We hope you have all had a good summer. This Autumn edition features the highlights of our conference to be held on the 10th and 11th of November. There are still places left if you would like to attend, so book now to be sure! Also, find out about guidelines for the ethical conduct of survivor research and how you can comment on options for ethics review of social care research. We are always interested to hear about your experiences of public involvement in research, so keep sending the articles in!

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This newsletter is also available on tape and in large print. If you would like a taped or large-print version, please let us know.

An interest that turned into a voice - a story of developing user involvement in research

Ruth Hunter, Sam Semoff and Ann Jacoby

The Cardiothoracic Centre Liverpool NHS Trust (CTC), is a large specialist heart and chest hospital. It has an impressive track record in research and carefully manages its research projects to ensure quality. The CTC believed that involving users in its research would further improve the quality of its research projects and so in 2000 it set about involving users in the research process. The CTC research and development team invited members of the organisation’s service user group to attend a taster session about research in the CTC. The session gave...
people a chance to see whether they would like to get involved further. Happily, after the session, a number of people did express an interest in becoming involved in research. However they identified that they needed more information about research and to have some research training.

The CTC arranged with a local research and development support unit, (Health R&D North West (HRDNoW), that they deliver a joint introductory training session on research for the service users.

After this session there was an opportunity for this group of users to attend a two-day introduction to health services research course run by HRDNoW. At that time this course was primarily attended by NHS staff.

As training progressed, the group of users and HRDNoW staff began to meet regularly and although the group did not yet have a name or a role, new members continued to join up! The group began to gel and in 2002 became the Service Users Research Awareness Sub-Group - SURASG. SURASG discussed the best way to have a voice in CTC research and voted to comment on patient information sheets and consent forms from research projects. SURASG wrote detailed terms of reference covering: its role in the research process, training needs, honorary contracts and how it would communicate with the Academic Committee in the CTC. (This Committee reviews research projects and oversees research in the CTC).

The role of SURASG continues to develop. A joint service user and NHS research project is currently being carried out, with service users undertaking the interviews. One substantial change for SURASG is that the Academic Committee have agreed that SURASG now has the final say about patient information sheets and does not just offer its view on them.

For further information contact Ruth Hunter, R&D Manager, Health R&D North West, Department of Primary Care, Whelan Building, University of Liverpool, Liverpool L69 3GB E-mail: hunter@liverpool.ac.uk

Department of Health consultation on options for ethics review of social care research

This consultation, launched on 1st September 2004, seeks views on ethics review of social care research. Comments are welcomed from those working in social care research and practice communities, from service users/carers or organisations representing them, and from members of the public with an interest in research.

Four main options (or models) for a national social care ethics review system have emerged from previous consultations, including those with service users and carers facilitated by INVOLVE in 2002 and 2003. The options are set out in supporting documents available on the Department of Health website. The Department of Health are seeking views on the relative strength and weaknesses of each model or ideas on possible alternatives. The consultation closes on 31st December 2004.

For more information see the website at: www.dh.gov.uk/Consultations/LiveConsultations or contact: Patricia Ladly, Rm 487D, Skipton House, 80 London Road, London, SE1 6LH. Tel: 020 7972 5615. Fax: 020 7972 5665. E-mail: patricia.ladly@doh.gsi.gov.uk
Support Unit News

4th National Conference ‘People at the Heart of Research’ 10th and 11th November, Nottingham

There are still a few places left! You’ll find a draft conference programme and booking form at: http://www.profbriefings.co.uk/involve.htm or you can telephone Professional Briefings for a copy on 020 7233 8322. Conference highlights include:
• A diverse selection of posters, papers and workshops for you to enjoy, all themed around the stages of the research cycle.
• Keynote speeches from Richard Smith, former editor of the British Medical Journal and Dr Diana Rose, Co-ordinator, Service User Research Enterprise.
• ‘Burning Issues’ - open discussion between the audience and a small guest panel, chaired by Harry Cayton, Director for Patients and the Public at the Department of Health.
• ‘Soapbox session’ - the chance to spend five minutes airing your ideas and opinions to the lunchtime audience.

After the conference is over, we want to capture some of what it was like by creating a record of the event. If you are coming to the conference and you enjoy writing (poetry or prose), drawing or taking photographs - then you might like to think about submitting something to be included. For more details, see the INVOLVE website www.invo.org.uk/new.htm or contact pyeeles@invo.org.uk Tel: 02380 651088.

INVOLVE has a new website!

Our new website will be launched in November 2004, using the same address www.invo.org.uk

On the website you will be able to:
• Join our mailing list, edit your mailing list details and receive the newsletter by email.
• Visit our noticeboard to share information on events, training courses and opportunities for public involvement in research.
• Send us details of your research project actively involving members of the public.
• For more information please contact Helen Hayes at the Support Unit Tel: 02380 626235 E-mail: hhayes@invo.org.uk

Guide to Involving Young People in Research

We are delighted to announce the publication of this Guide, now available on our website. Written by Perpetua Kirby, it highlights good practice for involving young people in research and discusses many of the practical issues which arise.

