Welcome to our Summer Newsletter. We are busy planning for our Conference in November and look forward to seeing you there!

INVOLVE 6th National Conference

INVOLVE’s 6th National Conference - Public involvement in research: getting it right and making a difference - November 11th and 12th 2008 at East Midlands Conference Centre in Nottingham.

We are delighted to announce that Joan Saddler OBE, Director of Patient and Public Affairs, has agreed to be the keynote speaker for our conference.

This promises to be an exciting event for everyone who is interested in public involvement in NHS, public health and social care research, and there will be plenty of time to discuss, reflect, network and socialise. We had an extremely successful response to our call for presentations with 160 submitted. Thank you to all of you who responded. The conference will include 8 workshops plus a number of additional single issue sessions, around 40 papers, a wide variety of posters and poster talks - and a pantomime!

If you would like a copy of the newsletter in an audio or large print version, or if you would like it in another format, please contact us.

www.invo.org.uk
These are some of the themes and key issues in the programme:

Knowledge about public involvement in research
• experiences of involvement in research projects or initiatives
• involvement in particular stages of research - e.g. prioritising or reviewing research applications, getting ethics approval, presenting research information and findings
• partnership working - e.g. between service users, researchers and /or practitioners
• involving communities in research including black and minority ethnic communities, children and young people, people with learning difficulties
• learning from user researchers

Debating future directions
• soapbox session - voicing issues
• taking stock more generally - e.g. reflections on where we have got to
• developing strategies for involvement
• policy or practice changes as a result of public involvement in research
• building knowledge and evidence of public involvement in research
• researching the impact of involvement
• planning future directions

Places are limited to 300 so register now to avoid disappointment. If you have any questions or need support in completing your registration form please contact our conference organisers, Professional Briefings:
Telephone: 01920 487672
Email: london@profbriefings.co.uk

Visit our conference website for further information on the conference, programme updates and information on how to register:
www.profbriefings.co.uk/involve2008

INVOLVE Support Unit
News

National Research Ethics Service
We are pleased to be working with the National Research Ethics Service and this summer we are to undertake a survey of lay Research Ethics Committee members on their behalf. We hope to find out more about who they are, the perspectives they bring and any support they need. We will update you on this work in future newsletters.

Inclusion and Exclusion Conference 2008

The Social Services Research Group (SSRG), the Race Equality Foundation (REF), and INVOLVE are calling for papers for their conference on 20th November 2008. The overall aim of the conference is to explore research on racism and ethnicity and the messages for policy and practice in key areas of public services, including: housing, health and social care for adults and children.

We are particularly interested in papers which explore the impact of research on policy and practice, where service users, community groups and practitioners are involved, and where papers are presented jointly by users/practitioners/researchers. The closing date for papers is 1st September 2008.

Further information and the call for papers can be downloaded from the Race Equality Foundation website:
www.raceequalityfoundation.org.uk/

The conference booking form will be available on the website shortly.

www.invo.org.uk
Social research and public involvement: colliding worlds?

INVOLVE and the Economic and Social Research Council (ESRC) National Centre for Research Methods are holding a joint seminar, entitled: ‘Social research and public involvement: colliding worlds?’ This will take place on Friday 26th September 2008, at the National Council for Voluntary Organisations, London N1 9RL.

Places for this one-day seminar are limited and priority will be given to researchers, including user researchers, with an interest in public involvement in applied social science research.

For a booking form and more detailed information about the programme please email researchseminar@involve.org.uk or contact Maryrose Tarpey on 02380 651088.

Out and about

Visit the INVOLVE stand and meet us at the following events:

• National Cancer Research Institute Conference – Making Cancer Research Partnerships work
On October 5th to 8th, 2008, we will be joining Macmillan Cancer Support on their stand. For further details please see the NCRI website: www.ncri.org.uk/ncriconference

• User Involvement in Research: The Keele Experience
Tuesday 14 October 2008
10am – 3pm at Keele University, Staffordshire

Sarah Buckland, Director of INVOLVE, will be opening the conference which will be led by the Research User Group discussing their involvement in all stages of research in relation to the INVOLVE cycle.

For further information please contact: Claire Ashmore at c.ashmore@cphc.keele.ac.uk
Telephone: 01782 584722

Interesting articles and publications

• Involving people affected by cancer in research: a review of literature
Hubbard G, Kidd L, and Donaghy E.
European Journal of Cancer Care, 2008
Volume 17, pages 233-244

The purpose of the literature review was to find out why people affected by cancer have been involved in research; how they have been involved and the impact of their involvement.

• Striving for independence: experiences and needs of service users with life-limiting conditions
Phil Cotterell
Journal of Advanced Nursing, June 2008
Volume 62, issue 6, pages 665-673

This paper is a report of a study to explore what service users with a range of life-limiting conditions identify as their key experiences and needs generally and specifically, from health and social care services. A participatory approach was used in 2003-2004 with both the researcher and a group of service users working together in all stages of the study.

