

newsletter

Welcome to the Autumn 2011 edition of the INVOLVE newsletter, which coincides with the launch of our new website – turn to Coordinating Centre News on page 2 for more details.

Public involvement in research applications to the National Research Ethics Service (NRES)

NRES / INVOLVE joint study published October 2011

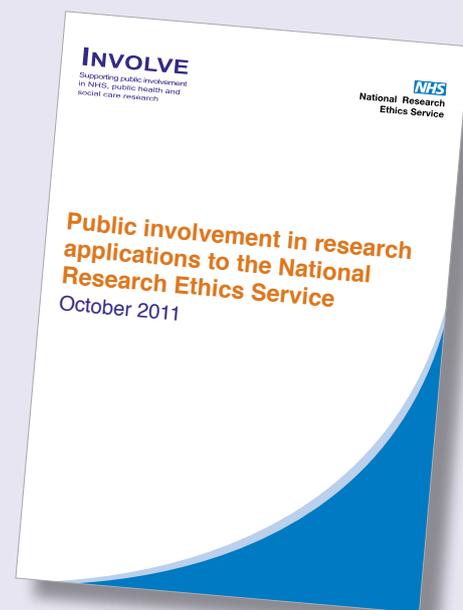
The National Research Ethics Service (NRES) and INVOLVE have published a joint study on the extent and nature of reported public involvement in health and social care research. The study analyses information routinely collected by NRES as part of the applications process for ethical approval of research projects.

The study was based on a sample of applications submitted to NRES in 2010. It focused on responses to the two-part question NRES asks applicants about how they will involve the public in their research. The question has a tick-box list of public

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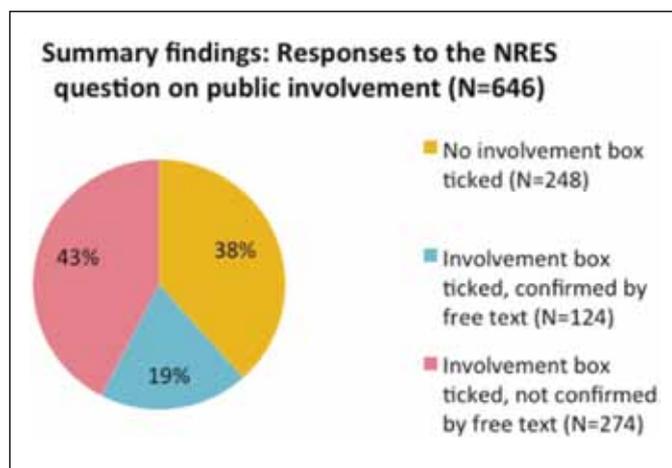


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involvement activities, and then a free-text box asking researchers to describe the involvement they have ticked. The study also looked at other information on the application form, such as the source of funding and the type of study, to explore possible links to researchers' responses to the question on involvement.

Main findings from the study:

- 19% of researchers reported involving, or intending to involve, the public in their research. They ticked one or more of the involvement boxes and their free-text responses confirmed their plans.
- 43% seemed to misunderstand what the question on involvement was asking. Whilst they also ticked at least one of the involvement boxes, their free-text responses described plans for engagement and not public involvement. They explained, for example, how they were going to recruit patients to participate in their research or how they would disseminate their study findings to research participants and to colleagues.
- 38% said they had no plans for involvement.



The report also comments on the key implications of the findings:

- the merits of asking free-text as well as tick-box questions as a way of checking the quality of responses
- the difference between engagement and involvement activities

- the potential benefits of encouraging funders to ask researchers about involvement as part of their funding application process, if they do not do so already
- the use of the public involvement question to help Research Ethics Committees (RECs) assess the ethical probity of the research
- the opportunity to draw more on the public involvement question for assurances of the ethical probity of studies they are assessing.

In conclusion, the report suggests a number of recommendations for funders, researchers and RECs.

The full report is available to download from www.invo.org.uk

Tarpey M. (2011) Public involvement in research applications to the National Research Ethics Service (NRES), INVOLVE, Eastleigh.

INVOLVE Coordinating Centre News

Membership opportunity update

If you have been keeping up with our news, you will know we have been advertising since early August for new members for the INVOLVE Working Groups. Applications had to be with us by 12 noon on 31 October 2011. Here's some feedback on the huge interest we've had in the opportunity.

There were over 600 downloads from the membership web page and around 150 people contacted us via email or telephone.

