Welcome to the Spring newsletter! There is certainly a lot happening in the world of public involvement in research at the moment. Amongst all the activity, INVOLVE has just published a new Public Information Pack and a leaflet on Good Practice. So read on to find out more about these and some of the interesting work that others have been doing.

INVOLVE is a national advisory group, funded by the Department of Health. If you would like to find out more about INVOLVE please visit our website www.invo.org.uk or call us on 02380 651088.

PIP is here!

March saw the launch of our Public Information Pack at a lunch event held in London for the many people who contributed to this important new publication. Harry Cayton, National Director for Patients and the Public at the Department of Health gave a keynote talk and put his support behind this new publication.

The Public Information Pack, or ‘PIP’ for short, was written for members of the public and deals with the why, what, who, how and where of getting actively involved in research. The pack is made up of four booklets in a folder. Each booklet can be used alone or they can all be used together. Continued’
• The first booklet introduces the pack and the basic concepts in public involvement in health and social care research.

• The second booklet looks at what kinds of activities and opportunities there are to get actively involved in research and how to get started. It includes information on how to approach researchers and research organisations and on thinking through what you might want to contribute by getting involved.

• The third booklet gives details of relevant groups, organisations, and research networks. It tells you what they do, and how they can be contacted.

• The fourth booklet is a ‘jargon buster’ with explanations of many of the research related words used elsewhere in the pack.

The pack is printed in A4 format in full colour and includes many examples and accounts from people’s experiences of being actively involved in research in order to give readers a ‘feel’ for what it might be like. It is also available as an audio CD. If you require a copy in another format, please contact us.

A wide variety of people were involved in different ways in the development and production of the pack, including a range of health and social care service users, carers, and researchers. Particular thanks go to Jenny Walton and Carey Ostrer who sat on the advisory group throughout the project, and gave us the benefit of their perspectives as people with experience of long term conditions who got involved in research.

The broad content of PIP was developed at a workshop where a variety of people who use services contributed to a discussion about what should be included. We continued to consult through the various drafts that were produced, and we hope that this exciting new publication will be helpful to members of the public interested in getting involved in health and social care research.

To order a free copy, contact the INVOLVE Support Unit - email pip@invo.org.uk or phone 02380 651 088, textphone 02380 626 239, or write to us at INVOLVE Wessex House, Upper Market Street, Eastleigh, Hampshire SO50 9FD.

INVOLVE Support Unit News

New INVOLVE Good Practice leaflet published!

We have also recently published a folded leaflet called ‘Good practice in active public involvement in research’. Aimed directly at researchers and research organisations, it should also be useful for research commissioners, research managers, members of research ethics committees, and research organisations in general. It is designed as a convenient quick reference guide to help researchers think through the key good practice issues when planning to involve members of the public in research work.

This leaflet condenses the key good practice points to be found scattered throughout INVOLVE publications as well as those written by others, and refers the reader on to more in-depth reading. It has been developed in consultation with a variety of researchers, research advisors and members of the public.
who have experience of being involved in research.

You can view the leaflet on the INVOLVE website, and we would be delighted to post you a supply if you can use them. As with all INVOLVE publications the leaflets are completely free.

Making Dutch connections
On March 29th 2007 members of INVOLVE and the Support Unit met with thirteen Dutch colleagues including members of ZonMw, a Dutch organisation for health research and development, as well as patients and service users and representatives from other Dutch health organisations. It was a very enjoyable day with opportunities to share information and experiences around public involvement in research. We made excellent contacts which we look forward to continuing to develop in the future.

People in Research
INVOLVE led on a UK Clinical Research Collaboration (UKCRC) project to develop a new website called People in Research www.peopleinresearch.org/

People in Research aims to help members of the public make contact with organisations that want to actively involve people in clinical research. The heart of the website is a searchable database of information about organisations or groups that sometimes look for members of the public to get actively involved in their work.

The involvement of members of the public has been a key part of the development of this resource. This has included membership of the project steering group, the website design team and also a larger group of people who will be involved in testing the site for us over the coming few months. So thank you for everybody’s help.

The site is currently a pilot and we welcome your feedback and comments - so please visit it and have a look. There is a feedback form on the website or for further information or details about how your organisation can become part of the website email peopleinresearch@ukcrc.org or contact Philippa Yeeles at the UKCRC on 02076 705153.

Email problems
Recently there have been some problems with people not always receiving emails from us. Please ensure that your system is set up to recognise and accept emails from INVOLVE so that we can continue to keep you up to date and in touch. If you have emailed us and haven’t received a reply, please call us. For further information contact Gill Wren at the Support Unit on Email: gwren@invo.org.uk Tel: 02380 651088.

