Well, summer is here, and we have a range of articles and news in this packed edition. Don’t forget that we have our National Conference coming up in the autumn - booking forms are now available. We recommend that you get your booking in early. If you are not on our mailing list, the details about how to get your booking form are in ‘Support Unit News’ on page 3.

User involvement in a primary care research project

By Carey Ostrer

In 2001, eleven research projects were funded by the London region of the NHS, which specifically asked that ‘user involvement’ be integral to the projects, and they were funded on that basis. The majority of these projects are now complete, although some are still ongoing. I am very happy to know that an evaluation* of the impact of the training of the research teams, and of the influence of ‘user involvement’ on the research is now underway. This piece is a reflection of my personal thoughts after being involved in one of them.

People who become involved in research as service users do so because they want to help improve services. Most of us are socially aware people who have learnt from our own experiences of health (and social care) services and believe that the substance of that knowledge can influence the development of both research and future services.
My experience of involvement in clinical research is that it is simply not the case that ‘scientific’ necessarily means ‘objective’. A great deal depends upon the research question, on how it is asked, how this reflects the particular interests of the researchers and clinicians, and on the many different methods or designs for collecting information and analysing it.

I believe that it is also influenced by the way ‘market forces’ encourage competition between researchers on the research being published in peer review journals, and that the nature of this type of competition has a way of encouraging insecurities between academics in the somewhat introspective world of academia. From my observations, this means that people can be scared of ‘user involvement’ partly because it doesn’t give researchers enough academic credit in research at the moment. So while for service users the major incentive is that a good collaboration between us and research professionals (including service user research professionals), will produce better research and services, that is unlikely to be the major consideration for many academic researchers.

Service users don’t know quite yet how many in the professional research world welcome us. I understand that this is partly due to ‘user involvement’ being relatively new in mainstream health research, lending itself to a sliding scale of interpretations. I absolutely understand that it takes longer, is, in the short term more expensive, and is seen to be yet another encroachment in the academic world’s already harassed and poorly appreciated existence. However, I can’t apologise for wanting to exert the maximum influence possible, and one thing that many of us come up against is a striking lack of democratic processes of working.

I think that many senior academics either lack confidence in reaching important decisions through open discussion, or they simply refuse to relinquish their power. My experiences have been that the design was poorly planned in terms of its ability to accommodate the research question, and, when it came to the crunch the senior academics lined up against the representative of the organisation contributing not only 15 years of her organisational experience in the issue, but her organisation’s membership, who were the women giving a major part of the information for the research.

One thing makes me quite nervous about this initiative of user involvement in research. Of course you get those who are scare-mongering and saying what poor research it will produce, without having read the results that it has already developed (again because it has probably not been published in those journals that they read!), but equally important, service users don’t want to be judged on the projects where user involvement has meant little real influence. If that is done, the mediocre research that will result from this cynical form of user involvement will deal a deathblow to this initiative before it has really begun. Also, individuals and specialist community organisations with a wealth of knowledge are already being alienated by the feeling that it’s just window-dressing.

However, I say to those who feel that way, once you have got over your disappointment, stress and fatigue, give it another go - but this time look more closely at the small print and try to draw up protocols (or rules of engagement!) that will ensure greater influence where it counts.

*NB. Further information about the evaluation is available from the Support Unit.
We are upper case!

We are always delighted to get a mention in any writing you do (even if you are disagreeing with us!), but when referring to INVOLVE in text, please make sure this is all in upper case. This helps to prevent confusion with the verb ‘involve’, and makes it clear that you are referring to an organisation. Many thanks!

Welcome

Following the very positive response to our call for new members for the INVOLVE sub groups, interviews were held in May and we are very pleased to welcome the following new sub group members:

• Sue Banton, Director, STEPS, Association for People with Lower Limb Abnormalities
• Karen Collins, Research Fellow, University of Sheffield
• Lester Firkins, Public Representative, Medical Research Council including co-chair of the Prion 1 Steering Committee
• Kirstine Knox, Deputy Director, National Translational Cancer Research Network (NTRAC)
• Maria Palmer, Director of Research and Clinical Effectiveness United Bristol NHS Health Care Trust
• Susie Parr, Connect, The Communication Disability Network
• Vanessa Pinfold, Research Manager, Rethink
• Tracey Williamson, Nurse Consultant, Research and Development, Intermediate Care, Penine Acute Hospitals NHS Trust
• Ayesha Wise, Independent Consultant and Researcher in Diversity Management

Thank you to everybody who applied for membership and please do apply again when we next advertise for new members.

Training Research report

Copies of the report ‘Training for service user involvement in health and social care research: a study of training provision and participants’ experiences’ undertaken by the TRUE project, are available from our website, and as hard copy from the Support Unit. The TRUE project was a collaboration of three organisations: CAPITAL (Clients and Professionals in Training and Learning, a user led training organisation), the Centre for Nursing and Midwifery Research at the University of Brighton, and the Research Department, Worthing and Southlands Hospitals NHS Trust.

The report of the INVOLVE Seminar on training for involvement in research will be available shortly.