We were especially pleased with the interest in the Membership Information Meetings as this is the first time we have offered them. Over the three meetings, 70 people attended. It was great to meet such enthusiastic people interested in our work. The people who came were actively involved in these sessions –

talking with current members, viewing the displays, watching short films and most importantly, asking us questions – for example about the value of the organisation, the work we do and how we can improve on what we do. Our current members who supported these events commented on how engaged attendees were with public involvement in research and how interested they were in the impact of INVOLVE.

All this interest has led to the receipt of 159 applications! This is a fantastic number and our challenge is selecting from this pool of committed people for the 15 places available. Details of the shortlisting process are on the Frequently Asked Questions part of the membership web page (www.invo.org.uk/Membership.asp)

If you have applied, we hope to let you know by early December whether you are invited to one of the Selection Days. These will take place on 5, 6 and 9 January 2012 at the National Council for Voluntary Organisations (NCVO) in London. Please do bear with us while we work through all the applications. We want to give each one the attention it deserves.



Picture: Bristol Information Meeting on 4 October 2011 – Our Resources display with Jim Elliott, a current member, talking with one of the attendees

New website to be launched in December 2011

We have refreshed our website to give it a new look and added some new features.



Visit the resource centre to find INVOLVE publications, databases of references and our new online resource for researchers. Try out the new ‘my clippings’ feature where you can add items on the website to your own space and either download or email them to a friend. We will be building on the content in the next few months. Please do complete the feedback form and let us know how easy it is to navigate the new site, if you find the information clear and easy to understand and if there are any additional features that you would like to suggest. www.invo.org.uk

Welcome to Erica

We are delighted to welcome Erica Ferry to the INVOLVE Coordinating Centre. Erica joins the administrative team as our new Operations Officer, having previously worked at the University of Southampton. She will be responsible for a broad range of clerical and administrative tasks to support the delivery of our activities. Erica will be working full-time Monday to Friday.

INVOLVE Briefing notes for researchers

December will also see the launch of the new edition of our briefing notes for researchers. Whilst some of the content is **Continued >>**

drawn from earlier editions this document is substantially different in both its format (available as an online resource) and its content, reflecting the changing environment since the original briefing notes were written.

The briefing notes are for researchers new to public involvement in research and just starting to consider how best to involve members of the public in their work. They will also be of interest to researchers with experience of public involvement in research who are looking to update and 'refresh' their knowledge and skills and helpful to others interested in public involvement in research. They link to a larger online resource for researchers on how to involve members of the public in research.

As the resource develops it will hold supplements with detailed information on public involvement in specific types of research and on specific involvement activities. There will also be case studies showing how members of the public have been involved in research projects and templates of useful documents such as job descriptions and terms of reference for committees and steering groups.

The resource will be available in the resource centre of the new INVOLVE website www.invo.org.uk/resource-centre/resource-for-researchers

Dates for your diary

The INVOLVE 2012 conference on public involvement in research will be held at the East Midlands Conference Centre in Nottingham on Tuesday 13 and Wednesday 14 November 2012. We will advertise for conference presentations in January 2012. Receive regular conference updates, sign up for email alerts and join our mailing list by visiting www.invo.org.uk

Interesting articles and publications

Child Surveillance Unit publishes review of patient and public involvement

The British Paediatric Surveillance Unit (BPSU) has published two reports reviewing patient and public involvement (PPI).

The processes for PPI in the research undertaken by the BPSU have been strengthened since 2006. These reports provide a review of these developments and how PPI has been adopted in studies on rare childhood conditions and disorders.

The review has been split into two stages using two different methods: The first was undertaken by a working group comprising of members from the BPSU Executive Committee. A summary of documentary evidence from the Unit, Executive Committee and individual studies which recorded decisions, discussion and use of new PPI processes was collated.

TwoCan Associates and a steering group were responsible for the second stage. Qualitative research in the form of semi-structured interviews with a range of BPSU stakeholders was conducted. The aim was to understand perception and views of PPI within the activities of the BPSU.

