

newsletter

Welcome to the Summer 2011 edition of the INVOLVE newsletter. These are exciting times for INVOLVE with the appointment of Simon Denegri as our new Chair and the recruitment of new members to our Working Groups. If you are interested in becoming involved in INVOLVE by applying to join one of these Groups, please take a look at pages six and seven.

Danish Study Group visits INVOLVE

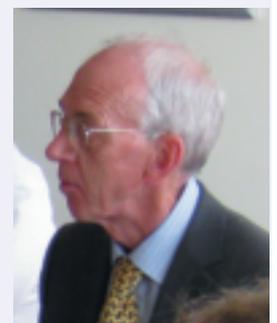
In June, we were delighted to welcome to the INVOLVE offices in Eastleigh members of the Danish Study Group for Patient Involvement in Research, part of the National Forum for Health Research.

The Group, which includes representatives from the Danish Cancer Society, the Ministry of Interior and Health, and Aarhus and Copenhagen University Hospitals, is chaired by Professor Mogens Hørder, Dean of the Faculty of Health Sciences at the University of Southern Denmark. The Group was established to describe the aims and potentials for further patient involvement in health research and recommend actions for improvement; and to identify and apply successful, feasible national and international experiences. Continued →

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**Professor
Mogens Hørder**

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. Printed on recycled paper.

INVOLVE Coordinating Centre News

We were joined for this visit by colleagues from Research Design Services South Central, the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC) and Clinical Research Network (NIHR CRN), and the Macmillan Survivorship Research Group, University of Southampton. Our Danish visitors were particularly interested in four key areas of public involvement in research:

- the current UK environment in relation to public involvement, e.g. regulatory initiatives and funding
- the barriers to public involvement, how to overcome these barriers and address scepticism
- how to get patients involved in various stages of the research process and the difference this is making
- practical considerations such as the recruitment and training of service users and health professionals.

We had a very productive day and our Danish visitors have commented on how much they valued this shared learning opportunity. We will be looking at ways of developing our relationship and we look forward to hearing more about the Group's work in future.



The Danish Study Group



Welcome to Paula

We are very pleased to welcome Paula Davis to the team at the INVOLVE Coordinating Centre. Paula joins us from the University of Southampton as an Information Officer and will be working with us to develop and edit content for the newsletter and our website. Paula will be working Monday, Tuesday and Wednesday. You can email her at pdavis@invo.org.uk



New INVOLVE website

We will be launching a new look for our website in Autumn 2011. We will have a new searchable resource centre where you will find:

- INVOLVE publications
- INVOLVE newsletters
- Putting it into practice database – which details references with practical information on public involvement in research
- Evidence library – which was previously know as the invoNET library and holds references looking at the nature, extent and impact of public involvement in research
- New online version of the INVOLVE briefing notes for researchers on how to involve members of the public in research.



INVOLVE Strategic Plan

Thank you to all of you who commented during our Strategic Plan consultation. We had an excellent response of very helpful and constructive comments. We will let you know as soon as the Strategic Plan has been finalised and is available on our website.

Interesting articles and publications

• **Public involvement in the systematic review process in health and social care: A narrative review of case examples**

Jonathan Boote, Wendy Baird and Anthea Sutton
Health Policy Journal (article in press), 2011
A new paper on patient and public involvement from colleagues working together at the University of Sheffield.

• **Seen but not heard – Ethnic minorities' views of primary health care interpreting provision: a focus group study**

Duncan Barron, Caroline Holterman, Pieter Shipster, Sherma Batson and Mohammed Alam
Primary Health Care Research & Development 2010, Volume 11, Number 2, pages 132-141
This paper, which was shortlisted for the Royal College of General Practitioners Paper of the Year 2010, was initiated by a Black and Minority Ethnic (BME) forum in Hertfordshire. As part of the project, training was delivered to members of BME communities to enable them to conduct research interviews with their peers.