Ethics? Whose ethics?
The Central Office of Research Ethics Committees (COREC) now renamed the National Research Ethics Service (NRES) partnered up with the NHS R&D Forum and INVOLVE recently to facilitate an event for people who use services and Research Ethics Committee members to explore different perspectives on research ethics review. The event, which took place in March, was lively and informative, and a report will be available soon. The event will help NRES in further developing its work in this area. For further information contact Roger Steel at the Support Unit Tel: 02380 626 233 Email: rsteel@invo.org.uk
Does your website link to ours?

Do you or does your organisation have a website? Have you thought about adding a link to the INVOLVE website? If you would like to do this you can direct your link to http://www.involve.org.uk

If you intend to provide a description with your link, our preferred wording is:

“INVOLVE is funded by the Department of Health to promote and support active public involvement in NHS, public health and social care research. INVOLVE believes that involving members of the public leads to research that is more relevant to people’s needs and concerns, more reliable and more likely to be used.”

INVOLVE internal reimbursement and payments policy

In line with the DH publication ‘Reward and Recognition’ we have produced our own INVOLVE policy document on paying and reimbursing members of the public when they work with us. This is available to view on our website by clicking Publications > About INVOLVE or we can send you a copy.

Interesting articles and reports

• Ethics in social research: the views of research participants
Undertaken by NatCen and involving 50 in-depth interviews, this suggests that the focus of ethical research conduct might usefully be based on sound judgments from researchers and interviewers, rather than prescriptive and bureaucratic approaches. The study has now been published by the Government Social Research Unit on: www.gsr.gov.uk/professional_guidance/ethics.asp
Government Social Research Unit, Room G.38, HM Treasury, 1 Horse Guards Road, London SW1A 2HQ.

A report written by Frederick Marais on behalf of the Community Advisory Panel of this study. March 2007
ISBN 978-0-9554779-0-4
Copies of the report can be downloaded free of charge from: www.imperial.ac.uk/medicine/pcsmpubs

• Including People with Communication Disability in Stroke Research and Consultation - A guide for researchers and service providers
Includes communication tips for making research interviews and conversations productive; practical suggestions to make research documentation accessible; help and encouragement to ensure everyone can share their views and experiences with you; ideas and inspiration to make your stroke research and consultation inclusive. ISBN 0-9536042-8-4
Costs: £20 (plus £1.50 postage and packing) UK only. To order or find out more see the Connect website www.ukconnect.org or contact Maria McDonnell. Tel. 020 7367 0866 mariamcdonnell@ukconnect.org or write to Connect, 16-18 Marshalsea Road, London SE1 1HL.
My experience of becoming a member of a volunteer panel

By Doreen Russell

Two years ago I saw an advert for Volunteer Research Worker Assistants. I had no training or specialist knowledge in research, but I did have an interest in health and social care and as this was all that was required, I went along to an information day.

The project was Public and Patient Involvement in Research (PPIRes). At the meeting I discovered it was now government policy to involve members of the public from all backgrounds and age groups to read and comment on pieces of research. This would give a voice to the public in planning and delivery of research undertaken by students and professionals from the University of East Anglia and all the local NHS organisations and Trusts. It is thought that this will, in time, improve the care of the NHS and make it more ‘user friendly.’ I would be part of a panel of volunteers and would, when I could, attend panel meetings, usually held in the evening in the centre of Norwich. These meetings would include talks by people involved in research and other topics of interest to volunteers. All out of pocket expenses such as travel costs, child care etc. would be refunded. There is a co-ordinator who supports the project.

As a volunteer I am sent research proposals to read and comment on, as it is important that information sheets and questionnaires are easily understood by patients and carers. I am able to say if there are any health related subjects I would be particularly interested in and I can decline to become involved without giving a reason. Some of the volunteers are retired but others have busy working lives and/or young families. Some with chronic illness are, for medical reasons, not always available.

Some volunteers meet with researchers and sit on project steering groups or on research committees. We have recently held a successful conference for researchers and volunteers. I have enjoyed working for PPIRes. I feel, as volunteers, our input to health is valued.

For further information about PPIRes, please contact: Barbara Staffa Tel: 01603 307346 Email: barbara.staffa@norwich-pct.nhs.uk

Deadline for contributions for our next newsletter:
5th June 2007

We welcome contributions about any aspect of public involvement in NHS, public health and social care research. Please ask us for information about submitting an article.
Involving excluded groups: user involvement in palliative care research

By Peter Beresford

As user involvement becomes more of a reality in research, questions are raised about the feasibility of involving particular groups; the particular obstacles and challenges that might emerge and how these might be overcome. One such group are people who use hospice and palliative care services. They include two groups of service users; people with life limiting illnesses and conditions and people experiencing bereavement. There has been some wariness in this field about involving such service users. Both groups can clearly be expected to be experiencing major personal and social difficulties. Patients, in addition, may have little time and be experiencing significant pain and discomfort towards the end of life.