• Clinical Trials - A Brave New Partnership. A new doctor-patient relationship in research
Hazel Thornton

An outline of the development of a ‘brave new partnership’ in clinical trials is provided in this specific personal account.

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@involve.org.uk

www.invo.org.uk
Patient and public involvement in research at Ataxia UK

By Laura Rooke, Research Officer, Ataxia UK

Ataxia UK is the UK’s leading charity for people affected by the ataxias, uncommon neurological disorders affecting co-ordination and balance. We fund quality scientific research to develop safe, effective treatments and provide services and support for people with ataxia, their families, friends and carers.

We involve our members (called ‘Friends’) in research through the Scientific Advisory Committee (SAC), which evaluates the research grant applications we receive and makes recommendations regarding which projects should be awarded funding, and through the Board of Trustees, which always has people with ataxia or with close links to someone with ataxia (e.g. parents) making up at least a third of its members.

The SAC has had lay members since its creation in the year 2000, and lay members attend the same meetings with the same voting rights as scientific members. The Committee presently consists of twelve people, including scientists, staff representing Ataxia UK, and lay members. Currently there are three lay members - two are people with ataxia and one is the father of a child with ataxia.

The lay members were recruited through an advertisement in our magazine, the Ataxian, and a number of responses were received, suggesting our Friends were keen to be involved. One of the problems we faced in selecting people to join the committee was how to define ‘lay’, as some of the respondents had scientific qualifications and we had to consider, when does someone become too qualified to be a lay representative? In fact, one person ended up being invited to join the Committee as a scientific adviser!

As well as these official routes of involvement, Friends of Ataxia UK are in frequent contact with the charity and sometimes contribute to research activities through suggesting lines of research which they would like to see investigated further.

My experience of involvement with Ataxia UK

By Nigel Kilvington

I was diagnosed with Friedreich’s Ataxia around two years ago after a year of various tests; my neurologist suggested that I contacted the Ataxia charity since they are very helpful.

After calling the Ataxia UK helpline* they sent me various documents which explained what the condition is, I also viewed all the information contained on their website www.ataxia.org.uk
From my initial contact I then became involved in the setting up and running of a support group in Ipswich for people with all forms of Ataxia to share experiences and to offer support to each other.

Ataxia UK produce a quarterly magazine, the Ataxian; in it Ataxia UK were looking for lay members to join the Scientific Advisory Committee (SAC) which is a group who review and make recommendations of funding of research projects to the board of Ataxia UK.

I decided to volunteer for the SAC after speaking to the Ataxia UK Research Projects Manager who explained what would be required and was able to allay my fears about not understanding the science and highlighted what input I could offer the SAC.

Having been accepted on to the SAC, I now find reviewing the scientific proposals very interesting. This is because it provides me with some insight into the approaches that the scientific community are taking to understand and hopefully find cures for all ataxia conditions.

Ataxia UK also hold an annual conference and during the 2007 conference we were asked if people could be interested in taking part in the Association of Medical Research Charities (AMRC) Natural Group Project which is where a group of charities review how they approach involving lay members in reviewing and recommending research projects.

The aim of the Project is to create a guideline of best practice for the involvement of lay members in all aspects of a charity’s research programme.

*Ataxia UK Helpline: 0845 644 0606

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Setting research priorities: a layman’s experience

Personal View: Lester Firkins

British Medical Journal

12 July 2008 Volume 337: a212

www.bmj.com/

In this excellent article Lester, a former banker, discusses his involvement in research following the loss of his 25 year old son, Ellis, to new variant Creutzfeldt-Jakob disease (CJD) seven years ago. As a result of this involvement he suggests that:

- Involvement of patients and their professional and lay carers in shaping clinical research should be seen as normal and should be welcomed by researchers
- It is illogical to begin planning new research without first finding out systematically what can be known from existing research
- Unpleasant elements of competition among individuals are as present in the public world as they are in the grimy world of banking. Academic status and fiefdoms must take second place to patients’ interests, particularly when funding for research is coming from the public purse, and there must be a totally open culture of sharing and publication, and
- Citizenship should encourage us all to know more about clinical trials and to participate in good trials, in the same way that we should all carry an organ donor card.

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Involving people affected by cancer in clinical trials

Lindsay Thompson, Claire Murphy, Claire Vale and Bec Hanley - Medical Research Council Clinical Trials Unit - Cancer Group

In the last 10 years or so, more researchers have recognised that public involvement can improve the quality of research. But this involvement is often piecemeal - with researchers involving the public in some pieces of research, but not others.

For the past two years we have been working to try to ensure that people affected by cancer are involved in all of the cancer research undertaken by the Medical Research Council (MRC) Clinical Trials Unit (CTU). We have received a lot of help from a number of people affected by cancer, and we're really grateful for that.

