

## newsletter

Welcome to the Autumn edition of the INVOLVE newsletter. While much has been achieved in establishing the authentic involvement of patients/service users and carers in health and social care research, there is still much to be done. The INVOLVE conference remains the unique forum for all those who wish to share their learning as well as debate and explore the way ahead. This year's conference has attracted a wide variety of abstracts for talks, workshops, posters and other forms of presentation. There are some fine examples of impact and innovation and we are looking forward to the thought provoking and informative debates that follow.

This edition of the newsletter contains articles from a few of the Conference 2010 presentations to give you a taster of what's in store. There's also a reflective piece on conferences past as well as present. I look

forward to meeting  
you on the day!



**Angela Barnard,**  
member of INVOLVE  
and Chair of the  
Conference Planning  
Group

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[www.peopleinresearch.org](http://www.peopleinresearch.org)

**People in Research** is a web-based resource for members of the public who are looking for opportunities to get involved in research. You can search the database for opportunities to get actively involved in research and publicise your opportunities for members of the public to get involved in your work.

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 conferences: a look back – and forward...

**The forthcoming INVOLVE conference will be the seventh national conference on public involvement in research. How have these conferences changed over the years? Has anything stayed the same? We look back over the six past conferences – and look forward to the seventh.**

### **Things have grown...**

The first conference, held in 1998 in London, attracted over 200 people, much to the surprise of the organisers, who had no idea what to expect. A further 50 people were turned away. This level of interest has grown, with nearly 400 people attending the sixth INVOLVE conference in 2008, in Nottingham. The number of presentations has also grown – up from 40 in 1998 to nearly 100 in 2010. And so has the length of the conference – it started as a one day event and now stretches over 1.5 days.

### **Some things have stayed the same**

All conferences have aimed to be interactive – there have been workshops, discussions, debates, theatre and music. And there has always been a soapbox, where any conference delegate can speak for up to three minutes about an issue that's important to them. But every year people say they want more time for discussion – perhaps this year we'll get it right!

### **Have the conferences always covered the same issues and themes?**

With the exception of the first conference in 1998, issues of funding have been discussed at every

conference. Involvement in social care research has had a very low profile at all conferences, as has public health research. We hope this will change in future conferences – if you're involved in research in either of these areas, please think about doing a presentation or running a workshop in 2012.

Some themes have appeared or disappeared. For example, ethics was very prominent in the first two conferences. Then it disappeared. It's back for 2010! There was nothing about the evidence for involvement in the earlier conferences – but there was more discussion about involvement in creating an evidence base for different treatments. Commercial research briefly appeared as a theme in 2006 along with 'clinical research' – perhaps because of the establishment of the UK Clinical Research Collaboration and the UK Clinical Research Network (now the National Institute for Health Research Clinical Research Network). Clinical research has emerged as a key theme for 2010.

User controlled and user led research was not discussed at the first conference. By the second conference this was the subject of a themed workshop and included in a plenary discussion. It has grown in prominence over the years and in 2010 we have a workshop based on our new publication Changing Our Worlds – examples of user controlled research in action.

### **Venue**

After the first two conferences, the event moved out of London – to Harrogate, Hertfordshire and more recently to Nottingham. This was because the conference planning group wanted to find an accessible, affordable venue. So far, the venue we are using again in 2010 (in Nottingham) seems to be the best we have found, but we are

always open to new ideas – please get in touch with us if you think you know of a better venue.

## Language

The language used to describe public involvement in research has changed over the years. This is reflected in the language used in the INVOLVE conferences. In 1998, the conference talked about ‘consumers’, and INVOLVE was called the Standing Advisory Group on Consumer Involvement in the NHS R&D Programme. In 2004, at INVOLVE’s 4th national conference, we talked about public involvement – a phrase we will be using at this conference.

The conference organisers have always tried to make the conference language as accessible as possible. We encourage everyone to avoid jargon, we ask for information in plain English, and provide guidance on how to make presentations and posters easy to understand and view. In 2004 all INVOLVE paperwork was checked by a readers’ panel to avoid jargon.

