



Welcome to the autumn edition of the *Consumers in NHS Research Support Unit* newsletter. In it you'll find a variety of articles on different aspects of consumer involvement, ranging from a project involving residents in housing research to an R&D Manager's solution to involving consumers in an NHS hospital Trust. There are also the usual news pages, plus a new section listing interesting articles that we have found in other journals.

Thank you to everyone who has contributed articles to the newsletter. We've been delighted to receive so many - please keep them coming!

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

Making a Difference 7th of November 2002

The programme and a booking form for our National Conference is now on the 'conres' website, so do have a look, or if you don't have access please get in touch with us and we will send you one.

The conference will be introduced by Nick Partridge, Chair of *Consumers in NHS Research*, and a keynote speech will be made by Hazel Blears MP, Parliamentary Under Secretary for Public Health.

The morning and afternoon sessions will each offer a choice of 13 workshops including discussion about involving consumers at different stages of research, and covering issues affecting the different groups of people who might be involved. There will also be four parallel discussion groups later in the afternoon:

- 'How representative should consumers be, and does it matter?'
- 'Ethics and consumer involvement'
- 'Cultural diversity and inclusion in research'
- 'Hearing the unheard.'

Even the lunch break will be busy! There will be a soapbox session for anyone who wants a five minute slot to air their ideas and views, and there will be a chance to meet members of *Consumers in NHS Research* and the Support Unit staff to find out more about the work of the group. In addition, there will be a number of small meeting groups, including an opportunity to discuss ideas for an information service for research participants with CERES members, and a discussion on payments for consumers and the problems raised by the benefit system.

For further information please contact Professional Briefings on 10920 487672 or e-mail London@profbriefings.co.uk

Support Unit News

A warm welcome to our new staff

We would like to extend a very warm welcome to four new members of staff in the Support Unit who joined us in the middle of September. Introducing themselves are:

Paul Jones

I am the Support Unit's new Liaison Officer. I joined the Support Unit on 16th September 2002 and I will be working full time alongside the Development Worker, Roger Steel. For the last three years I have worked for a variety of statutory and non-statutory groups and organisations as an Independent Research Consultant, mainly in the field of mental health. I also have experience of working for an NHS Trust, a Housing Association, and managing a day centre for people with physical disabilities. I can be contacted by e-mail at pjones@conres.co.uk or by phone on 023 80 626234.

Fran Christopher

I work on a part time basis, as the Research Programme Co-ordinator, to oversee training and commission and manage evaluations for eleven London Primary Care research projects who are involving consumers. The London Directorate of Health and Social Care (formerly London Regional Office) has funded the projects and money was set aside to provide training and support to the consumers and researchers involved. In addition, funding was provided for two evaluations

of the impact of the training and consumer involvement on the programme. I will usually be working Monday to Wednesday, and can be contacted by phone on 023 80 626231 or by e-mail at fchristopher@conres.co.uk

Achara Western

I joined the Support Unit on the 17th of September this year as part time Office Co-ordinator Assistant. I have been working for the last 5 years in administrative roles for the higher education sector. I am job sharing this position with Sarah Bayliss and I cover the first half of the week. I am friendly, approachable and happy to help (whenever I can!). I can be contacted by phone on 023 80 651088 or by e-mail on awestern@conres.co.uk

Sarah Bayliss

I have recently joined the Support Unit as a part time Office Co-ordinator Assistant, job sharing with Achara, and cover the second half of the week. During the last 15 years I have been working in an administrative role for a bank and a legal company. I am looking forward to providing admin support to the unit. I can be contacted by phone on 023 80 651088 or by e-mail on sbayliss@conres.co.uk

New Toronto Group seminar series supported by the Joseph Rowntree Foundation and Consumers in NHS Research

The Toronto Group are organising four seminars under the overall theme of 'Research as Empowerment.' They are:

- Research, empowerment and the inclusion of black and ethnic minorities;
- User involvement in peer review;
- Traditional research methodologies; and
- New methodologies for the emancipation of service users.

The overall series has been funded by the Joseph Rowntree Foundation with *Consumers in NHS Research* funding the 'User involvement in peer review', and joint funding the 'Research, empowerment and inclusion of black and ethnic minorities' seminars. The Support Unit will be working with the Toronto Group to help organise these, but no dates have so far been set. We will be advertising the dates in future newsletters.

Have you any examples you can share?

I have had a number of enquiries from researchers interested in developing job descriptions, contracts and indemnity and insurance guidelines for involving consumers in their research projects. We are looking for examples.

If you have developed any of these that you are willing to share then we would appreciate copies to build up a resource of examples in the Support Unit that can be used by researchers or consumers.

