

noticeboard

Autumn 2014

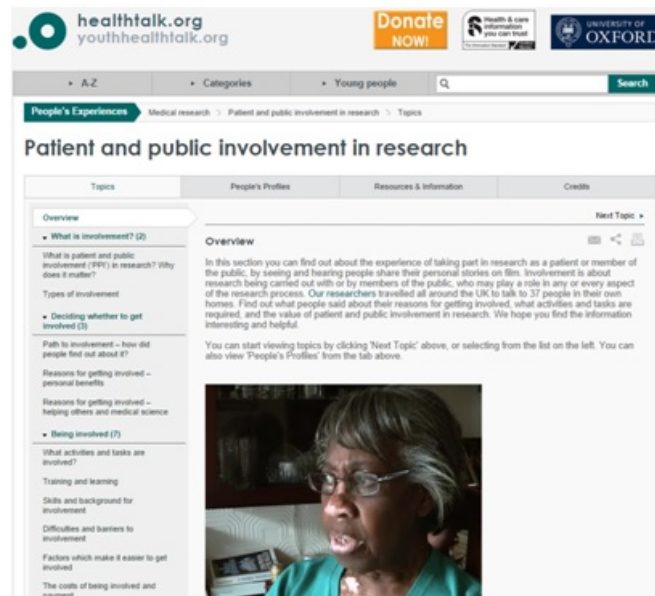
Patient and public involvement on healthtalk.org

healthtalk.org (www.healthtalk.org) contains rigorously researched information for patients, carers, and health professionals about patients' experiences of health and illness conditions. The research is conducted by researchers at the University of Oxford. Funded by the National Institute for Health Research (NIHR) Biomedical Research Centre (<http://oxfordbrc.nihr.ac.uk/>), a new section has been launched on the site about patient and public involvement (www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics). It contains interviews with 37 patients and members of the public about their experiences of getting involved in health or medical research.

The project was overseen by a panel of patients, public members, health professionals and academics. After analysis, 22 reports were written on the key findings including how people became involved, why they stayed involved, and debates around payment and capturing the difference involvement makes. All the main points are illustrated by video or audio clips from the interviews, ensuring the patient/public voice is always present. In addition to creating this freely available online resource, other outputs will include several academic publications co-authored by the researchers (www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/credits) and public members. The next stage of this project is to find out about

involvement from the researchers' point of view. It will go live on healthtalk.org next year.

Dr Anne-Marie Boylan, University of Oxford



North West London Hospital NHS Trust Patient Research Forum

North West London Hospital NHS Trust has a well-established Patient Research Forum. Thirty members provide support to researchers for their research applications, working closely with and guiding researchers throughout the process. The group has been actively involved in service and quality improvement projects in the Trust and won first prize for a poster in the Trust's Annual Research Awards. The group is now planning a project to be conducted in the community in North West London. The Collaboration for Leadership in Applied Health Research and Care (CLAHRC) and Academic Health Science Network will be working closely with R&D as this model is being seen as excellent practice. For further information please contact Sunder Chita on 020 8869 5829 or email: sunderchita@nhs.net

Summer 2014

Four Nations Conference report

Involving People and Marie Curie Palliative Care Research Centre Cardiff hosted the Four Nations Conference on 9 May 2014. The day provided an exciting opportunity to share examples of public involvement in health research, with speakers from across the UK. A Conference report has been produced giving an overview of each presentation and workshop, together with a summary of delegate feedback.