• **Evaluation of the User Involvement in Local Diabetes Care project**

Bec Hanley, Kristina Staley and Charlotte Stevens, TwoCan Associates, May 2011
This evaluation report looks at the impact of user involvement in three NHS organisations and focuses on the steps and resources needed to develop good quality involvement in diabetes care.
www.twocanassociates.co.uk/pubs.php

• **Making the Difference. Patient and Public Involvement The Way Forward: Examples and evidence from the Clinical Research Network**

Edited by Derek Stewart, May 2011

This collection of factfiles and case studies from the National Institute of Health Research (NIHR) Clinical Research Network shows that the involvement of patients, carers and the public is making the difference in research. The examples are based on the Topic Networks (diabetes, mental health, cancer, dementias, stroke and medicines for children). Further information from the Comprehensive and Primary Care Network will be added in the future. www.crnc.nihr.ac.uk/ppi

• **Patient and Public Involvement Toolkit**

By Julia Cartwright (Author), Sally Crowe (Author), Carl Heneghan (Series Editor), Douglas Badenoch (Series Editor), and Rafael Perera (Series Editor)

Published March 2011, BMJ Books
ISBN 1405199105

A pocket guide providing advice and tips on involving the public in health service design and research.

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



Understanding and improving transitions of older people: a user and carer centred approach

By Jo Ellins

This project explored older people's experiences of transitions in care, what needs older people have during times of transition, and whether those needs are being met by local services. The project focused on four groups of older people whose needs are not well understood and/or whose needs might be expected to be more complex. This article is about one of those groups, older people from black and minority ethnic (BME) communities, and the research that explored the experiences of this group took place in Leicester. Eight people from Leicester's BME communities contributed to the project as co-researchers.

The co-researchers were found by the research lead forming a partnership with the local branch of Age Concern, with the organisation's BME community development worker team playing a particularly important role. Working through Age Concern's networks, information about the project and the opportunity to become a co-researcher was distributed to many local BME groups across the area. Given the responsibilities associated with the role, people were asked to submit an application and a short (informal) telephone interview was carried out. All co-researchers were Criminal Records Bureau (CRB) checked.

The co-researchers were involved in:

- identifying key issues to explore in the in-depth interviews, helping to ensure that the research

focused on the issues that mattered most to older people from their communities

- developing interview tools, including a visual representation of the transition and interview prompt cards
- reviewing data to identify the main themes and make sense of any complex issues emerging from the interviews
- presenting the findings at feedback events
- participating in 'All Sites Days' which brought together people from the different areas taking part in the project.

Training

A training programme was designed for co-researchers, which was delivered at various stages of the project. In addition, the research lead also met with the co-researchers as a group as and when needed. The training programme was designed to fulfil three aims:

1. to support co-researchers to develop the knowledge and skills needed to fulfil their role
2. to enable relationships and trust (between co-researchers, and between co-researchers and the research lead) to develop
3. to create opportunities for co-researchers to shape the research process.

Early training sessions included role play activities to practise interview skills and the research team developed a DVD (with members of a service user and carer network at the University of Birmingham) with good and bad interview scenarios to encourage discussion. Support was offered to co-researchers on an ongoing basis in many ways, including debriefs at the end of each interview. The involvement of the voluntary sector partner was also vital in this respect, as it gave co-researchers a source of support from somebody who was independent of the research team.

What difference did public involvement make?

The project's participatory approach was evaluated to explore what difference it made in terms of the research process and outcomes. The evaluation clearly demonstrated that both the academic researchers and co-researchers really enjoyed working together and learning from one another. The involvement of co-researchers in Leicester benefitted the project by:

- helping to ensure that the research focused on issues that matter to older people
- putting people at ease in interviews and helping to elicit richer insights
- playing a vital role in approaching and recruiting people to take part in the research
- carrying out a number of interviews in their own community languages
- their involvement in feedback activities which was particularly beneficial: they 'gave voice' to the people who had shared their experiences by selecting and reading out quotes from interviews at feedback events.

