outside the NHS, the group will be called:

INVOLVE

Promoting public involvement in NHS, public health and social care research

We think this will be much easier to use, and will help avoid the misconception that the group and its Support Unit are only concerned with NHS funded research. It will also enable us to drop the sometimes controversial 'consumer' label.

The next newsletter (Summer) will not only carry the new name, but will also look different! In our publications and talks we are increasingly encouraging researchers and commissioners to think about accessibility of information to the public, patients and service user groups, so we want

In this issue:

- 1 Announcing a new name...
- 2 Support Unit News
- 3 TRUE Project update
Recent reports and journal articles
- 4 The voices of older people
- 5 Older women in Sheffield
- 6 User involvement in cancer research
Parents as researchers
A development tool for user representation
- 7 Shaping Our Lives
Trent Institute for Health Services Research
- 8 Notice Board

to do more about practicing what we preach. At the same time, we want to keep the overall appearance attractive, and we will of course keep using Angela Martin's cartoons!

We also want to attract more articles which are relevant and readable for the broad audience we now have, so that involvement ideas and practice issues in research can be shared as widely as possible. We have therefore produced a two page A4 'Guide for Contributors' which can be sent to you on request, and will soon also be available on our website. So go on, have a go, and get that idea, issue or example into print!

Please contact Helen Hayes or Roger Steel at the Support Unit for more information.

**This newsletter is also available
on tape.**

**If you would like a taped version,
please let us know.**

Support Unit News

Social care workshop

In partnership with Shaping Our Lives National User Network, *Consumers in NHS Research* held a second social care workshop in London on 12th February. The aim was for *Consumers in NHS Research* to report back on progress with the recommendations from the first workshop and for users of social care services to advise us on what further could be done to incorporate the views of service users. There was some lively discussion on a range of issues and a full report written by the Support Unit and Shaping Our Lives will be available shortly.

Research Governance Framework (RGF) for social care consultation

We have already reported that we facilitated a consultation workshop with social care service users last November. A report on this is now available. It has been agreed to hold a follow up workshop later this year, which will be open to all service users who attended the first workshop. For information on Research Governance: Social Care, visit www.doh.gov.uk/reseach/rdl/researchgovernance/socialcare.htm

Definitions of user controlled research

Consumers in NHS Research is calling for expressions of interest in undertaking a small scoping exercise to understand definitions of user controlled research. The need for this work has been identified through discussions over recent months with users of health and social care services, and with user-researchers. A key issue raised in these discussions is that there is no single accepted definition of the term “user controlled research” and that this may be a factor in hampering the understanding and funding of such work.

We have decided to commission user-researchers or a service user controlled organisation to undertake this work. Up to £15,000 will be available. An application pack is available by post from the Support Unit - call 02380 651088 or e-mail admin@conres.co.uk.

‘Young People and Research’ workshop and guide

We have recently commissioned some work to produce a practical guide to involving young people in research. As part of the development of this guide, two workshops will be held over the summer to hear the views of young people about what should be included. If you are a young person, or know a young person who has been involved in research

who might be interested, please call Roger Steel at the Support Unit on 02380 626236 or e-mail rsteel@conres.co.uk

Commissioners’ workshop

Later in the summer we will be holding a research commissioners’ workshop (this will be an invitation-only event). It will explore, from the expertise of experienced commissioners and consumers who have already been involved in commissioning, what further guidance is needed to promote and support consumer involvement in the commissioning process. This will include discussion around consumer involvement on commissioning groups, peer review, and guidance for grant applicants about consumer involvement. For more details, call Jane Royle on 02380 626237 or e-mail jroyle@conres.co.uk

New consultation document and checklist on involving vulnerable and marginalised people in research

A document originally written as a ‘think piece’ for the Empowerment sub group of *Consumers in NHS Research* is about to be made publicly available on our website. It is not meant to be a definitive guide to involving vulnerable and marginalised groups in research, for the issues are complex, but it is rather a ‘consultation document’ aiming to stimulate discussion, raise awareness of some of the issues, and stimulate the further development of ideas.