[www.wales.nhs.uk/sites3/documents/1023/Four Nations Conference Report May 2014 Final.pdf](http://www.wales.nhs.uk/sites3/documents/1023/Four_Nations_Conference_Report_May_2014_Final.pdf)

Booklet celebrating 15 years of Alzheimer's Society's Research Network

In 1999 Alzheimer's Society created its pioneering Research Network of people with dementia, carers and former carers. The Research Network has played an active role in setting the dementia research agenda, through the Society's own research programme and in a growing portfolio of research funded elsewhere. Two founding members, Barbara Woodward Carlton and Shirley Nurock, worked with current staff to collect the thoughts of researchers, Research Network volunteers, external organisations and current/former staff to celebrate this landmark anniversary in this new publication.

www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2261

Research Design Service launch new website

The National Institute for Health Research (NIHR) Research Design Service (RDS) has recently launched its new website (www.rds.nihr.ac.uk/). The RDS advises and supports research teams in developing high quality applied health and social care grant applications to NIHR and other national peer-reviewed funding programmes. It does this through a regionally-delivered service across England. The new website includes information on patient and public involvement written for [researchers](http://www.rds.nihr.ac.uk/patient-and-public-involvement/for-researchers/) (www.rds.nihr.ac.uk/patient-and-public-involvement/for-researchers/) and members of the public (www.rds.nihr.ac.uk/patient-and-public-involvement/for-patients-and-the-public/).

Spring 2014

'The value of working together in health research' event report

A report on 'The value of working together in health research' event, held by the North West People in Research Forum on 9 December 2013, is now available on their website: <http://northwestpeopleinresearchforum.org/wp-content/uploads/2014/03/Report-of-Working-Together-Event.pdf>. The event, which was organised by a working group of professionals and members of the public, aimed to identify ways to improve the process of working together towards positive shared outcomes in health research across the North West. The outcomes of the event will inform the North West People in Research Forum Strategy.

Future events will examine key issues raised and support further networking activities.

Helping to choose which trials Cancer Research UK funds: a patient's perspective

Cancer Research UK is a major funder of more than 250 trials into cancer treatments. Decisions about which trials to fund are made by a committee of independent experts and patient representatives. The latter are able to give their views and perspectives on clinical trial applications and help ensure that the trials are practical and that patients' needs are at the centre of decisions. You can read an account of how one of these patient representatives got involved and her experiences of working on the Clinical Trials Advisory and Awards Committee on the Cancer Research UK website: <http://tinyurl.com/map5bzy>

Focus on Stroke

The National Institute for Health Research (NIHR) has launched 'Focus on Stroke' (www.crn.nihr.ac.uk/focus_on/stroke/), a new online resource aimed at raising public awareness about developments in stroke research. The resource highlights some of the work the NIHR is doing in this area and includes experiences of some people who are living with stroke and contributing to research.

The NIHR encourages members of the public to become actively involved in clinical research, forming a partnership with researchers to improve the relevance and design of studies. Information on ways to get involved with stroke research and the difference that involvement can make can be found on the 'Getting involved' section of the site: www.crn.nihr.ac.uk/focus_on/stroke/getting_involved.htm

Winter 2013-14

Preparing for patient and public involvement in research: training for researchers workshop

On 28 February 2014, the University of Salford is holding a full-day workshop on public involvement in research for researchers and research active staff. The facilitator is Dr Tracey Williamson (Research Fellow Public Engagement/User Involvement in Research) and she will be accompanied by Elaine Jones (Lay Researcher). The objectives of the day are to:

- identify good practice principles for successful public involvement in research
- understand the application of involvement principles in research design
- appreciate how to strengthen public involvement aspects of funding applications
- consider the impact of involvement – its ‘measurement’ and how to maximise it
- explore the realities of public involvement – challenges, benefits and difficulties.

For details of costs and other information and to book a place see

www.salford.ac.uk/spd/coursedetails?courseid=PREPARwiCD&course name=course%20Details

Round 3 of the NIHR New Media Competition

The National Institute for Health Research (NIHR) has launched Round 3 of their New Media Competition. For the first time they are including two categories: one for researchers and one for patients and the public involved in NIHR research. The competition allows researchers, patients and members of the public involved in research to communicate their research, enthuse audiences, get creative and win prizes. The competition closes at midnight on 30 March 2014. For more information and guidance on how to enter see: www.nihrtcc.nhs.uk/NIHRNewMediaCompetition/

Update: The Public Involvement Impact Assessment Framework

The INVOLVE Autumn 2013 newsletter included an article introducing the Public Involvement Impact Assessment Framework (PiiAF), which has been produced to help researchers assess the impact of public involvement in their research.