What we learnt

Learning from the project suggests that the following factors contribute to the success of co-research approaches:

- recognise the value of peer support and take opportunities to develop this as part of the research process
- always be open to the unexpected and to new ways of doing things
- be open and flexible in your own boundaries, for example regarding self-disclosure
- make sure that practical matters – like payment, transport, CRB checks – are properly thought out
- allow enough time for regular communication and effective support
- constantly work at building and maintaining relationships and trust

- treat co-research as a learning process, and work together to try and solve problems and overcome challenges
- keep co-researchers informed about what's happening, even if nothing's happening!

Contact: Jo Ellins, Health Services Management Centre, University of Birmingham
Email: J.L.Ellins@bham.ac.uk
Website: www.hsmc.bham.ac.uk

Developing consumer involvement in primary care research: final report of a developmental evaluation

Rachel Nickeas and Jane Stewart on behalf of Nottingham Primary Care Research Partnership (NPCRP) July 2010

This report is the result of an evaluation of the development of consumer involvement in primary care research activities in Nottingham. The evaluation highlights how the involvement of consumers (patients, users and carers) works in practice, identifies challenges to the process and makes recommendations to help others develop their own strategy. Key findings include the serious and professional manner in which consumers approach public involvement and the surprise shown by researchers about the positive impact on their work of such collaboration. Recommendations include training for consumers and researchers throughout the process; peer support in the form of regular 'get together' sessions; paying consumers for their time; and appointing a coordinator as a point of contact for all involved. The report can be downloaded from the Putting it into Practice database on INVOLVE's website: www.invo.org.uk/useful_Resources.asp

Would you like to get involved with INVOLVE?

We are looking for new members

It's an exciting year at INVOLVE. Our new Chair, Simon Denegri, has been appointed and one of his first tasks is to support the recruitment of new members to our Working Groups. Members are recruited through an open process and are appointed for a three-year term initially. As current members come to the end of their term we refresh the Working Groups, bringing in new people with varied skills and experiences to support the work of INVOLVE. This year we have places for up to 15 new members.

What would I be expected to do?

The Working Groups meet four times a year, usually in London. Currently, each Group leads on one area of INVOLVE work:

- **Strategic Alliances** develops and promotes alliances with key groups
- **Empowerment** works to develop a research environment conducive to involvement
- **Evidence, Knowledge and Learning** works to create, gather, disseminate and promote the active use of evidence/knowledge about involvement in research.



Evidence, Knowledge and Learning meeting

Members work collaboratively within the Working Group meetings to provide advice and comment on the work programme carried out by the team at the INVOLVE Coordinating Centre. Between meetings, there may also be other opportunities, such as being part of a project advisory group, attending events organised by INVOLVE, or attending meetings/events on behalf of INVOLVE.

What experience do I need to have?

We invite applications from anyone with experience and understanding of public involvement in NHS, public health and social care research. This might be from your involvement in research as a member of the public/patient or as a researcher/clinician involving members of the public in your work. We hope applicants will bring diverse backgrounds, experiences and research interests – this will help us to feed a wide range of perspectives into our work. Across our membership, we aim for an equal balance of public and professional perspectives. We currently have more professional members, so in this recruitment round we will be seeking to appoint more public members.

What's it like being a member of INVOLVE?

Let's hear from two of our current members.

“Being an INVOLVE member is exciting. I get to meet people and hear ideas which I would not have done otherwise – distinguished people, people who have triumphed over adversity, people with new ways of seeing social and academic issues. I can tell people I meet as a service user/researcher about all this – many of them have no idea of what is going on in the world of research and involvement and quickly become interested. As an organisation which I have been with for several years, I have found INVOLVE to have a very open style of working, similar to that of a service user-controlled

organisation, and I think that its friendliness is a great strength.”