Training seminar report

The report of INVOLVE’s seminar on training for public involvement in research (held in April 2004) is now available on our website and as hard copy. It records the discussions and recommendations generated at the seminar, many of which arose from issues highlighted by the TRUE research project commissioned by INVOLVE.

Training database

A key recommendation from the Training Seminar was the need to match trainers with those requiring training. In response, INVOLVE are developing a public database of trainers who provide training which is specifically or broadly relevant to public involvement in research. This will go onto our new website. People using the database will be able to run searches for the sort of training and trainers they are looking for. We hope to have a pilot version of the database ready for the INVOLVE conference in November so that participants can give it a try.
A new website for all on clinical trials - what do you think?

By Bec Hanley and Kristina Staley
TwoCan Associates

It can be hard to be told you have what may be a life threatening condition, and then be asked if you’d like to take part in a clinical trial. Many of us don’t understand what trials are, and don’t feel confident to make an informed decision about whether to take part.

The National Electronic Library for Health has developed a website about clinical trials, written for people who have been invited to join in a trial. It aims to help people make a decision about whether they want to take part. The site will be made freely available to the public via NHS Direct Online.

We wanted the site to cover what people want to know, rather than what researchers want to tell them. So we talked with people affected by a wide range of conditions to get their thoughts and feedback. We asked what questions they wanted the website to address, and then we asked for comments on our drafts. We also drew on information about taking part in a trial produced by a range of voluntary organisations.

The website is now available in draft form and we would really welcome your comments. There’s a button to click on the site if you’d like to give feedback. Go to: www.nelh.nhs.uk/clinicaltrials
The Ethics of Survivor Research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors

By Alison Faulkner

These guidelines were developed as the result of a one year project funded by the Joseph Rowntree Foundation. The aim was to develop an accessible manual on ethical practice for researchers, trainers in research skills and interviewers working from the perspective of mental health service users and survivors. There is a distinction to be made between ‘survivor controlled research’ and ‘user/consumer involvement in research’, and the focus of these guidelines is on the former. However, many of the ethical issues are common, making the guidelines valuable in the support of the Research Governance Framework (Dept of Health, 2001) which encourages the involvement of consumers in research.

The Guidelines are not intended as rules, but as helpful guidance on some of the difficult and important issues to be considered prior to a research project or research training programme. There are helpful hints and suggestions, as well as quotations and ideas reflecting the experience of the people who were consulted for the development of the guidelines. In some cases a particular view is given by the author on behalf of the research undertaken, but in other cases it is made clear that the issue in question needs to be discussed and decided by the research team or individual researchers involved. Considerable time and space is given to such key ethical issues as informed consent and confidentiality with particular reference to mental health settings. However, the guidelines also address a number of less commonly discussed issues such as feedback to participants, dissemination and a commitment to change based on research findings. In addition, guidance is given on the role of training for service users and survivors and the support and supervision necessary to make the research feasible.

The guidelines would also be useful for academic researchers looking to involve service users in their research activity, and any researchers working in the mental health field, Research Ethics Committees and NHS Research & Development Committees. The report will be published in November by Policy Press and available from the Joseph Rowntree Foundation: www.jrf.org.uk Tel: 01904 62924. For further details from the author, e-mail: alison.faulkner2@btinternet.com

The PIN Project (Patient and Public Involvement in Nursing, Midwifery and Health Visiting Research)

The Nursing Research Unit, at King’s College, London has been funded by the Department of Health Service Delivery and Organisation Programme to find out what is known about patient and public involvement in nursing, midwifery and health visiting research. They are currently undertaking a review of published literature but they would also like to include work that is unpublished, ongoing or recently completed. If you have been involved in such a project, let them know by filling in the short questionnaire on the project website http://www.kcl.ac.uk/nursing/nru/pin.html or by contacting Elizabeth Smith by e-mail: elizabeth.m.smith@kcl.ac.uk
Public involvement in identifying important evidence gaps faced by the NHS

By Joy Stokes, National Co-ordinating Centre for Health Technology Assessment

The NHS R&D Health Technology Assessment (HTA) Programme is the largest of the NHS research and development commissioning programmes funding over £10 million worth of research a year. It aims to address, through research, the most important evidence gaps in health technologies faced by the NHS. In this context, the term ‘technologies’ is not confined to new drugs or pieces of equipment, but covers any intervention used by those working in the health services to promote health, prevent and treat disease and improve rehabilitation and long term care.

Do the public have a role?
Members of the public are well placed to suggest topics for HTA research that are important to them and their families. We are therefore actively seeking suggestions from members of the public, and have recently developed help sheets to support people in this task.