In 2010, however, we are seeing the language used becoming more complex again – for example, titles for presentations and workshops include phrases like ‘complexity theory’, ‘conceptual model’, ‘formative evaluation findings’ and ‘community of practice approach’.

## And finally...

Perhaps the most important constant in all six conferences so far has been the enthusiasm of people who have come along – to share with others what they have been doing or just to listen and learn.

We’re looking forward to another interesting and exciting conference in November – hope to see you there!

# INVOLVE Coordinating Centre News



## New members of staff

We are delighted to welcome two new members of staff to the Coordinating Centre:

**Sarah Howlett** started with us in September 2010 and will be working full time as a Public Involvement Advisor (Trainee).

**Alison Faulkner** has joined us for three days a week in the temporary post of Public Involvement Advisor. Alison will work with us until the end of January 2011.




## People in Research

People in Research is a web-based resource for members of the public who are looking for opportunities to get involved in research. Following an evaluation in 2009 the People in Research website has been redeveloped. Members of the public can search the database of opportunities to find out about available activities. They can also listen and view videos of people talking about their experience of being involved.

If you are a researcher or a research organisation, register and publicise your opportunities for members of the public to get involved in your work at [www.peopleinresearch.org/](http://www.peopleinresearch.org/)

People in Research was initially developed by the UK Clinical Research Collaboration [www.ukcrc.org](http://www.ukcrc.org) and is now managed and facilitated by INVOLVE.



## Count us in! Involving everyone in health and social care – a report of a workshop run by Shaping Our Lives for INVOLVE

This is the report of a workshop held in March 2010 with a diverse group of service users interested in health and social care research.

The aim of the workshop was to find out how more people can be actively involved in research, especially groups and people whose views are heard less often in wider society. The report details the ideas and perspectives from the 11 service user participants, summarises the discussion between the service user participants and INVOLVE, and sets out the service user identified recommendations for future work to improve and expand the groups and people getting involved with research. The report is now available on the resources section of the INVOLVE website: [www.invo.org.uk](http://www.invo.org.uk)



## Building on Success – the report

This is the report of a ‘think tank’ event jointly organised by the Association of Medical Research Charities (AMRC), the James Lind Alliance (JLA) and INVOLVE, with the support of the UK Clinical Research Collaboration. It brought together representatives from large and small research funding organisations, research commissioners and other groups and individuals with experience of patient and public involvement in research priority setting and commissioning.

The purpose of the meeting was to reflect on progress and to consider the future development of patient and public involvement in research priority setting and commissioning processes. The report is available to download from the resources section of the INVOLVE website: [www.invo.org.uk](http://www.invo.org.uk)



## invonet online library and Bibliography

The invonet library has recently had 44 new references added that cover:

- The nature and extent of public involvement in research eg mapping public involvement
- The impact of public involvement on research
- Reflections on public involvement in research

The references are also available in the third edition of the invonet Bibliography published October 2010.

invonet is a network of people interested in working to build evidence, knowledge and learning about public involvement in health and research. The library is available on the INVOLVE website [www.invo.org.uk/invonet.asp](http://www.invo.org.uk/invonet.asp)



## Examples of public involvement in research

Two new INVOLVE publications, available in November 2010, are:

- **Changing Our Worlds: examples of user-controlled research in action** – full report and summary.
- **Turning the pyramid upside down: examples of public involvement in social care research.**

Both of these publications will be available to download from the resources section of the INVOLVE website and we will discuss them in further detail in our Winter newsletter.

[www.invo.org.uk/INVOLVE\\_Publications.asp](http://www.invo.org.uk/INVOLVE_Publications.asp)

Deadline for contributions for our next newsletter: **29th November 2010**

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

# Interesting articles and publications

- **Mental health users' experiences of being interviewed by another user in a research project. A qualitative study**

A Bengtsson-Tops and B Svensson. 2010  
Journal of Mental Health, Volume 19, issue 3,  
pages 234-242

This project explored the experience of service users being interviewed by other service users. Interviews were carried out with seventeen mental health service users with experience of being interviewed in a research project by another service user.