A summary and the full reports can be downloaded from the BPSU website: www.rcpch.ac.uk/bpsu/ppi

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Independent Cancer Patients' Voice (ICPV)

Yearbook 1: Opening the Conversation: A Record of Achievement 2009-2011

ICPV is a patient advocate group led by patients for patients. They believe that clinical research is improved by patients being partners with clinicians and healthcare professionals, rather than passive recipients of healthcare. This report includes a review of the group's activities from their inception in July 2009 to June 2011 and sets out their action plan for the year ahead.

www.independentcancerpatientsvoice.org.uk

The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies

Steve Iliffe, Terry McGrath and Douglas Mitchell

Health Expectations – published online August 2011

This paper describes patient and public involvement (PPI) in a network promoting research in dementia and neurodegenerative diseases, in terms of activity at the different stages of the research cycle and within the different levels of the research network. It uses case studies to reflect on: what benefits (if any) does PPI in research bring to the research process?

Close to the bench as well as at the bedside: involving service users in all phases of translational research

Felicity Callard, Diana Rose and Til Wykes

Health Expectations – published online March 2011

This paper develops a model of translational research in which service user and other stakeholder involvement are central to each phase.

International Journal of Consumer Studies

The guest editors of an international consumer journal would like to thank everyone involved who either contributed articles or reviewed articles for publication.

Two special issues have now been published that carry articles relevant to service user and carer involvement in health and social care. Christine Wilson from the University of Glamorgan, along with Dr. Penny Llewellyn, Howard Moskowitz and Professor Colin Torrance guest edited two Special Issues which feature key articles reflecting recent developments in consumer involvement. This year's publication is entitled: Consumer involvement in health and social care: Dividing Fact from Fiction. Details of the special issue can be found at: <http://onlinelibrary.wiley.com/doi/10.1111/ijcs.2011.35.issue-6/issuetoc>

Details of last year's special issue, Consumer, user and carer involvement in health and social care, can be found at: <http://onlinelibrary.wiley.com/doi/10.1111/ijc.2010.34.issue-5/issuetoc>

For further details please contact one of the guest editors: Dr. Penny Llewellyn pjllewellyn@ntlworld.com or Christine Wilson cawilson@glam.ac.uk

Consulting parents about the design of a randomized controlled trial of osteopathy for children with cerebral palsy

Vanessa Edwards, Katrina Wyatt, Stuart Logan and Nicky Britten
Health Expectations – published online October 2010

This study demonstrates how consulting parents about the design of a study, including which outcomes to use, led to the design and successful delivery of a randomized controlled trial of osteopathy for children with cerebral palsy.

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Healthcare professionals' representations of 'patient and public involvement' and creation of 'public participant' identities: implications for the development of inclusive and bottom-up community participation initiatives

Alicia Renedo and Cicely Marston

Journal of Community and Applied Social Psychology 2011 Volume 21 page 268 – 280

This paper draws on the case of healthcare delivery in the UK and examines key socio-psychological elements at the heart of community engagement with participatory processes.

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

Involving men affected by prostate cancer: some reflections from the research team

By Iain Dickson, Peter McAlear, Andy Wallace and Dr Liz Forbat

Introduction to the project

We worked together on a project which examined the reasons for the timing of men's diagnosis with prostate cancer. The study investigated the profile of men diagnosed in Greater Glasgow over a two-year period (2008-9). We explored the experiences of men before they were diagnosed, including finding out what triggered them to or prevented

them from presenting their symptoms to a healthcare professional. The study was based on clinical information (pathology records), a postal survey and interviews.

In April 2011, a research team from the Cancer Care Research Centre (CCRC) at the University of Stirling won the prestigious Award for User Involvement at the COMPASS Annual Scientific Meeting in Edinburgh. INVOLVE invited some service user advisers involved in the project and the project leader to reflect upon their experiences of user involvement.

How members of the public were involved

As service user advisers we had the privilege of sitting in on, and contributing our ideas to the whole research process. This included:

- selecting and prioritising research projects
- developing the research method (including suggesting the involvement of male interviewers to put patients at ease)
- reviewing / assessing the study paperwork (such as survey and interview questions)
- commenting on the results and conclusions.

We see the role of the patient adviser as bringing the experience of patients to bear on the prioritising of investigations, ensuring the patient friendliness of any communication or survey, and ensuring the validity of the results and conclusions from a patient's perspective. Communication is a top priority for the special adviser, who is the interpreter between the academic and the research participant.

If well exercised, the role of the service user should enhance the quality and relevance of the investigation, enable the service user to engage effectively in discussions and give the researcher the confidence of knowing that the

subject matter has been 'test driven'. Thus the impact of this form of public involvement is very important in reassuring all those involved, especially the research community, that it is an important and valid piece of work.

What we might do differently in the future

We feel that the objectives and the implementation of this project were well thought out because the researchers and patient representatives discussed how to tackle each phase.