In this project we were anxious to involve such service users as fully as possible in the research. The focus of the project was what service users want from specialist palliative care social work. This was a large scale UK wide qualitative study of service users supported by the Joseph Rowntree Foundation, involving a total of 111 service users in individual interviews and group discussions. Nine percent of participants identified themselves as black and/or members of minority ethnic groups. The only service users not included were those in serious distress, or very close to death, according to the professional judgement of social workers.

The research approach adopted here was user involvement research, because palliative care service user organisations were not available to take a controlling or collaborative role. However, the focus of the project was inspired by previous work involving palliative care service users and from the user controlled work of Shaping Our Lives, on user defined outcomes in support, practice and services In addition, the research shared the commitment of seeking to make change at personal and broader social levels explicit in the philosophy of user controlled research. This was signified by an ongoing process of actively seeking to engage with and influence specialist palliative care social work practitioners and educators and of engaging with palliative care service users.

Specialist palliative care service users were involved in both the design and management of the project. They were involved in all its stages, including finalising the research focus, developing the research schedule, analysing and disseminating findings. This involvement had a number of expressions. Palliative care and other service users were included in the Advisory Group which met regularly through the life of the project. Three Steering Groups of palliative care social work service users were also set up and met during the project. Their purpose was to enable there to be continuity of user involvement in the project, offering ideas and feeding back on its progress. It was expected that their membership might alter during the course of the project, given that some service users were likely to die. Newsletters were also produced to keep everyone who participated in the project informed about and involved in the progress of the work.

This project showed that palliative care service users can be involved in research ethically and effectively if appropriate forms of and support for involvement are provided.
Public involvement in the HTA programme assessed

The Health Technology Assessment (HTA) programme is taking forward recommendations from the first detailed study of public involvement in research management. A free standing executive summary of the study, ‘Evaluation of public influence on the HTA programme’ has now been published and can be viewed on the HTA programme website www.hta.ac.uk/consumers/evaluation.htm

The research was commissioned by the National Coordinating Centre for HTA to assess the HTA programme’s efforts to involve the public in its work identifying NHS evidence gaps and commissioning and publishing research to fill them. From the results an action plan has been put together to progress public involvement in the HTA programme. This includes increasing the guidance, written information and financial support provided for patients and the wider public (collectively known as service users).

The HTA programme provides information about the effectiveness, costs and broader impact of health care treatments and tests for those who use, manage and provide care in the NHS. The programme actively pursues public involvement in its research activities by working together with people who use NHS services, carers, and the organisations that represent them.


Led by Sandy Oliver, Reader in Public Policy at the Institute of Education, University of London, the research looked at the numbers of service users involved in the different stages of the HTA programme, the different ways they were involved with its work, what sort of support they were provided with and how their input was used by the programme.

The researchers found that service users have successfully influenced the HTA programme’s work identifying and prioritising research topics. Their contributions have highlighted patient and carer views, changing the focus of research topics or endorsing plans for research in the area. However boundaries were identified between the HTA programme and service users which have caused difficulties with effective working and communication. Issues identified are now being addressed through the action plan, including improving the support and guidance offered to service users, raising the profile of service users internally, and increasing training and support for HTA members recruiting service users.

“The HTA programme provides a reliable, sustainable system for public involvement, but public input and influence is limited by organisational boundaries,” says Sandy Oliver. “This report will help the programme to advance its existing work in this area, as well as informing others more widely, developing and encouraging public involvement in all areas of health research.”

For more information visit www.hta.ac.uk or contact Naomi Stockley at the NCCHTA, Wessex Institute for Health Research & Development, Mailpoint 728, University of Southampton, Boldrewood, Southampton SO16 7PX Telephone: 02380 595646 Email: ns5@soton.ac.uk
“How can clinical trialists serve the needs of clinicians and patients more effectively?”

This is a one day conference jointly organised by The James Lind Alliance and The Lancet. It will take place on Monday 25 June 2007 at the Royal Society of Medicine, 1 Wimpole Street, London.

The morning session will address whether the right trials are being carried out, the right questions are being asked, whether the trials are done in the right way, and if this results in the right outcomes. The afternoon session will consider how the evidence can help individualise treatment decisions.

For more information and to register please view the James Lind Alliance website www.lindalliance.org or contact Marty Kilby, JLA conference coordinator at marty.kilby@virgin.net or telephone 01763 289191.

A collection of useful examples

A collection of case studies of user and carer involvement in systematic reviews has been produced to complement SCIE’s Research Resource 1: Systematic review guidelines.

The intention is that this document will be updated as new reports of user involvement in reviews become available. The three examples included provide an overview of user and carer participation in systematic reviews in different aspects of the review process.

Available to download from the publication section of the Social Care for Excellence (SCIE) website www.scie.org.uk or from Social Care Institute for Excellence, Goldings House, 2 Hay’s Lane, London, SE1 2HB Telephone: 02070 896840.