- **Involving burn survivors in agenda setting on burn research: An added value?**

Jacqueline Broerse, Marjolein Zweekhorst, Annemiak van Rensen, and Monique de Haan. 2010. Burns, Volume 36, issue 2, pages 217-231  
In this article the authors compare the research priorities of burn survivors and professionals and investigate to what extent it is possible to come to a joint research agenda.

- **Public involvement at the design stage of primary health research: A narrative review of case examples**

Jonathan Boote, Wendy Baird and Claire Beecroft  
Health Policy, Volume 95, issue 1, pp 10-23, 2010  
This paper reports on a review of published examples of public involvement in research design. The authors discuss the impact of involvement at this stage, the tensions and the barriers and facilitators to involvement.

- **The PIRICOM Study: A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research**

Jo Brett, Sophie Staniszewska, Carole Mockford, Kate Seers, Sandy Herron-Marx, and Helen Bayliss. 2010 UKCRC

This review commissioned by the UK Clinical Research Collaboration synthesises the evidence on the conceptualisation, measurement, impact and outcomes of patient and public involvement (PPI) in health and social care research. The full report and the summary can be downloaded from the UK Clinical Research Collaboration website: [www.ukcrc.org/systematic-review-on-ppi-in-clinical-research/](http://www.ukcrc.org/systematic-review-on-ppi-in-clinical-research/)

- **Involving lay and professional stakeholders in the development of a research intervention for the DEPICTED Study**

Lesley Lowes, Michael R. Robling, Kristina Bennert, Charlotte Crawley, Helen Hambly, Kamila Hawthorne, John W. Gregory and the DEPICTED Study Team.

Health Expectations early view – article first published online: 23 September 2010

This paper focuses on the active involvement of stakeholders' at key stages of the research, particularly in the context of lay stakeholder involvement. Some challenges that can arise and wider issues (e.g. empowerment, the impact of user involvement) are identified and explored within the literature on service user involvement in health care research, reflecting on the implications for researchers.

**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](mailto:hhayes@invo.org.uk)**

# Patient and public involvement in the ICONS: Identifying Continence Options after Stroke study

**By the ICONS Patient, Public and Carer Involvement Groups, Thomas L, Pearl G, Forshaw D, Dickinson H and the ICONS Project Team**

## Introduction

Around half of people who have had a stroke get problems with their bladder. Our study is trying out new ways of assessing and treating bladder problems after stroke. We are looking to see if these lead to an improvement.

ICONS is funded by the National Institute for Health Research (£1.2 million over 3.5 years). Our user involvement strategy is based on a model of collaboration. We have two Patient, Public and Carer (PPC) Involvement groups; one for people who have difficulty communicating (aphasia) and one for people who do not have difficulty communicating. These user groups contribute to all aspects of the research and members of the groups are part of the project's Steering and Management groups.

The user groups have helped us in: writing the grant application, preparing documents for the Ethics Committee and developing materials in an aphasia-friendly format. Some of the specific tasks our groups have worked on are listed below:

- critical review of documents including patient and carer information leaflets; questionnaires for patients and carers and health professionals;

and on-line training materials for health professionals

- developing a theoretical model based on findings from the literature review and 'gaps' in the evidence
- participating in the development of a proposal to evaluate our patient and public involvement (PPI)
- participating in evaluation activities, for example focus groups with an external researcher
- contributing to conference presentations on early phases of the study.

## Lessons learned:

### 1) Including people with aphasia

People with aphasia are often excluded from projects, but in ICONS we specifically sought their involvement. The aphasia user group has been involved in the development of aphasia-friendly materials for patients taking part in the study who have aphasia (around one third of stroke survivors have aphasia).

### 2) Having two user groups

The aphasia user group valued having their involvement supported in an appropriate manner. Meeting rules were agreed, such as only one person speaking at a time, the use of appropriate vocabulary and appropriate timing and pacing of meetings.

The user groups meet separately to allow for the additional support required for involving people with aphasia, but in order to promote unity in the study the two groups have met to establish links. Members from both groups have presented jointly at conferences. The facilitator for the aphasia group additionally attends the non-aphasia group meetings. The commitment to user involvement at all levels and stages of the research process was

important both in the research process and in heightening the sense of worth in user group members.