Conference 2004: People at the Heart of Research. Book now!

INVOLVE’s national conference is an event for people who are interested in public involvement in research and who want to share information and ideas, discuss current practice, and reflect on future challenges and opportunities. There will be keynote speakers, presentations, workshops, poster walks and the chance for people to share their experiences and opinions.

If you are on our mailing list you should receive the booking form with this newsletter. If you are not on our mailing list please contact Professional Briefings for a copy:

Telephone: 020 7233 8322
Fax: 01920 487672
Email: london@profbriefings.co.uk
Post: Professional Briefings, Registration Dept, 37A Star Street, Ware, Herts. SG12 7AA
• Black and minority ethnic older people’s views on research findings
Consultations with groups of older people from black and ethnic communities found that older people often felt they had been ‘researched to death’ over the past 15 years. The work by REU highlighted the need to move beyond traditional research issues into ways of bringing change in practice. The study also drew on a literature review.

• Life on the Wards: Patient and Staff Views and Experiences of Acute Mental Health Care in Haringey
Undertaken by Researchers from Matrix Service User Group and Middlesex University, March 2004. This report is available on the research section of the Social Perspectives Network web site www.spn.org.uk or you can request a copy of the report by e-mail by contacting Brigid Morris, Project Co-ordinator, at brigidm@morrisb.fslife.co.uk or Michael Trifourkis, Member of Matrix Research Group, at trifourkis@aol.co.uk

• Consulted but not heard: a qualitative study of young people’s views of their local health service
Katherine Curtis, Kristin Liabo, Helen Roberts and Maggie Barker, Health Expectations 2004, Volume 7, Issue 2, pages 149-156
The objective of this study was to identify what children and young people in a health district in a large urban area experience as positive, and not so positive, about their local health services, in the light of a growing expectation that users play a more central role in the design and delivery of services.

• Patient and Public Involvement in Health: The Evidence for Policy Implementation
A summary of the results of the Health in Partnership research programme. Health in Partnership is a programme of twelve research projects exploring different aspects of patient and public involvement in health. Published May 2004, available on the publications section of the Department of Health website: www.dh.gov.uk

If you have written or know of any publications or articles relevant to public involvement in research that might be of interest to readers please contact Helen Hayes at the Support Unit with details hhayes@invo.org.uk

Interesting articles and publications

• Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach
Sandy Oliver et al 2004, Executive Summary, Health Technology Assessment Vol.8: No.15
The objectives of the study were to:
• Look at the process and outcomes of identification and prioritisation in both national and regional R&D programmes in health and elsewhere, drawing on experiences of success and failure.
• Identify the barriers to, and facilitators of, meaningful participation by consumers in the research identification and prioritisation.
Available on the HTA website: www.ncchta.org/
ALL TALK: Creating spaces for talk and change through experience-led research in mental health

Slough User Led Consultation (SULC) was established in 2002 with funding from Slough joint mental health services and supported by East Berkshire Mind. SULC provides the locality with an ‘experience-led’ consultation resource, but also enables people using mental health services to explore issues that are priorities for them. The research project ALL TALK - a study of talking and mental health - aimed to give people who had themselves experienced emotional distress control over all stages of the research process. It was hoped the findings would be more meaningful and relevant to mental health service users as a result.

Firstly, the group chose the research topic, feeling very strongly that the way in which mental health is talked about has a huge impact on people’s lives. The group designed an interview that used an interview ‘map’, allowing them as interviewers to follow issues that were important to the interviewee. Group members recruited many of the interviewees through their own peer networks, reaching people less engaged in services that would be beyond access to many research projects. They then carried out all the interviews.

Finally, interview transcripts were analysed individually, then brought to the group so that themes could be identified, and observations and recommendations made. The group was aware that their own issues continually emerged, but rather than try and eliminate this as ‘subjective bias’, felt that their experiences played an integral role in the process and should be recognised.

Findings looked at talking to family and friends, formal talking therapies, and culture and mental health among Slough’s South Asian communities. However, interviews and analysis often focused on the dynamics of conversations with mental health professionals, and the impact this had on the effectiveness of therapeutic interventions. Rewarding and difficult experiences were explored, insights made into barriers to developing therapeutic relationships, and recommendations made for moving beyond those difficulties.

The ALL TALK report has had an impact on the provision of talking spaces within local day services, the involvement of people using services in training staff teams - including formal nurse training - and a review of talking therapies in the locality. The project demonstrated that a research space created by people using mental health services, for people using mental health services, can be a powerful tool for change that makes a meaningful difference to people’s lives.

For a hard copy or pdf version of the report - ‘ALL TALK: a study of talking and mental health’ - contact Steve Gillard, Research & Development Manager, East Berkshire Mind, Email: stevegillarduk@yahoo.co.uk or Phone: 01344 861195.

Deadline for contributions for our next newsletter:
20th of September 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.
Public Awareness Strategy Group

In autumn 2003, the National Cancer Research Institute (NCRI) Consumer Liaison Group, which is led by people with experience of cancer, set up a new Public Awareness of Research Strategy group (PAWS).