The document covers what we might mean by ‘vulnerability,’ ‘marginalisation’ and associated concepts. It goes on to suggest that these can be much more than just labels for certain individuals or groups - vulnerability and marginalisation should also be thought of as states or conditions caused by the way we do things. It therefore encourages researchers to think carefully through the issues of how involvement is done.

The document is fairly long, but a summary of the recommendations is also available in the form of a practical checklist for researchers.

TRUE Project Update

TRUE = Training in Research for service users: Evaluation

The TRUE project was commissioned by *Consumers in NHS Research* to look at what training for consumer involvement is going on and what elements of that training are effective. Here are some personal views from the experiences of one of those involved:

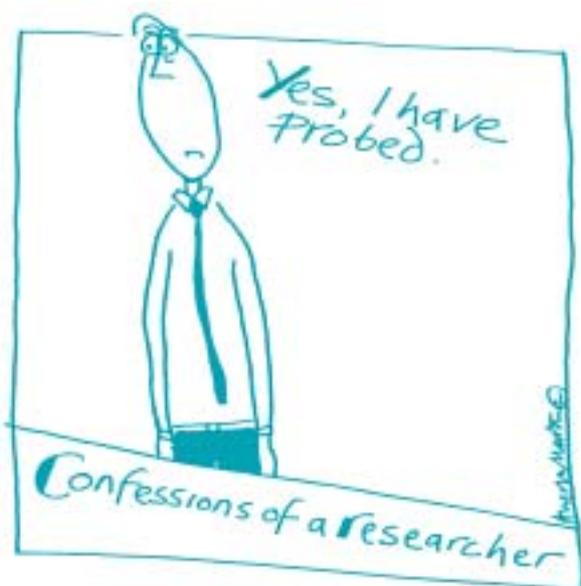
I am one of the mental health service users working on the project, and am greatly enjoying the work. I was awarded a BSc (Honours) degree in the year 2001 from the Open University in social sciences and psychology and when I was given the opportunity to work on the project, I was very excited, feeling that I could build on some of the skills that I have.

At the present time, we are still in the process of conducting telephone interviews and arranging further case sites in order to interview consumers and trainers who have undertaken training in research. We have begun to summarise and analyse the data that we have. This will be the first stage of a deeper analysis and preparation of the final report.

I have researched and written guidelines on how to conduct interviews, which were used for one of our training days, and have also written guidelines on how to facilitate focus groups.

The research work encompasses many activities that I enjoy: reading, writing, presenting data, computer work, talking to people and learning more about our world.

- Jan Millyard



Interesting recent reports and journal articles

From passive subjects to equal partners

Premila Trivedi and Til Wykes

British Journal of Psychiatry

December 2002: Volume 181, pages 468-472

Redesigning mental health services: lessons on user involvement from the Mental Health Collaborative

Glenn Robert, Jeanne Hardacre, Louise Locock, Paul Bates and Jon Glasby

Health Expectations

March 2003: Volume 6, pages 60-71

Lay evaluation of services for childhood asthma

Mary Dixon-Woods, Zarina Anwar, Bridget Young and Adrian Brooke

Health and Social Care in the Community
Volume 10 (issue 6), pages 503-511

Overcoming the challenges to consumer involvement in cancer research

Tony Stevens, David Wilde, John Hunt and Sam H Ahmedzai

Health Expectations

March 2003: Volume 6, pages 81-88

Cases for Change in Mental Health is a review of literature published between 1997 and 2002 on what works and what does not work in adult mental health. Commissioned by the National Institute for Mental Health in England and carried out by researchers at the University of Birmingham, the study included a mental health service user as a core member of the research team and has critical commentaries by practitioners and service users in every chapter.

The report is published as a series of nine individual booklets covering areas including user involvement, anti-discriminatory practice and partnership working between health and social care. The user involvement booklet considers the reasons for involving users, possible barriers and potential ways forward. Copies are available from the NIMHE website (www.nimhe.org.uk). For more information, e-mail J.Glasby@bham.ac.uk at the University of Birmingham.