If you can help, please contact Helen Hayes, Information Officer at the Support Unit, on 023 80 626235 or at hhayes@conres.co.uk
Thank you.

INTERESTING recent journal articles

Consumer involvement in Health promotion and Health Education research

I am in the process of completing an MSc in Health Education and Health Promotion and as part of my dissertation I am exploring the scope and nature of consumer involvement in health promotion and health education research. If you have been involved as a consumer or have involved consumers in any research in this area then I would love to hear about it. I am interested in published and unpublished research projects. Please contact me, Helen Hayes, Information Officer at the Support Unit, by e-mail at hhayes@conres.co.uk or on 023 80 626235. Thank you for your help.

Have you involved children or young people in a research project?

Consumers in NHS Research wants to find out how research in health and social care can best involve young people. We are working with the Social Policy Research Unit (SPRU) at the University of York to look at young people's views about what is good and bad practice in user involvement in research. SPRU will work with a group of young people to plan a 'workshop' where young people who have some experience of involvement can get together to discuss this.

If you have involved young people in research in any way, from the design of the research to carrying out the study, or if you are a young person who has been involved in research, we would be very grateful if you would get in touch with SPRU. They would be very interested to hear about your experiences.

If you can help, please get in touch with:
Tricia Sloper,
Social Policy Research Unit
University of York,
York YO10 5DD
Telephone: 01904 433608
E-mail ps26@york.ac.uk



Consumer Involvement in Health Research: a review and research agenda

Jonathan Boote, Rosemary Telford and
Cindy Cooper
Health Policy
Volume 61, Issue 2, August 2002, pp 213-236

Thrombolysis for acute ischaemic stroke: consumer involvement in design of new randomised controlled trial

Liedeke Koops and Richard Lindley
British Medical Journal
Volume 325, 24 August 2002

How cancer service users can influence research and practice

Hunt, John et al
Nursing Times
13 August 2002, pp 32-33

From local concern to randomised trial: The Watcombe Housing Project

Somerville, M. et al
Health Expectations
Volume 5, Issue 2, pp 127-135

Harnessing expertise: involving peer interviewers in qualitative research with hard to reach populations

Elliott, E., Watson, A. and Harries, U.
Health Expectations
Volume 5, Issue 2, pp 172-178

Over to you...

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.

Psst! Do you want to involve consumers in your research?

Dr Art Ationu, R&D Manager, East Kent Hospitals NHS Trust

Why?

It is now mandatory for all research active NHS organisations, and professionals within the NHS and Social Care Services in England and Wales, to involve members of the public in research. The new NHS Plan (2000) states that the health and social care systems must be shaped around the needs of patients. This includes research too.

So what?

Well, common sense dictates that involvement of members of the public in research will lead to directly relevant projects that will address the needs of service users, consumers and clients. It makes sense, my good friend.

How do I go about it?

Very simple. In East Kent Hospitals NHS Trust, involvement of members of the public in research is right at the top of the agenda of the Research and Development (R&D) Department. The Trust's R&D Department started out without a single public member on its committee that helps shape strategies and policies on research. Today, we have at least three lay members on the committee who also serve to review research projects before they are given Trust's approval. We are still poised to recruit more members of the public!

How did you get the lay members?

Well, the Director of R&D, Dr David G. Smithard, and myself gave a commitment to involve members of the public in the R&D process. As a first step towards achieving this, we advertised in the local newspaper for volunteers. In addition, we also decided on our own accord to circulate the Trust's R & D Annual Reports to all secondary schools, local libraries, voluntary organisations, local GPs and Universities in East Kent, in order to inform members of the public on the types of research being undertaken in their local hospitals. We also stressed that we would very much need input from members of the public.

Tell me, what else did you do?

We have a bi-annual R&D Newsletter that has a regular column for consumer involvement in NHS research and a wide readership. All research protocols/proposals that are submitted by researchers to the R&D Department for funding

must have a lay summary written in plain English. This is now Trust policy, as well as in the Local Research Governance Implementation Plan submitted to the Department of Health. All Trust's researchers are encouraged to involve members of the public in their projects; and we are continuing to monitor and evaluate this with keen interest.

Is that all ?

Not quite. I have been very vociferous in encouraging consumer involvement in research. Within the South East, I took part in giving seminars on NHS Research to some members of the public. I am also actively involved, both internally and externally, in giving seminars/lectures on Research Governance to members of the public and health and Social Care professionals in Kent.

We are continually looking for more members of the public to be involved in the research process. It will take time to completely achieve our goals, however, one must start somewhere. The tide is changing pretty fast and we must change with it. The voice of service users/clients/consumers is here to stay.