In terms of the research itself, we feel that the project could be repeated using data from other health boards, with the objective of seeing if men's attitudes to going to their General Practitioner vary around the country. We might also want to add new questions to the survey, for example: "How far do you live from your GP surgery?" During the interviews we think it would have been advantageous to ask the respondents more questions about Prostate Specific Antigen (PSA) testing and their GP's role. For example, questions to determine patients' views on screening, knowledge of the PSA test, and whether GPs are pro-active enough. Perhaps these ideas could be worked into another project.

We also wonder about the role of service users in conducting interviews. Patient advisers, after adequate training, could help carry out interviews and download taped conversations. However, we would want researchers to recognise that we are not seeking nine to five employment!

Analysis and final reporting would have to be the researcher's responsibility as many of us are retired and don't wish for that level of involvement. Of course, research is done on quite rigid, tight timescales and this may not knit favourably with service users' availability.

The difference public involvement made

We believe that more men answered the survey (we had a 70% response rate) because of the involvement of those affected by prostate cancer, which helped to ensure the survey asked the right questions and was readable / accessible. We also think that more men agreed to be interviewed because of our suggestion to include a male interviewer alongside the female team members.

About the team

Iain Dickson was diagnosed in 1995 and his disease is still under control. He has been involved in the support group movement since 1999, has contributed to the Scottish Cancer Group, the CCRC, the West of Scotland Managed Clinical Network and the Scottish Prostate Alliance. He is also a volunteer helper with the Prostate Cancer Charity Scotland.

Peter McAlear was diagnosed with prostate cancer in 1999. He is a patient representative with CCRC and a volunteer helper with the Prostate Cancer Charity Scotland.

Andy Wallace was diagnosed in 1997 and was eventually cured by radiotherapy in 2003. He has been involved in the support group movement and is currently a patient representative with CCRC, the Scottish Radiotherapy Advisory Group, North of Scotland Cancer Managed Clinical Network for Urology, Tayside Cancer Network Patient and Public Information Forum, and local GP management.

Dr Liz Forbat is a Reader and Co-director of the CCRC at the University of Stirling.

Other project members included: Bob Cromb (patient adviser), Gill Hubbard (Reader), Professor Daniel Kelly, Professor Hing Leung, Malcolm Nixon (patient adviser), Morag Place (research assistant) and Jim Steel (patient adviser).

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User involvement in research initiative for Long Term Neurological Conditions

By Sandra Paget

In 2004 I was invited, as someone with a neurological condition, to participate in an advisory group for the Department of Health's Policy Research Programme, which was commissioning research into the implementation of the National Service Framework for Long Term Neurological Conditions (NSF for LTNC). I said yes and my journey on the path of patient and public involvement (PPI) in research began.

At that time I knew very little about PPI in research but I did a bit of 'googling' and discovered a growing interest in patients and the public being seen more as active participants in many aspects of health care services and, in particular, in a collaborative role with researchers.

So, I went along to the first meeting at Friends House in London and any pre-conceived ideas I had about not being accepted as an equal member of the group quickly went away. The advisory group had about 16 members from a range of disciplines: doctors, occupational therapists, speech and language therapists, neurological charities, the Disability Rights Commission, civil servants, the National Centre for Independent Living and five service users.

Carol Lupton from the Department of Health's Policy Research Programme, who chaired the group and Maggie Winchcombe, the Scientific Advisor paved the way for the service users to be seen and treated as equal members. We participated in all discussions and all stages of the group's work from writing the briefing tender for the research to reading

and discussing the research applications, making decisions about which projects to fund and participating in discussions with researchers about their research applications. The research brief required research teams to involve service users in defining research questions and developing research instruments and outcome measures. Three service users participated in the Working Group responsible for writing the overview report with two service users taking the lead for writing a section about service user participation in the advisory group.

All members were kept informed between meetings and were able to raise queries about different aspects of our work. I believe the service users made a good contribution and brought their lived experience and expertise to the discussions. We were well supported and any special needs were always considered. At one meeting a service user attended via a video link which made it possible for her to contribute to the discussions. We were so integral to the team and collaborated so closely that it was difficult to assess what difference we made compared to the researchers on the team. 'Nothing about us without us' seemed to be embedded in the ethos of the group and the same service users remained involved throughout - for seven years. 'Nothing about me without me' - I definitely felt that my contribution was valued.