Education for Participation: The voices of older people

By Belinda Dewar, Queen Margaret University, Edinburgh

Why is this important?

The improvement of the quality of life for older people is high on the agenda of national and local government, funding bodies, the health service and a large number of voluntary and non-governmental organisations. All recognise and emphasise the importance of involving older people in the planning and delivery of services and in the research process. This may include a presence on steering groups, reviewing research and policy papers, participation in surveys and focus groups or as research assistants, interviewing older people.

However, evidence suggests that although efforts are being made to make such involvement happen, it is not as effective as it might be. This is principally because older people are not being sufficiently prepared to be advocates for their own needs, opinions and experiences. They can lack confidence to express themselves and may be unfamiliar with the kinds of materials, meetings and tasks they encounter. The Education for Participation course is being developed to address this need. The aim of this course has been to work with older people to enable them to feel more confident about participating in and influencing the development of services.

The Education for Participation Course

The course has 4 parts. Each part consists of 10 hours input, which is spread across 4 weeks.

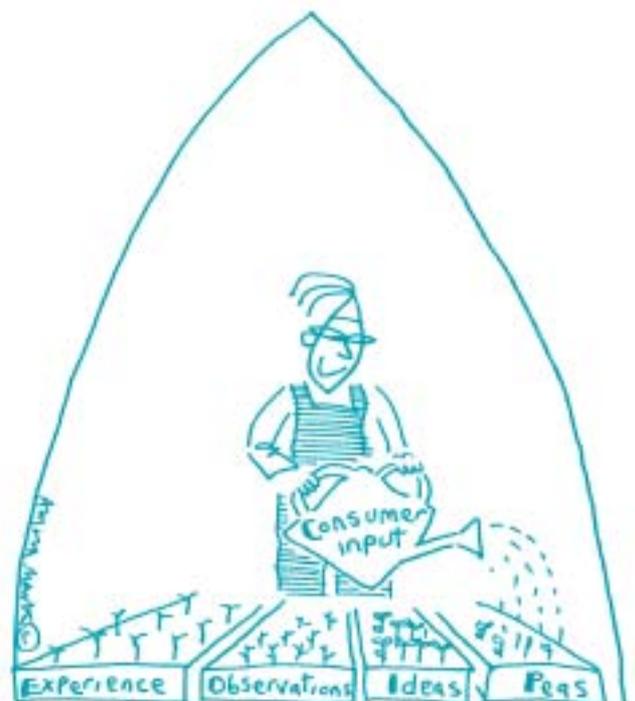
- 1) Drama for democracy. Using drama techniques to build confidence and to explore different ways of expressing points of view.
- 2) Reviewing documents to enable the older person's voice to be heard. Equipping older people with skills to make judgements about published policy documents, particularly those relating to older adults.
- 3) Having a voice in formal arenas. Learning how to participate actively in meetings by sharing views and experiences.
- 4) Helping older people to "tell their stories". There is some evidence to show that older people are better at getting older people's views than service providers or other researchers. This part of the course explores ways of gathering information and how to develop confidence in helping others tell their stories.

The course is rounded off by an evaluation day which includes brief presentations from organisations outlining how older people could use their new skills in working with them.

What older people have said about the course:

- 'I learned that I am not the only one who feels shy about putting my points across and frightened that others would dismiss my opinions. I learned that people did listen to me and gained a lot of confidence from this. I also learned to focus on the proceedings (of a meeting) instead of worrying about my own personal inadequacies.'
- 'It showed how even as senior adults, many of us lack confidence in ourselves and do not want to voice our views and feelings. That was quite an amazing feature of the course.'
- 'I learned to question the assumptions on which the documents are based.'
- 'I learnt the value of co-operating with others to achieve the best results for everyone in community situations.'