– Patsy Staddon, Member of the Empowerment Working Group

“The most important aspect of being a member of INVOLVE – for me, as a service user and ex-carer – is the opportunity to be involved at a strategic level. I learn more about the bigger picture and contribute towards the bigger picture, which then enriches what I bring to my other public and patient activities, such as sitting on grant application boards and being a member of a Local Involvement Network. Recently, I’ve been helping to update INVOLVE’s online materials and with the process for recruiting new members. Last year, I was facilitating activities at the INVOLVE conference – now there’s an inspiring conference – which reminded me of why I do what I do. There’s a buzz and a real sense of satisfaction when taking part in activities where everyone has a different perspective but all share a commitment to genuine involvement and respect is given to all. It’s demanding, it’s hard work, it’s fun and the people are great. Come on in – the water’s lovely!”

– Christine Vial, Member of the Strategic Alliances Working Group

Where can I find out more?

Go to the membership page on our website: www.invo.org.uk/membership.asp. Here you can find links to more detailed information about what’s involved in being a member, what experience, skills and attributes we are looking for and how to apply. We have put up some replies to frequently asked questions and we will add more as we receive them.

You will also find a link to information about the three, free Membership Information Meetings we are holding in October. These are afternoon

sessions where people thinking about applying can meet some current members and find out more about being a member and the application procedure. But don’t worry if you can’t get to one – you can still apply and information we share at these meetings will also be on our website.

If you need any information in a different format, e.g. in printed form, then please contact us at INVOLVE – it’s no problem.

We hope you will be interested in supporting our work by applying. As Simon says in his letter of introduction to applicants:

“If you are successful, you will be joining a vibrant network of public members, patients, researchers and supporters who are passionate and committed to public involvement in NHS, public health and social care research... INVOLVE is one of the few government funded programmes of its kind in the world. Since our establishment in 1996, we have made great strides towards our goal of active public involvement in research. Nonetheless we still have much to do.”

– Simon Denegri, INVOLVE Chair

www.invo.org.uk/membership.asp



INVOLVE Group meeting

The Standards We Expect project

By **Peter Beresford**

The Standards We Expect consortium, funded by the Joseph Rowntree Foundation, was a four-year collaborative research and development project, which aimed to develop person-centred support in social care and other services. The project team drew on the values and principles of user-controlled research by working with service users, informal carers, face-to-face practitioners and middle managers to explore what person-centred support means to them, how to develop it effectively, what barriers it faces, and how these barriers can be overcome. The main output of this extensive UK-wide study is a new publication, “Supporting people: towards a person-centred approach.” The book, which examines hopes and frustrations in the everyday practice of person-centred support, is accompanied by a collection of free guides and studies.

What person-centred support means to people

A consensus-definition of person-centred support emerged from the project, one that is consistent with ideas of ‘person-centred planning’ and ‘independent living’. These are concerned with putting in place the support people need to live their lives on as equal terms as possible with non-service users, rather than seeing service users as needing ‘care’. Project participants’ definition of person-centred support is strongly based on values rather than techniques or procedures and includes such key components as treating service users as individuals, and listening to and acting upon what they say.

Further information

“Supporting people: towards a person-centred approach” is available to buy from The Policy Press (www.policypress.co.uk).

A free summary and a collection of free guides and studies to accompany the project are available to download from:

www.jrf.org.uk/publications/transforming-social-care-person-centred-support

Service user involvement in research in Coventry and Warwickshire Partnership NHS Trust

By **Nicola Standen**

Coventry and Warwickshire Partnership NHS Trust provides mental health, learning disability and substance misuse services to the local population. The Trust has a growing portfolio of national and local research studies and a commitment to ensuring the active participation of service users in these studies. In recognition of the importance of service user involvement in research and using funding from West Midlands (South) Comprehensive Local Research Network, the Trust appointed me as Service User Involvement in Research Development Officer in September 2009.

I work closely with individual service users and service user groups and networks across the region to let people know about opportunities for involvement in research and to identify those who have an interest in being involved in Trust research-related activity. This has led to the

discovery of individuals with a wide range of research skills and experience.

We record the contact details of those who have expressed an interest in getting involved in research on a database, which is used to match interested service users with research studies. Through the database, we are also able to find out about service users' experience and skills and address individual training needs to build capacity for meaningful involvement in research.