Many of my colleagues at the first meeting were also at the last meeting in September 2011. I believe the reason for this cohesion was that the work we were involved in mattered to us as service users/carers, clinicians, therapists and charities. After all, policy that is poorly implemented or remains unimplemented achieves very little for anyone and is not in the best interests of society. We were all encouraged and empowered to contribute by the Chair and the Scientific Advisor.

Did this experience make a difference to me as an individual? Yes, I now have a better understanding

of health research, policy implementation and issues around implementation of the findings of research. I have a greater appreciation of the financial constraints and more confidence to contribute and offer my opinion. I have a better understanding of the importance of research design and my knowledge of PPI has grown – it is now part of my lived experience and expertise.

Since that first meeting in 2004, I have also been a PPI member on a National Institute for Health Research (NIHR) commissioning panel for the Research for Patient Benefit Programme, as well as a PPI sub panel member for the Programme Grants for Applied Research and a lay member on three publicly funded research projects. All have been good experiences but I do not think I would have participated in any of these without that early positive experience.

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For more information about the research initiative for Long Term Neurological Conditions visit www.ltnc.org.uk

John's cheese sandwich: taking on PPI, with relish

By Duika Burges Watson, Sue Lewis and John Buckley

John's face said it all. Months before, the chef had promised him a cheese sandwich, and there it was in front of him. He tucked into it with relish, and barely paused until the plate was clean.

What could possibly be special about a cheese sandwich? For John, it was the first taste of his favourite snack for more than three years, since the treatment that had saved his life left him with eating difficulties that may stay with him for the rest of his life. The radiotherapy received

by head and neck cancer patients often results in saliva loss and narrowing of the gullet, leaving them with eating disorders, including problems with food texture and taste. As a result, they can lose interest in food (causing nutritional problems for some) and eating socially is embarrassing, which leaves survivors feeling isolated and families confused.

Because of the scientific and practical complexity of the problem – each survivor seems to have a slightly different response to foodstuffs – very little research has been done in this area. However, Duika believed that molecular gastronomy might have something to offer. She found a chef (Sean Wilkinson) with the right expertise, and together they started to ask survivors and clinicians more about the problem. In April 2011, a project committee of John and his wife, an interdisciplinary academic team and the region's Patient and Public Involvement (PPI) Officer, met for the first time. John agreed to be the project's recruitment co-ordinator, and also mentioned the cheese sandwich; he cannot manage bread or cheese because he has no saliva, and a traditional cheese sandwich was what he missed the most. The chef promised him a sandwich that he could eat.

Although the team was still unsure about the scope of the problem, or that a research question should be formulated without further survivor input. A small amount of funding from the Wolfson Research Institute, Durham University, enabled us to run three PPI workshops over the summer. Survivors and their partners were invited along to a community centre chosen for its geographical convenience and because it had a suitable kitchen – these workshops would go further than a simple focus group. Together, the group watched short videos on the science of molecular gastronomy, and on case studies, which prompted sometimes emotional discussion. The chef led light-hearted demonstrations, altering the texture of foods and even of the liquid 'sip feeds' **Continued >>**

People and Research South West

By Catrin Richards

People and Research South West is a collaborative initiative set up to support and signpost researchers and members of the public with an interest in public involvement in health and social care research locally. We are a partnership of NHS and academic organisations.

The initiative evolved from a scoping study on public involvement in research published last year. (http://hls.uwe.ac.uk/suci/Data/Sites/1/public_involvement_in_research_report_april_2010_final..pdf)

Although there are examples of active involvement in our area there was no co-ordinated approach locally and a danger of duplication of work. As many research projects link to more than one NHS trust and university and to NIHR research networks, it was decided that a more shared approach was needed. A Steering Group was set up of interested stakeholders to develop a co-ordinated local strategy. Although the Steering Group already had two patient partner representatives, one of our first objectives was to set up a Public Reference Group of members of the public already actively involved in research who could ensure that public/patient views could be heard and addressed by the Steering Group.

In May 2011 we invited applications to the Reference Group by advertising through our stakeholder networks and local voluntary and charitable organisations. We received 16 applications which we shortlisted to 10 on the basis of their experience in research. A patient research partner (who had not applied) chaired the selection process, which included a group discussion about public involvement in research so that we could observe how the candidates contributed and then each

that many survivors depend on. Survivors gave feedback – not all positive – and discussions were recorded on audio and video (with consent). The relaxed, inclusive process and John's support encouraged one survivor to try eating for the first time in nine months.