Since its launch, the PiiAF website has been improved and is now easier to navigate. It includes a summary of the research on which development of the PiiAF was based as well as a new guidance document.

www.piaf.org.uk/

Autumn 2013

The Value of Working Together in Health Research

The North West People in Research Forum is holding a one-day free event 'The Value of Working Together in Health Research' in Manchester on 9 December 2013. The event will look at the benefits of patients, the public, carers, health professionals and researchers researching together and the different values that people bring to this process. It aims to identify ways to improve the process of working together in health research across the North West. Speakers include Dr Katherine Froggatt (Lancaster University), Professor Ann Jacoby (Liverpool University), Professor Carrol Gamble (Liverpool University) and Dr Philip Bell. The day will be facilitated by Derek Stewart, OBE. In the afternoon people will discuss their own experiences in small groups to explore the benefits and challenges of working together in health research and how working together is viewed from different perspectives. The event aims to ensure an equal spread of members of the public, patients, carers, researchers and health professionals. There is a small budget for travel expenses for non-professionals who might not otherwise be able to attend.

For further information contact the North West People in Research Forum Facilitator:
melanie.chapman@researchnorthwest.nhs.uk

Making sure the voice of patients and carers is heard in primary care research

Are you a patient, carer or member of the public who has been involved in **primary care research** or a member of staff who has supported involvement? If so, we want to hear from you! We know that patients, carers and the public are involved in many

different aspects of primary care research. Sometimes this works well, other times the work is not always shared and celebrated to promote more involvement. We want to learn from examples that have worked well, and where there have been problems so that we can develop new resources to make sure that patients' and carers' voices are heard in all future primary care research. We are looking for examples and case studies of experiences and impacts both positive and challenging. Examples can relate to any aspect of primary care research including: setting the strategic direction for research, identifying research priorities, designing research, overseeing the progress of research and helping to disseminate findings of research. If you have an example to share, or know of someone who does, please send details to Maryrose Tarpey at the INVOLVE Coordinating Centre: mtarpey@invo.org.uk

Summer 2013

PURSUN UK

By Delia Muir

The Pressure Ulcer Research Service User Network (PURSUN UK) is a network of service users, patients and carers with personal experience of living with pressure ulcers or being at risk of developing pressure ulcers. Our network aims are:

- to help provide service users, patients and carers with a voice within pressure ulcer research
- to raise awareness of pressure ulcers and improve patient care
- to develop mechanisms which allow service users, patients and carers to be ethically and meaningfully involved in research

- to recognise and develop the skills and expertise of network members.

The network is supported by the Clinical Trials Research Unit at the University of Leeds. We try to offer a variety of involvement activities which build on the existing skills of our members. One example of our work is our involvement in interpreting data from the Severe Pressure Ulcer Project. We ran an innovative workshop which utilised theatre techniques and videos to help make the interpretation process inclusive and engaging for everyone involved. For more information see the videos at <http://youtu.be/bgg6zkbILrg> and www.invo.org.uk/resource-centre/conference/involve-conference-gallery/

www.pursun.org.uk

NIHR Launches Journals Library

The National Institute for Health Research (NIHR) has launched a new Journals Library, providing full publication and open access to an extensive body of health research. It comprises a suite of five programme-specific journal series, published online, which are fully searchable and provide a comprehensive record of work funded by these NIHR programmes. Building on the success of the existing Health Technology Assessment journal, the library will give accessible full publication of findings of the research commissioned by these programmes and will provide an important permanent and comprehensive record of the work which has been funded.

www.journalslibrary.nihr.ac.uk/

Spring 2013

Be Involved – a new PPI website

South Yorkshire Collaborations in Leadership in Applied Health Research and Care (CLAHRC) have launched an exciting new website designed with a small group of service users and carers.