Alongside our outreach work we have also established research advisory groups within specific services. These groups recognise service users' experiential understanding and use of services relating to their particular condition.

Our approach enables us to build fundamentally important relationships with service users and encourages them to have meaningful involvement, in a paid capacity, in a range of research related tasks and activities including:

- advising researchers on issues relating to the recruitment of research participants. Locally we have demonstrated how service users working within research teams can impact positively on recruitment by promoting the study and being available to discuss any concerns potential service user participants may have. Service users report feeling more relaxed when speaking to other service users (rather than clinicians or researchers), and feel better able to ask questions about the research.
- evaluating the relevance of proposed research for users of mental health services and providing advice and guidance on study design including methodology

- reviewing study documentation including patient information sheets and the development of user friendly and accessible information in appropriate formats
- reviewing research questions, e.g. supporting research teams to clarify questions included in interview schedules and questionnaires
- data collection including the distribution of questionnaires and supporting participants to complete the questionnaires where appropriate.

We are now looking to extend service user involvement in research through working with service users to identify areas of research of particular relevance to them. To undertake this work we have established a collaborative grouping of service users and Trust-based researchers who, through regular meetings, will work together to develop research ideas and, in the longer term, to seek funding to undertake this research. At the first meeting of the group there was a demonstrable enthusiasm for working together to take this agenda forward. Subsequent meetings will use a 'world café' methodology to identify areas of research interest and ways in which we can develop these ideas.

If you are interested in getting involved in research in Coventry and Warwickshire Partnership NHS Trust or if you would like to know more about our work, please contact Nicola Standen.
Email: nicola.standen@covwarkpt.nhs.uk

Deadline for contributions for our next newsletter: **10 October 2011**

If you have any questions on contributing to the newsletter, please contact Helen Hayes Tel: 02380 651088
Email: hhayes@invo.org.uk

New Research Excellence Framework welcomed by the National Institute for Health Research

The Research Excellence Framework (REF) is the new system for assessing the quality of research in higher education institutions (HEIs) in the UK, and replaces the Research Assessment Exercise (RAE). The Higher Education Funding Council for England (HEFCE), which will use the outcome of the REF to inform its research allocations to English universities, has recently published its “Assessment framework and guidance on submissions” for 2014. The Guidance has been welcomed by the National Institute for Health Research (NIHR) as it contains a number of measures to ensure that REF panels will view clinical and applied research on an equal footing with other types of research and treat NIHR funding as being of the same quality as Research Council funding.

These measures include:

- applied and practice-based research to be assessed on an equal basis with other types of research
- HEIs to separately identify research income awarded through open competition from NIHR in their REF submissions
- NIHR research income to be reported to REF panels alongside income from the Department for Business, Innovation and Skills (BIS) Research Councils
- provision for recognising ‘research income-in-kind’ from NIHR alongside that from the Research Councils
- assessment of the impact of research which

can include evidence of public involvement

- provision for staff who hold HEI/NHS joint appointments, or who are employed by an NHS organisation to do research in collaboration with an HEI, to be submitted to the REF.

For more information on REF2014 visit www.hefce.ac.uk/research/ref/

Information on the National Institute of Health Research website: www.nihr.ac.uk

New resources to support involvement in research from the NIHR Mental Health Research Network (MHRN)

By **Thomas Kabir**

Over the last year the NIHR MHRN has been busy producing very practical services and resources to help researchers and others involve service users and carers in research. All the following pieces of work were produced by staff, users, and carers from the MHRN’s regional offices (‘hubs’) that are based across England.

The service user consultants of the NIHR MHRN North London hub have produced a toolkit to help researchers involve service users (and others) in their research. The whole ethos of this toolkit is to give researchers the practical tools that they need to actually involve people in research. Whilst there is lots of high quality guidance out there as to how to involve people in research some of the more practical things that are needed for involvement work (role descriptions, application forms, claim forms, etc) are not widely available. This toolkit squarely addresses this problem.