HTA research is concerned with the effects and cost-effectiveness of diagnostic tests, screening tests and interventions - such as new and existing drugs for particular conditions, surgical techniques, therapeutic interventions and specific aspects of nursing clinical care. People who are or could be recipients of these ‘technologies’, the public, might well ask themselves: What technologies would I like to use? Do I know that they work? Am I interested in comparing them with something else? How would I judge whether they work? What do I worry might happen? What effects might these technologies have immediately and in the long term?

How can suggestions for topics be made?
Members of the public can submit their suggestions online by using the National Co-ordinating Centre for Health Technology Assessment (NCCHTA) through the website: http://www.ncchta.org/CONSULT.HTM This page gives links to the suggestion form and help sheets. The number of research topics taken forward annually by the HTA programme is in the region of about 40-50, so a lot of the suggestions put into the programme do not result in a piece of commissioned research. Experience shows that the better defined a suggestion is, the better its chances of success in progressing through the prioritisation process. The online form is designed to help people define their suggestions as clearly as possible and the separate help sheets give detailed guidance and examples.

What happens next?
The annual process of identifying health technologies for possible assessment is central to the HTA programme’s mission of addressing the information needs of those who use, manage and work in the NHS. About 1000 suggestions for research are received annually from a variety of sources including the online suggestion form. Other sources include: scanning the conclusions of earlier research and National Institute of Clinical Excellence (NICE) research recommendations, and direct consultation with 25 affiliated organisations (e.g. royal colleges and societies; consumer organisations).

All suggestions are checked by Public Health doctors working at the NCCHTA, and an initial
decision is made whether each suggestion should be considered further (this process involves removing those suggestions that do not have a researchable question, are not related to HTA or are already covered by current HTA research). Selected suggestions are then considered by advisory panels of clinical experts and service user representatives. A shortlist of topics is produced. Further work is then undertaken by the NCCHTA staff to clarify the scope and importance of the question for each shortlisted topic. This information is then used in subsequent meetings of the advisory panels to decide which topics should be recommended for research funding by the HTA programme.

http://www.ncchta.org/CONSULT.HTM

Development of Consumer Research panels within Cancer Research Networks - coming soon!

You may be aware that significant progress has been made with User Involvement within Cancer Networks around the country feeding back on services and getting involved in the decision making and planning for future cancer services. The aim of the project is to establish consumer research panels and to involve them in the research activities taking place within the Networks. The National Cancer Research Network (NCRN) and Macmillan Cancer Relief are working together on an initiative to develop and evaluate Consumer Research Panels within Cancer Research Networks, where patients, carers and the public can get involved in cancer research.

If you are interested and would like to be involved, and live in one of the areas where this is taking place, please contact:

- Central South Coast Cancer Research Network (starting Autumn 2004):
  Andrew Gallini User Involvement Facilitator
  Tel 02380725518
  Email Andrew.Gallini@hiowha.nhs.uk

- Yorkshire & Humber Coast Cancer Research Network:
  Joanna Richardson User Involvement Facilitator
  Tel 01482 806009
  Email Joanna.Richardson@hey.nhs.uk

- Surrey, West Sussex & Hampshire Cancer Research Network:
  Angela Rayner, User Involvement Facilitator
  Tel 01483 783208
  Email Angela.Rayner@gwpct.nhs.uk

Full article on the INVOLVE website
www.invo.org.uk/new.htm

Deadline for contributions for our next newsletter:
10th of December 2004

We welcome contributions about any aspect of public involvement in NHS, public health and social care research. Please ask the Support Unit for information about submitting an article.
Does understanding our difference make a difference?

Have your say on genetic testing for learning disability. At the Cambridge Genetics Knowledge Park we are undertaking a project that - with your input - we hope will improve the advice and support that can be provided to families affected by learning disability. If you, a family member, or someone you care about has a learning disability we would greatly appreciate your expertise and experience.

If you would like more information, please contact Brendan Gogarty, Public Involvement Manager, Cambridge Genetics Knowledge Park, Worts Causeway, Cambridge CB1 8RN E-mail brendan@srl.cam.ac.uk Tel: 01223 740784

Your unique contribution is valuable to us, so please help us make a difference.

Care Research and Audit Group

A new group for carers interested in getting actively involved in research and audit is being formed to work across Avon and Wiltshire Mental Health Partnership Trust. The group will be run for carers by carers and will enable them to become actively involved in the design, management, data collection and dissemination of projects.

If you are interested in becoming a member of the Group or if you wish to obtain further information please contact: Ron Ritson by e-mail at ron.ritson@blueyonder.co.uk

Training for new researchers in Partnership Research

The University of Manchester is running a three-day introductory training course on collaborating with service users in research projects. It is aimed at new researchers and final year students, and will be held at the University from 6th to 8th December. The course is supported by the Economic and Social Research Council (ESRC).

Contact: Ian Kaplan, Department of Education, University of Manchester, Oxford Road, Manchester M13 9PL E-mail: ian.kaplan@man.ac.uk