My friend, whether you call it "tokenism" or not, you must start somewhere and pretty soon too.



Community Action to Housing and Health Research

Meryl Basham on behalf of the Torbay Healthy Housing Group

Following concerns expressed by a local GP about high callout rates in an area of South Devon, and consultation with local people, statutory and voluntary organisations, a three-year community health development project was funded by the Health Authority in 1995. Three residents represented local people on the steering committee of the project.

Community Action

In one area, some residents expressed concerns about damp and condensation within their houses, and children reported having asthma. The community worker supported them to undertake a questionnaire-based survey of 96 council houses and tenants using a pictorial guide to condensation/damp and mould drawn by one resident. Dampness was reported by 64% of residents and 56% (47/84) reported a health problem, the most common being asthma.

Moving forward

In response to this survey, an inter-agency steering group, including a tenant representative, was formed to put forward a research proposal to address these problems. Following much lobbying by the group, agreement was gained in 1998 from the Council Housing Committee that £600,000 of the maintenance budget, over three years, would be allocated to address the problems identified, and funding was obtained from the regional NHS Research and Development Committee to evaluate the proposed improvements. The community worker was appointed as research co-ordinator, which provided a continuous link with residents and agencies.

Involvement of consumers

It was recognised that more than one tenant representative was desirable to provide support, and although they changed over time, usually two people were involved throughout the three-year project. The relationships already established during the community project helped to ensure that residents were continually consulted, through newsletters and their representatives on the steering group. The Christmas parties organised with tenants were much appreciated - the Research Manager being Father Christmas!

Participation was high, only eight out of an original 127 households refusing to take part. Evaluation included questionnaires to identify household and illness factors, and

environmental testing of houses for each of three years. The latter included hoovering beds for dust mite samples (an ideal place for this test!) and testing air quality and wall dampness. In health interviews undertaken by community nurses, specific illness (asthma, angina and arthritis/rheumatism) and general health questionnaires were undertaken with over 80% of households participating.

Key roles of tenant representatives

One role was to report any difficulties with the renovation process. Representatives completed a survey of houses when it became apparent that some of the ventilation fans installed were not working. These were important to the indoor air quality and environment and a research outcome. Following the results being presented to the steering group the fans were checked and replaced.

Viewpoints of consumers

About the renovation process - as one householder put it, "It's not just a house, it's your home." More consultation with tenants is needed both before and during renovation to ensure satisfaction with the improvements and "respect for people's homes."

Regarding the research - there were concerns raised about the type of questionnaires used. Some people found the questions about their health intrusive. Some residents questioned the randomisation of houses to two phases - should the allocation have been done by need?

Lessons learned

- Clear communications are important and consumers could be involved more in improving the planning process and research methodology.
- It takes time to form collaborating partnerships and understanding of each other's priorities that do not always coincide.
- Taking account of accessibility of meetings times, childcare and venue, language used and valuing the contribution that consumers can make can contribute to the success or otherwise of partnerships.
- Conference presentations by consumers and researchers are a valuable learning tool.

Successful consumer involvement in research: what does it mean and how do we measure it? A progress report.

By Rosemary Telford, Jonathan Boote and Cindy Cooper

A research team from Community Health Sheffield NHS Trust and Sheffield University are developing a tool to assess the successful involvement of consumers in health research. There are three stages:

1. Developing principles of successful involvement of consumers in health research, and measurable indicators of those principles, by means of an expert workshop.
2. Refining the principles and indicators, and widening consensus by means of a two-round postal Delphi process.
3. Developing an audit tool from the indicators, and using this to conduct a national postal survey of recently completed health research to identify the number of projects that meet the developed principles of successful consumer involvement in research.

How far have we got with this? An expert workshop of 6 researchers and 7 consumers generated 12 principles, and indicators for each principle.

We widened the influence on developing the principles, by means of a Delphi process. This method uses a series of questionnaires (or rounds) to obtain agreement, and provides feedback to participants on how others have responded. It gave an opportunity for people to suggest additional principles and/or indicators, as well as commenting on those that had emerged so far.

People responded to our invitation in this Newsletter to take part, and we were delighted to receive lots of comments, despite the questionnaires being very lengthy. We are only sorry that it was not possible to incorporate all the suggestions. Questionnaires were sent to 131 consumers and researchers and 95 people returned two rounds. A high level of consensus was found on 8 of the refined principles and a number of indicators.

Thanks to many people who have helped us so far, including our advisors. The last stage is a national postal survey. If you receive a questionnaire from us (this time very brief!), please return it as we very much want to hear from you.