Visit the website to:

- view a film about why the voice of the public is vital in health research and to the work of CLAHRC for South Yorkshire
- find out how members of the public are working with researchers when they are planning their research
- find out how you can share your experiences and ideas with cutting-edge researchers developing treatments and services within the CLAHRC for South Yorkshire
- find out who was involved in developing the website.

<http://beinvolved-sy.org.uk/>

Patient, carer and public involvement seminar series

Elaine McNichol from the University of Leeds has received funding from the Higher Education Academy to coordinate a series of five seminars about patient, carer and public involvement in health, education and research. Three seminars have already taken place and the next two are coming up in May and June 2013. A few places are left at each one and there is a waiting list in case of cancellations. If you can't get along in person, there is a collection of web-based resources to catch up on topics, presenters and discussions.

www.healthcareconferences.leeds.ac.uk/conferences/details.php?id=10

Involvement4Access

A new web resource has been launched to support patients having a say in health research as a treatment choice in their local NHS hospital or health centre. Involvement4Access aims to encourage initiatives that support patients as 'Research Ambassadors' to help improve access to health research in the NHS locally.

The new web resource is the first step in creating a 'community of practice' to support the patient voice for research in the local NHS. It outlines what Involvement4Access is and what you can do locally, supported by hot tips, examples and resources. It also invites you to log your plans or initiative online.

Phase 2 of the web resource will see it becoming increasingly interactive with sharing of local initiatives across the country and the opportunity to interact with the people involved in them as part of a developing community.

www.crncc.nihr.ac.uk/ppi/why_is_research_important/involvement4access

Winter 2012-13

Clinical Trials Toolkit

The National Institute for Health Research (NIHR) has launched a new online Clinical Trials (CT) Toolkit. The Toolkit

provides practical advice to researchers in designing and conducting publicly funded clinical trials in the UK. Through the use of an interactive, colour-coded routemap (based on the design of a tube map), the site provides information on best practice and outlines the current legal and practical requirements for conducting clinical trials.

www.ct-toolkit.ac.uk/home

Professional Development Award: User Involvement in Teaching and Research

UNTRAP (University User Teaching and Research Action Partnership) at Warwick Medical School, University of Warwick is running an accredited training course for service-users, carers, and professionals. The course covers various aspects of user involvement, including teaching, research and committee work in health and social work. It consists of six modules running on six Saturdays over 12 months and the next course starts in Autumn 2013. On completion participants receive a Level 3 or Level 4 'User Involvement in Teaching and Research Professional Development Award' through the Centre for Lifelong Learning at the University of Warwick. For more information, email untrap@warwick.ac.uk or phone 024 7652 3164.

www.warwick.ac.uk/go/untrap

Autumn 2012

NICE Public Health Advisory Committee seeks community members

The National Institute for Health and Clinical Excellence (NICE) is setting up new Public Health Advisory Committees to develop national guidance on actions to promote

health, prevent ill-health, and reduce inequalities in health between social groups. NICE is seeking applications from members of the public with experience of public health action to join the committees as 'core' community members alongside a small core group of professionals with technical expertise. The 'core' members will work on a range of different public health topics. They will be joined by professional and community 'topic expert' members who will be recruited later in the year and will cover specialist areas such as the health of people in prison or other offender institutions, work and health, oral health, older people's health and needle and syringe programmes.