The purpose of this new group is to critically examine approaches to promote public awareness of medical research, with a particular focus on cancer. Its members are drawn from the NCRI Consumer Liaison Group, representatives from the National Translational Cancer Research Network, the National Cancer Research Network Accrual Sub-Group, Macmillan Cancer Relief, the Medical Research Council Clinical Trials Unit, and the newly formed James Lind Alliance.

As an initial step, PAWS have commissioned three systematic reviews from the Centre for Reviews and Dissemination at York University. These will report on past and existing public awareness initiatives in research, strategies to impart messages, and initiatives that have resulted in changes in awareness or behaviours.

In future the work of PAWS will focus closely on improving awareness of research among patients and the general public, and will also develop educational initiatives targeted at younger people. The group plans to hold a one-day meeting in Spring 2005 to draw together the key stakeholders in this field with a view to identifying current activity in this area and to explore the potential for more integrated work.

If you would like more information about PAWS and its programme of activities please contact: Dr Tony Stevens, Consumer Liaison Lead, National Cancer Research Network, Arthington House, Cookridge Hospital, Leeds LS16 6QB. Telephone: 0113 392 7570; Email: t.stevens@ncrn.org.uk

The James Lind Alliance

A coalition of organisations representing patients and clinicians collaborating to confront important uncertainties about the effects of treatments.

The James Lind Alliance has been established to foster discussion among patients and clinicians (doctors, nurses, therapists, and others who treat patients) about variations in clinical practice, and to identify which uncertainties about the effects of treatments are sufficiently important that they should be addressed in clinical trials. The Alliance is being co-convened initially by INVOLVE, the Royal Society of Medicine, and The James Lind Library.

An ongoing series of meetings will be held at the Royal Society of Medicine to help promote discussion about how important uncertainties about the effects of treatments can be identified and confronted. The first annual meeting of the Alliance will be held as part of the annual Clinical Excellence conference, on Wednesday 1 December 2004, at the International Convention Centre in Birmingham.

If you would like any further information on the James Lind Alliance or you are a coalition of patient and clinician organisations in the UK interested in helping to develop the James Lind Alliance, please contact:

Patricia Atkinson, Administrator, James Lind Alliance Secretariat, Summertown Pavilion, Middle Way, Oxford OX2 7LG. Email: patkinson@jameslindlibrary.org
Does it make a difference?

After all the effort of finding people who can bring the perspectives of patients and carers to research, convincing them their efforts will be valuable, and telling them enough about what is needed to help them do a good job.... does involving them actually make a difference? That is what the NHS Health Technology Assessment programme (HTA) is trying to find out.

Since 1997 the HTA programme has been making a real effort to involve people from patient and carer organisations, and others with non-research roles, such as science writers. We have been trying things out on a small scale first, to learn as we go along. We've listened to feedback from the newcomers, other advisors and staff coordinating the whole programme. Then we've drafted and amended ways of working, and information resources, to help everyone involved.

You can read about how we are working now on the pages about consumers and the HTA programme on the website at: www.ncchta.org/consumers/index.htm and in a series of journal publications (listed at the end of this article). Now we are inspecting programme documents for a record of what people advising the programme (including people from patient and carer groups) have suggested, and for evidence of their suggestions having an influence on the programme’s research. We shall also be interviewing people involved in these processes.

What have people advised when commenting on research priorities? Has their advice been heeded when the research agenda has been set? How have people commented on research proposals? Have their comments influenced discussions and decisions about commissioning research? Do patients and carers say different sorts of things from clinicians and researchers when doing the same tasks? Are the views of patients and carers more or less likely to be taken on board than those of clinicians and researchers? How easy or difficult is it to take into account all these different views when setting the research agenda or commissioning a research project?

These are all questions we are trying to answer. With the help of programme staff and advisors, we hope to give you some answers next year.

By Sandy Oliver and David Armes (Social Science Research Unit, Institute of Education, University of London) and Gill Gyte (Cochrane Consumer Network).

NB. Since 1997, the NHS HTA Programme has described this work as involving consumers rather than patients and the public.

Journal publications for further information:


Guidelines for the Ethical Conduct of Survivor Research

These guidelines, by Alison Faulkner, 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 (Department of Health, 2001) which encourages the involvement of consumers in research.

Further details on the guidelines will be available in our next newsletter and a report will be available from the Joseph Rowntree Foundation from October 2004: to obtain a copy see the website at www.jrf.org.uk or call 01904 629241. For further information from the author, Alison Faulkner, Email AlisF@aol.com

Recruiting now for Consumer Research Panel!

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. Three Networks are taking part, with a staggered approach to initiating activity in each. The Central South Cancer Research Network are looking to establish a panel of patients, carers and the public in autumn 2004, and are recruiting now. Contact Andrew Gallini, User Involvement Facilitator, Telephone: 02380 725518 Email: Andrew.Gallini@hiowha.nhs.uk

The other two Cancer Research Networks involved are Humber and Yorkshire Coast, establishing a panel in spring 2005, and Surrey, West Sussex and Hampshire in summer 2005. Contact the Support Unit to contact these two Networks. More about this in our next newsletter.