For more details please visit the web site:
<http://www.shef.ac.uk/~scharr/public/research/consumer.htm>



The TRUE Project

Training in research for service users: Evaluation

You may have read about this research project on page three of the Summer 2002 newsletter. It was previously known as 'Research into training for consumer involvement in research' but we have now named our project the TRUE Project and are 3 months into this 15-month long project. The summer was very fruitful for us and we are now a much bigger team of 12 people. The team is made up of 9 service user researchers from the CAPITAL project (Clients And Professionals In Training And Learning), one research co-ordinator and three research supervisors.

Over the summer we have had several training days. For the CAPITAL researchers, there have been 2 training days which included an introduction to research, interview techniques and practice, and designing questions for telephone interviews. The next training day includes putting our data into a computer spreadsheet and data analysis. CAPITAL have also provided some of us with training around mental health issues and more information about how and what the CAPITAL Project does.

CAPITAL researchers have started working on a daily basis in the office where we continue training based on individual needs. We have also had our first advisory group meeting which gave us plenty of ideas for future work.

We have begun the piloting of telephone interviews to providers of training so that we can begin to map out how and why it is done; who does it and who it is aimed at. As well as all this, we have been having a lot of fun including learning to use a digital video camera and a recent expedition to Exeter where we attended the Folk.us conference, all about service user involvement in research. Coming up next is our first case site visit and a trip to Harrogate for the *Consumers in NHS Research* conference, where we will be doing a poster presentation. Come and visit us!

Thank you to all those people who got in touch with us after the last newsletter. If you know of any training designed to facilitate service user involvement in research then please get in touch by e-mail at Rachael.Lockey@wash.nhs.uk or by telephone on 01903 205111 ext 4193. Alternatively, you can write to us at: The TRUE Project, c/o Rachael Lockey, Research and Development 2, Worthing Hospital, Lyndhurst Road, Worthing, West Sussex BN11 2DH.

The NHS Research and Development Forum

The NHS Research and Development Forum is an organisation for individuals and departments involved in the management and planning of R&D activities and in conducting R&D in health and social care. The purpose of the Forum is to improve the environment for research within organisations delivering health and social care by encouraging high standards and providing support and communication networks.

The Forum is an inclusive organisation open to all involved in R&D, including directors, managers, administrators, consumers and researchers themselves. The activities of the Forum encompass research across the full range of health and social care including community and primary care, secondary and tertiary care, public health and social services.

Membership is free and gives you access to information from the Forum and allows participation in all our activities. We also welcome anyone interested in our activities to contact us for information or to attend our events. We would particularly like to make contact with consumers involved in research design or commissioning through NHS Trusts or other organisations.

Further information is available on our website www.rdforum.nhs.uk or contact the Forum by telephone on 01570 421172 or by e-mail at info@rdforum.vispa.com

Deadline for contributions for our next newsletter: 5th December 2002

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 Works series

The Social Policy Research Unit at the University of York (SPRU) have recently published a new issue in their Research Works Series. This presents the findings from the work of Jane Lightfoot and Tricia Sloper on 'Involving Young People in Health Service Development.' It is available on the Social Policy Research Unit's website at: <http://www.york.ac.uk/inst/spru/pubs/researchwks.htm>

Health Voice Network

The Network is a self-help network funded by the Department of Health and run independently by the UK Health for All Network. Launched in March 2002, the Network is free and open to anyone who wants to help people to have more of a say in planning and improving services that affect their health.

Over 500 NHS and Local Authority staff, community groups and individual members of the public are using the Network to explore ways of coming together to put the health back into health services. The Network has a monthly newsletter, plus an email list and a website on which members may post information directly. Contact:
Website: www.healthvoice-uk.net
E-mail: info@healthvoice-uk.net
Telephone: 0151 231 4284

Social Care research Ethics Consultation

As part of a Department of Health consultation to develop a Research Governance Framework for Social Care, a workshop to find out the views of social care users and carers on what research ethics issues should be considered will be held on 13th November in London. Places are limited, but if you are a user of social care services or a carer and would like to contribute your views on social care research ethics please contact Roger Steel at the Support Unit on 023 80626232 or e-mail rsteel@conres.co.uk

In plain English...

The Plain English Campaign are holding a Conference on Friday the 6th of December 2002. The cost is £100 and it will be held at The Brewery, Chiswell Street, London.

For more details or to book a place, please contact Jennie Eley on 01663 744409.

Access difficulties?

I would be really interested to hear from anyone who finds it difficult to access or benefit from the newsletter in this format. This might be because of the language used or the way it is set out. I am also keen to hear about organisations and groups of people who might benefit from getting the newsletter on audio tape. Our aim is to reach a wide audience of people who are interested in consumer involvement in research. I can be contacted on pjones@conres.co.uk or 02380 626234.

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.