In 2006, we set up a Consumer Involvement Group within the Cancer Trials Group at the MRC CTU. We recognised that there was no policy in involvement in our trials, and that the amount of involvement in different trials was very varied - some trials had a lot of involvement and others had none. We wanted to achieve a more consistent approach. Our first job was to develop some guidelines for consumer involvement. Roger Wilson, the former chair of the National Cancer Research Institute Consumer Liaison Group, played a major role in putting together these guidelines.

We also decided to interview all of the senior cancer project leads within the CTU to ask them about how they were involving consumers and what they thought the barriers to involvement were. We hoped that these interviews would also raise awareness about the importance of involving people affected by cancer in our trials, and enable managers to ask questions about the guidelines we had produced.

As well as listening to the views of staff within the CTU, we also wanted to listen to the views of people affected by cancer who were involved in our trials. So, in November last year, we had a meeting. 11 people affected by cancer, most of whom were members of one of our cancer trial management groups, came along. The meeting was really useful. One of the key recommendations was that we should develop some information for people who are new to trial management. So we have now developed an induction pack. And we’re hoping to plan some training.

We certainly aren’t there yet - but we feel we are getting closer to the point where it’s the norm for people affected by cancer to be actively involved in all of our trials. We’re very grateful to the people affected by cancer who have helped us to take this work forward.

We’ll be sharing our experience at the INVOLVE conference, but would be very interested to hear from anyone working within clinical trials, and especially cancer clinical trials, who has experience we could learn from.

For further information please contact Lindsay Thompson lt@ctu.mrc.ac.uk

Deadline for contributions for our next newsletter:
28th November 2008
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 People in Research Symposium

Bec Hanley, Jill Thompson and Rosemary Barber

In 2004, Anne McKenzie came over to the INVOLVE conference. Anne’s role is to support public involvement in research that is undertaken at the School of Population Health at the University of Western Australia, and by a charity called the Telethon Institute for Child Health Research. In Australia, public involvement is called ‘consumer and community participation.’

Anne was inspired by what she saw at the INVOLVE conference. She managed to get some funding from the Australian government to organise a similar event in Australia. The Involving People in Research Symposium, which took place at the University of Western Australia in March this year, was the first of its kind in Australia.

We were lucky enough to be able to attend this symposium. Australian researchers, community members and consumers talked about the work they are doing to promote involvement. We were particularly interested in and inspired by the work that people from the Aboriginal community have done to ensure that they have a say in research. For example, any research that will affect Aboriginal people has to be approved by an Aboriginal ethics committee, and must actively involve Aboriginal people. We also heard about the training of Aboriginal researchers.

We were struck by the fact that there seemed to be more of a focus on community participation. We felt that involvement at a community level (rather than at an individual level, which is what seems to often happen in England) seemed to promote more sustainable relationships between community members, researchers, research commissioners and policy makers. Perhaps this is a lesson that could be usefully applied in the UK?

Although the Australian government seemed in principle to be committed to involvement, we noticed that there were far fewer examples of involvement in individual research studies than we see in the UK, and that there is little support available for researchers who want to actively involve people in their research. The notable exception to this is the work that Anne McKenzie and her colleagues are doing at the University of Western Australia and the Telethon Institute for Child Health Research. You can read more about this work in a publication by Anne and Bec Hanley. There is a link to this on the INVOLVE website.

Being part of the conference was a wonderful opportunity. Special thanks to Anne McKenzie and her team who looked after us during our stay.

More information about the conference is available at: http://www.sph.uwa.edu.au/go/sph/involvingpeopleinresearch
People in Public Health study
The People in Public Health study is being undertaken to improve understanding of approaches to support lay people in public health roles. The researchers want to find out about the different ways people are involved and what health services can do to recruit, develop and support them.

The study aims to find out as much as possible about what is happening in practice and also give people the opportunity to link into this national study. They are inviting individuals and organisations to join their Register of Interest and give brief details of any projects or schemes involving lay people. There will eventually be a database to promote shared learning about this type of scheme. Further information and the Register of Interest www.leedsmet.ac.uk/health/piph/

Reminders!
Don’t forget, on our website www.invo.org.uk you can:
• sign up for email alerts and be one of the first to find out about INVOLVE news
• add the INVOLVE website to your list of favourites

If you are a member of the public who would like to find out which organisations are looking for people to get involved visit People in Research www.peopleinresearch.org/

Outcomes in clinical research - whose responsibility?
A seminar organised jointly by the James Lind Alliance and the Social Science Research Unit, Institute of Education, Thursday 20th November 2008, 10am-4pm, Institute of Education, University of London.

For further information please visit the James Lind Alliance website: www.lindalliance.org/News_Events.asp

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INVOLVE is a national advisory body that is funded through the National Institute for Health Research to promote and support public involvement in NHS, public health and social care research and development.
If you would like to receive a copy of the newsletter or find out more about INVOLVE, please contact us.

Friendly disclaimer: The views expressed in this newsletter and in any enclosures are those of the authors and not necessarily those of INVOLVE or the National Institute for Health Research. Articles are selected for the sole purpose of stimulating ideas and debate on public involvement in research.