For information on the skills and experience required for this role, the support available to members and how to apply visit www.nice.org.uk/getinvolved/joinnwc/LayMemberPHAC.jsp

Closing date for applications: 5pm on 2 November 2012

FAST-R service

Feasibility And Support to Timely recruitment for Research (FAST-R) is a national service provided by the South London and South East hub of the Mental Health Research Network (MHRN). FAST-R aids researchers with public involvement, recruitment, regulatory requirements and funding support. It offers researchers across England access to people with experience of mental health problems and their carers, who have been trained to offer advice about patient information sheets, consent forms, recruitment strategies and other protocol materials. All researchers including students and principal investigators working on large multi-centre and industry studies with a mental health focus can apply to use this fast, free and confidential service. To apply to use the service please visit www.mhrn.info/pages/fast-r-service.html

Summer 2012

UK Clinical Trials Gateway survey

The [UK Clinical Trials Gateway \(UKCTG\)](#) provides information for members of the public and clinicians on clinical research trials being carried out in the UK. This information aims to help people to find out about trials that are relevant to their condition and which they may be able to participate in. An online survey is being carried out to find out your views on the Gateway and how best to strengthen and improve the website and the information it provides.

To give your views visit <https://www.surveymonkey.com/s/XK7NTBB> by the end of Tuesday 31 July 2012.

Engaging patients in research

On 24 May Guardian Online hosted a live Question and Answer session on what are patients' perceptions of research and how can we improve their involvement? Simon Denegri, Chair of INVOLVE, was a member of the panel responding to the questions. You can view comments about the discussion on the [Guardian website](#)

Information to share or not to share?

An independent panel of experts chaired by Dame Fiona Caldicott is conducting a review of information governance (the principles, processes and legal and ethical responsibilities for managing and handling information).

The review will make recommendations aimed at:

- improving the sharing of personal information to support the care of individuals
- enabling the further use of information more widely to improve health and social care services

- protecting individuals' confidentiality and respecting their wishes in relation to how their information is used.

<http://caldicott2.dh.gov.uk/>

Spring 2012

Launch of clinical trials online resources

Insight into the experience of being a child taking part in a clinical trial designed to test new medications or vaccines – as well as the experience of deciding whether to allow your child to participate in such a study – is provided in two new online resources.

Two new sections* of the experiential health websites, www.healthtalkonline.org and www.youthhealthtalk.org, contain interviews with parents and children talking about how they found out about trials, why they decided to take part, or in some cases, decline an invitation to participate, as well as what information they needed and were given and how they felt about the experience.

*Clinical trials: parents' experiences: www.healthtalkonline.org/medical_research/clinical_trials_parents

*Clinical trials in children and young people: www.youthhealthtalk.org/Clinical_trials_in_children_and_young_people/

New accessibility resource

The Social Care Institute for Excellence (SCIE) has launched a new online resource for anyone who is organising an event and wants to make it accessible and inclusive. The resource is

based directly on the views and experiences of people who use services and is split into three main sections:

- choosing a venue
- planning the event
- the event.

www.scie.org.uk/publications/accessibleevents/index.asp

‘Research People’ videos

The National Institute for Health Research (NIHR) Clinical Research Network has developed a series of short videos to increase understanding of the range of people involved in NHS-based research, what they do and how this benefits treatments and services.

www.crncc.nihr.ac.uk/about_us/research_people/

Winter 2011/12

Launch of International Collaboration for Participatory Health Research (ICPHR) website

The ICPHR was established in 2009 to strengthen the role of participatory health research in intervention design and decision-making on health issues. It is open to stakeholders from all countries interested in promoting the dissemination and further development of participatory health research approaches. The ICPHR carries out its work through three cross-cultural, multinational Action Groups. Learn more about the work of the Collaboration, find out how you can get involved with the Action Groups, and sign up for the quarterly newsletter by visiting the new website: www.icphr.org

New Wellcome Trust Sanger Institute survey

A new online survey has just been launched by an ethics team

from the Wellcome Trust Sanger Institute to capture public attitudes to sharing genomic results. They hope it will be the largest collection of opinions gathered to date.

Details of the survey project can be found in the press release at www.sanger.ac.uk/about/press/2012/120131.html . The survey itself can be accessed at www.genomethics.org