For further information or a copy of the report please contact Belinda Dewar, Development and Research Manager, Scottish Centre for the Promotion of the Older Person's Agenda, Queen Margaret University Edinburgh
E-mail: bdewar@qmuc.ac.uk
Telephone: 0131 317 3575



Older Women in Sheffield: Lives, Voices and a Video

By Lorna Warren, University of Sheffield

Lorna Warren and Joe Cook, from the Department of Sociological Studies, and our colleague Tony Maltby from the University of Birmingham, have recently completed a 28-month project aimed at raising awareness of issues affecting the quality of life of older women across different ethnic groups and their involvement in services available to them. The project has taken a participatory strategy: older women have taken part in designing and carrying out the research, evaluating the process and in promoting change.

Findings from this ESRC-funded project were launched at a very successful dissemination event held at Sheffield United Football Ground last year. Over 100 people attended the launch conference, including older women who were involved in the project, local policy makers and service providers, and academics. Interpreters were available for members of the Somali and Chinese communities with whom the project team worked, alongside Black Caribbean, Irish and White British groups.

The event provided an important forum for discussing:

- barriers and incentives to the involvement of older women in shaping service provision,
- ways in which services might better meet the needs of older women in Sheffield,
- lessons for participatory research.

The main presentation was by eight older women volunteers from the project: Norma Clarke, Pat Hadfield, Pam Haywood-Reed, Lileith Millen, Movania Parkinson, Judy Robinson, Jean Wilkinson, and Winnie Winfield. These volunteers were recruited to work with the project team in carrying out the research. Since their debut presentation at the project dissemination event, the volunteers along with the research team have been invited to give talks at seminars and conferences UK-wide. The most recent was the *Consumers in NHS Research* Third National Conference, Making a Difference, at Harrogate on 7th November - a very enjoyable and useful opportunity to network with others concerned with user involvement. In addition, we are continuing to meet with key local service providers to try and find ways of carrying forward the project and building on the important lessons learnt.

Last but by no means least, the project team have also collaborated with colleagues from the Learning and Media Unit to

produce a video documenting how the research was carried out and what it found. Older women from the project feature on the video discussing their lives and daily activities and also what stops them from participating and 'having a say' such as ageist stereotyping, racial prejudice, and lack of cultural awareness in service provision. The video is already proving to be an extremely valuable resource:

- for *local community groups* as an illustration of their experiences and needs
- for *service providers and policy makers* interested in finding out more about older women services users and how they might be involved in decision-making processes
- for *academics* both in teaching and learning about older women and about involving older people, in general, in research.

Copies of the video will soon be available in Cantonese and Somali as well as English. For further details, please contact the Learning Media Unit, The University of Sheffield, 5 Favell Road, Sheffield S3 7QX.

Tel: 0114 2220400 Fax: 0114 2762106

Email: learningmedia@shef.ac.uk

Website: <http://www.shef.ac.uk/learningmedia>

For more details about the Older Women's Lives and Voices (OWLV) project please visit the website: <http://www.shef.ac.uk/uni/academic/R-Z/socst/OWLV>

Dr Lorna Warren can be contacted at the Department of Sociological Studies, University of Sheffield, Elmfield, Northumberland Road, Sheffield S10 2TU.

Tel: 0114 2226468 Fax: 0114 2768125

Email: L.Warren@sheffield.ac.uk

The OWLV project was funded by the Economic and Social Research Council (ESRC) Project No. L480254048

Deadline for contributions for our next newsletter: 4th June 2003

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 the Support Unit for a copy of our 'Guide for Contributors.'

User involvement in cancer research - a beginning

Exciting developments in the structure and delivery of cancer research in the UK will result in more cancer patients having the opportunity to participate in a cancer clinical trial as one of their treatment options. This increase in cancer research activity brings with it the responsibility of ensuring that user views are harnessed to shape practice. With this in mind, a user group focussing on cancer research is being developed in the Central South Coast Cancer Research Network (CSCCRN) under the guidance of Anne Croudass, Cancer Research UK Lead Research Nurse. The remit of this group is likely to include:

- Advising on best practice
- Contributing to recruitment strategies
- Discussing dissemination methods
- Advising on local protocol development
- Liaising with the National Consumer groups
- Identifying gaps in the local research agenda
- Generating and executing user led research initiatives

A research open day is being held on 31 May 2003 in the Somers cancer research building at Southampton General Hospital for anyone who is interested in joining the group or learning more about the nature of cancer research. If you would like more information about the research open day, or would be interested in being involved in the user group, please contact: Anne Croudass, Cancer Research UK Lead Research Nurse, Somers Cancer Research Building, Southampton General Hospital, Southampton SO16 6YD
Tel: 023 8079 5112 E-mail: A.L.Croudass@soton.ac.uk

Parents as researchers: The Child Health Surveillance Project Research Overview

Child health surveillance (CHS) has, in recent years, undergone significant changes in service design and delivery. Increasingly there is a shift towards services that are more inclusive of parents in the process of monitoring and evaluating their child's health (Hall 1996). However, little attention has been paid to what parents think about these changes in policy and practice. This study examined parents' views about child health surveillance and health promotion programmes offered during the first year of their child's life. Unique to this project was the involvement of local parents as researchers, which was instrumental to the success of this research study. Three local parents were recruited from the participating surgeries, and have been involved in

all aspects of the research: recruitment; data collection; data analysis; and dissemination. The lead parents underwent specialised focus group training - tailored to suit the particular needs of involving parents as researchers - through King's College, London,

Having parents as researchers created a non-judgemental environment for participants, one that benefited from their 'first-hand' experience and established research credibility. However, this type of participatory research is not without its obstacles. Practical issues continually tested the ability of parents and researchers to work together in an easy and timely fashion. The success of the project hinged on the ability of all involved to demonstrate their commitment, not only to the research, but to issues of communication and partnership. Our lead parents are currently working with the research staff to formally write up their experiences and examine the processes of conducting consumer-led research.

For further information please call Brenda Roche at BRG on 020 7223 4222 or e-mail brenda.roche@lshtm.ac.uk

A Development Tool for User Representation

The group Maternity Alliance has developed a tool for consumer representation on committees and research projects. This takes the form of two questionnaires. The first asks those organisations or projects wishing to involve consumers who they are looking for, what sort of background and knowledge they are expected to have, whether training and support is provided and so on. Maternity Alliance then use this to identify a suitable representative from their membership. The second questionnaire asks the consumer representative, at the end of the project, what it was like and whether they were properly involved and supported.

We hope to include an article about this scheme in a subsequent newsletter. For more details contact Helen Burchett at Maternity Alliance on 020 7490 7639 ext 132 or by e-mail at hburchett@maternityalliance.org.uk

Shaping Our Lives - New core funding and a conference to launch research findings

New core funding

Shaping Our Lives, a national user led organisation, has been given funding from the Department of Health to develop its National User Network. The funding comes from the section 64 scheme and is due to last for three years. Shaping Our Lives National User Network (SOLNUN) have been working with user-controlled groups of people with physical and/or sensory impairments, people with learning difficulties, users/survivors of mental health services and older people. Now the network has funding to work with additional groups of service users. These include young people and families, people using palliative care services, people with HIV/AIDS and people with drug and alcohol problems.

SOLNUN's aims, as a user controlled organisation, are:

- to support the development of local user involvement that aims to deliver better outcomes for service users
- to give a shared voice to user controlled organisations
- to facilitate service user involvement at a national level
- to work across all user groups in an equal and accessible manner
- to improve the quality of support people receive
- to enable groups to link to other user controlled groups
- to develop links with world wide international user controlled organisations

A conference to launch new user controlled research findings

The launch of research findings of two user controlled research and development projects funded by the Joseph Rowntree Foundation and undertaken by Shaping Our Lives will take place at a conference on 25th June, 2003 in Central London. The research projects involved black and ethnic minority service user groups, disabled people's groups, older people's action groups and mental health service + user groups. The launch conference is free for service users with all costs met, and £60.00 for professionals and funded researchers. The conference speakers will be:

- Jacqui Smith, Minister of State for Health
- Jane Campbell, Chair of Social Care Institute for Excellence
- Peter Beresford, Chair of Shaping Our Lives
- Michael Turner, also from Shaping Our Lives

For more details contact Jenny Willis or Eamon Andrews at Shaping Our Lives National User Network, Unit 57, Eurolink Centre, 49 Effra Road, London SW2 1BZ. Tel: 0207 0951159
E-mail: information@shapingourlives.org.uk

Trent Institute for Health Services Research

We were formed in December 1994 as a joint venture between the Universities of Leicester, Nottingham and Sheffield. Our primary objective is to increase the capacity and capability in Trent to plan and carry out excellent health services research. One of the ways this is achieved is by providing education and training for health and social care professionals and consumers. We have a variety of courses which will suit people with various levels of research experience, from short courses (such as focus group training, statistics, questionnaire design, etc.) to a one year long, one day a week course which will enable you to design and complete your own small research project to get an overview of the full research process.

We have consumers taking part in some of our courses at the moment and finding the experience rewarding and enjoyable. We are also involved with some local consumers in research groups such as Nottingham Service Users in Research (Nsure) in Nottingham, and run courses for experienced researchers to develop their skills in why and how they should get consumers involved in their projects.

We run courses covering the geographical areas of Leicestershire, Northamptonshire & Rutland; Trent; and South Yorkshire - and some people from South Humberside (within the North and East Yorkshire and Northern Lincolnshire Strategic Health Authority area) continue to look to the Trent Institute for support.

If you would like any further information regarding the Trent Institute or what it can offer you, please contact your Research and Development Manager, or look at our website <http://www.trentinstitute.org.uk> Alternatively, you can contact me: Ms Dawn-Marie Walker at Trent Institute for Health Services Research, B Floor, Queen's Medical Centre, Nottingham NG7 2UH. Telephone: 0115 924 9924 ext. 42557
E-mail: dawn-marie.walker@nottingham.ac.uk

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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 for Cardiovascular Health in the Community' - Monday 30th June 2003

This one day event will be held at the Queen Elizabeth II Conference Centre, Broad Sanctuary, Westminster, London. It will include a series of presentations to be given by key researchers who have undertaken studies relevant to the prevention, diagnosis and treatment of coronary heart disease. The conference will be of interest to anyone with an active interest in current R&D undertaken across the NHS. Presentations will cover work undertaken in both primary and secondary care.

The day will feature speakers including Sir John Pattison, Director of Research, Analysis & Information; and Dr Roger Boyle, National Director of Heart Disease, Department of Health. There is no charge to delegates. For further information, a booking form and draft programme please call Beverley Hilton on 0151 794 4887 or e-mail bhilton@liv.ac.uk

Your experiences of obtaining honorary contracts?

We would be interested to hear from consumers - or from researchers who have involved consumers in research projects - about their experience of obtaining honorary contracts in NHS establishments. We have heard that in some cases the experience has been of difficulties and potential discrimination for some patients and service users. We would be interested to hear about both positive and negative experiences. Please contact Roger Steel at the Support Unit: rsteel@conres.co.uk . Direct dial: 02380 626233.

NHS Executive North West - 'Making it happen'

A series of conferences and workshops were held here in 2000 and 2001, bringing together NHS Trust R&D leads, researchers, and consumers to share ideas and experiences and develop ways to support user involvement in NHS research. A report of the work in the North West, *'Making it happen: User involvement in research in the North West, a summary of developing user involvement 2000-2002'* is now available. It can be downloaded directly as a Word or Acrobat file from the User web page at Health R&D NoW: <http://www.lancs.ac.uk/depts/ihr/hrdn/users.htm> Or you can request a copy of the report from Dr Sara Morris, R&D Manager, Health R&D NoW, Bowland Tower East, Lancaster University, Lancaster, LA1 4YT Tel: 01524 592656 E-mail: s.m.morris@lancaster.ac.uk



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 or for the Policy Research Programme 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, or wish to contribute to our next newsletter.

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