The toolkit is split into two parts. The first explains how and why service users should be involved in research and provides some guidance on how to safely make payments for involvement work. The second part of the toolkit contains a set of template documents (such as a sample job description for a service user researcher, a sample 'involvement agreement', etc) that can be used and changed as needed. The toolkit is available freely online in pdf or Word format. All the template documents are also available to be downloaded at: www.mhrn.info/toolkit

Service users, carers and staff from the NIHR MHRN's North West and North East hubs have recently produced case studies of five MHRN-supported research projects with particularly good levels of user involvement. The case studies really show how user and carer involvement makes a positive difference to research. Four out of the five studies involve service user researchers. As with the toolkit, an emphasis throughout all the case studies is placed on the more practical aspects of user involvement (how to pay people etc). All the case studies are available to download from the publications section of the MHRN website (www.mhrn.info) and can be found at the bottom of the page in the section entitled 'Involving service users in MHRN-supported research: case studies'.

Service users and carers from the MHRN's South London and South East hubs provide the new FAST-R Service (Feasibility and Support to Timely recruitment for Research) for researchers. The FAST-R service provides mental health researchers across England with access to a trained group of service users and carers that can offer researchers expert advice about any matter relating to patient information sheets, consent forms and recruitment strategies. The FAST-R team can advise on any potential recruitment barriers to your project and make

sure information for potential participants (such as patient information sheets and consent forms) is clear and easily understood. The FAST-R service is available to mental health researchers from across England at no charge. For more details about the FAST-R service please see: www.mhrn.info/FAST-R.

For more information, contact Thomas Kabir, NIHR MHRN Service Users in Research Coordinator, at email: thomas.kabir@kcl.ac.uk or by phone on 0207 848 0644.

Diabetes Care and Education Group celebrates 10th anniversary

Congratulations to Warwick Medical School's Diabetes Research and Education User Group (WDREUG), which marked ten years of activity in July. The Group was set up in 2001, aiming to bridge the gap between research carried out at the University and patient support and treatment. WDREUG provides advice on a variety of issues including the design of research projects, recruiting patients and writing survey questions. One of its early successes was contributing to the development of the Diabetes Manual, a comprehensive reference document to help patients adjust to treatment or lifestyle changes.

Geoff Aitchison, the Group's Lay Secretary, reflects: "A method was needed to connect the research process with people living with diabetes. This collaborative working has brought real benefits and advancement to diabetes research at Warwick and led to improved patient care and education of patients and health professionals."

We wish WDREUG continued success for the next decade. For more information about their work see <http://go.warwick.ac.uk/diabetesusergroup>

noticeboard

This is a regular column which can be used to advertise events, initiatives and publications about public involvement in Research and Development. If you would like to put an article on our noticeboard please contact the Coordinating Centre.

Glaucoma and Birdshot Patient Days

The Biomedical Research Centre for Ophthalmology at Moorfield Eye Hospital is organising the following events, bringing together patients and healthcare professionals:

- **Glaucoma Patient Day: Bridging the Gap**

Saturday 1 October 2011, 10.00-17.00 at Central Hall, Westminster

This one-day event on different aspects of glaucoma aims to build a network among patients and healthcare professionals and enable them to learn from each other.

- **Birdshot Patient Day II**

Saturday 3 March 2012 (venue to be confirmed)

This follows on from the success of last year's Birdshot Patient Day which attracted over 120 attendees, raising the profile of this rare disease and reducing the sense of isolation among patients.

For more information and to register for the events, please visit:
www.brcophthalmology.org/Events/Default.aspx

The North West People in Research Forum launches their website

The North West People in Research Forum is a new organisation that is devoted to supporting

patient and public involvement (PPI) and public engagement (PE) in health research in the North West. The Forum aims to support researchers and the public, share learning about involvement and engagement, and raise awareness about health research and opportunities to get involved across the region.

For more information, see:

www.northwestpeopleinresearchforum.org/

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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 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.