The enthusiastic reception the workshops received enabled the research team – including John, who is co-applicant on the funding application – to hone the research question, but also to plan with confidence a project that will require considerable survivor input. The proposal, is more meaningful and patient/survivor-focused in its questions, research processes, planned milestones, outcomes and methods of dissemination than it would have been without the PPI. If funded, survivors will be central to the running of research workshops, in analysis, project management and in planning and designing the key output – a book of recipes, survivor commentaries on the suitability of new cooking techniques, and advice for the benefit of future patients.

The team has since secured funding from Beacon North East to run further workshops, enabling us to maintain our links and further develop the skills needed to maximise the potential of this collaborative project. Everyone's expertise has been placed on an equal footing during this process, and as a result this project is 'ours' in the full sense. It belongs to everyone involved in its journey so far. And it has already spread beyond the immediate team; John now makes and shows off his cheese sandwich to his mates down the club, a big step for someone for whom the link between food and socialising had previously been broken. You can see and hear John – and the group – enjoying his cheese sandwich at <http://vimeo.com/groups/96345>

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candidate had an informal 15 minute interview. Nine members were chosen.

The first meeting was held at the beginning of July and was attended by eight members along with myself and Professor David Evans, who is heading up this initiative. The meeting was facilitated by a member of the University of the West of England academic staff. I sent out a draft proposal for the terms of reference and ground rules to each member in advance as a starting point for discussion on the objectives and purpose of the group and how it should run. There was a careful negotiation about how they wanted to work together as they all have different perspectives and experiences of patient and public involvement.

Discussions on the terms of reference covered the group's purpose and membership as well as a role description, person specification and the benefits of being involved, which I re-drafted to send out after the meeting for approval. The group adopted the ground rules for meetings from INVOLVE's guidance. Another important decision was around the chairing of meetings. Rather than appoint a chair at this early stage, while still getting to know each other, the group agreed to have an independent facilitator to chair the meetings for the next 12 months.

Until the formation of the Reference Group the Steering Group had two research partner members. The Reference Group decided to increase this to three as this would mean that two members were always likely to be present to give each other support. It was seen as important to have some continuity so one of the existing representatives has continued with two new representatives.

Another effective suggestion was to set dates for both the Steering and Reference Group meetings for the next 12 months as this makes it easier for all members to have advance notice. The Reference Group meetings take place a week ahead of the Steering Group, giving the group time to

comment on agenda items or highlight any issues to the representatives to take to the Steering Group. The representatives then report back to the group at the next meeting.

I am new to the world of public involvement in research so working with the Reference Group has really helped me to get a better understanding of the sometimes complex issues in health and social care research. They are so knowledgeable, willing and helpful. In between the agreed meetings they are always happy to comment or advise on any documents or issues. We have a lot we want to achieve and the next couple of months are going to be busy with members helping us with training, developing a communication strategy and looking at the thorny subject of payments and expenses across the consortium organisations.

If you would like to find out more about People and Research South West, please contact me on: catrin.richards@uwe.ac.uk or **0117 3288809**.

Deadline for contributions for our next newsletter: **3 January 2012**

If you have any questions on contributing to the newsletter, please contact Helen Hayes
Tel: **02380 651088**
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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.

Participative research and policy

This online course will enable you to involve policy makers, practitioners and service users in doing and using research. You will critically engage with the latest theories and debates about the relevance and application of research findings for policy, practice and personal decisions.

On successful completion of this course you will be able to conduct and use research collaboratively in order to promote change for better health, education or well-being.

To take part you will usually need a second-class degree in health, education or another area of social science or policy, or have another professional qualification, for example for teaching, police force, health care, social work. If you have other kinds of qualifications you may be eligible but we may ask you to take a qualifying test (see webpage listed below for full detail).

Course dates: Online (18 January to 2 May 2012)

Fees: from £525

For further information and to register online visit: <http://eppi.ioe.ac.uk/MSc/prp> or contact Kim Reynolds (k.reynolds@ioe.ac.uk) or telephone +44 (0)20 7612 6280.

Your health record saves lives

A new patient information booklet produced by the UK Clinical Research Collaboration (UKCRC), explains why access to health data is important, how it is used and the safeguards that exist to ensure it is used responsibly. www.ukcrc.org/patients-and-gps-encouraged-to-give-researchers-access-to-health-records/

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INVOLVE is a national advisory body funded by the National Institute for Health Research to 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 do 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.