### **3) Use of 'closed' groups**

The use of 'closed' groups with stable membership was felt to be important for both user groups. In the aphasia group, group cohesion was enhanced because members were recruited from an aphasia charity, Speakeasy. Members already knew each other and were familiar with the processes used to engage people in research. Group members felt there was value in having previous contact with each other for discussions in general but for this research on a sensitive topic it was particularly important.

#### **Difference to service users**

Our two groups were asked to tell us what difference being involved in ICONS had made to them:

#### **Personal benefits**

- becoming more confident
- feeling useful and respected
- "we feel involved and included"
- "we have fun and good cake!"
- "we all get something from the group"

#### **Research-related benefits**

- working as a team
- developing joint expertise: service users and researchers learning together
- telling researchers about aphasia
- contributing to the health of people with stroke

#### **Process benefits**

- having group rules and taking notice of them

#### **Difference to researchers**

Working with our groups has reinforced the

research team's appreciation of the value of patient and public involvement in research. Our groups have improved the skills of the researchers in ensuring the research protocol takes into account the needs of patients with stroke. The user groups have helped develop materials for participants that are understandable to people with and without aphasia. We hope these materials will:

- encourage participants to take part in the trial phase of our study and
- maximise the potential for trial participants to benefit from the interventions (e.g. through providing patient-friendly information leaflets).

We have also learnt how to keep our groups happy by:

- Creating a welcoming, sociable atmosphere
- Understanding needs of service users (short meetings, jargon-free language, comfort breaks)
- Providing a fee and travelling expenses
- Striving towards equality by giving equal weight to everyone's views
- Creating new opportunities, for example in 'spin off' grant applications

#### **The ICONS Patient Public and Carer team are:**

Birchall V, Brand D, Brand P, Britt D, Griffiths M, Helvin P, James B, Pearl G, Whitewood J, Vella J, Childs A, Childs R, Crosby S, Hall S, Lewin A, Raw B, Royle L, Scott C and Wright J.

#### **The ICONS Project team are:**

Watkins C, Thomas L, French B, Forshaw D, Dickinson H, Mitchell D, Nelson L, Cheater F, Roe B, Booth J, Sutton C, Leathley M, Carter B, Brittain K, Burton C, McColl E, Rodgers H, O'Donoghue J, Gotaas J, Walker A and Barrett J.

# The impact of PPI on clinical trial design and operations – can we demonstrate value for money?

**By Sue Pavitt, Shirley Swithenbank and Carol Lee**

The NHS is constantly striving to improve its knowledge and understanding to deliver the best patient care. While clinical trials are commonly regarded as the best way to test new treatments and to determine which one works the best and for whom, they are complex to design and resource intensive to run. There is a fundamental belief that clinical trial research which reflects the needs and views of patients and carers is more likely to produce robust clinical trials where the research question is focused on patient benefits, is designed to deliver meaningful outcomes for patients, will be ethically conducted and produce results that can be used to improve NHS practice.

Clinical Trials Units (CTUs) have used Patient Public Involvement (PPI) for many years but largely this has been limited to the development of clinical trial literature, notably patient information leaflets. Similarly, research on the impact of PPI has also centred on the improvement to trial literature and more recently grown to include documentary-style qualitative case study reports on PPI in research. Whilst this is important it significantly understates the importance and true potential of PPI and leaves commissioners and funders lacking quantifiable strong evidence of the impact of PPI across stages of the research cycle.

Recruitment and retention (R&R) is a key concern of clinical trial (CT) delivery, with two thirds of trials failing to meet their planned recruitment target. This results in further demands on funders for costly trial extensions and approximately 50% of these still fail to achieve planned recruitment. When a trial fails to recruit the analysis is unable to categorically conclude if the intervention tested works or not.

We are evaluating the ways in which PPI can help recruitment and retention in clinical trials. We have been granted access to data from i) the National Institute for Health Research Health Technology Assessment (NIHR-HTA) funder's database of trials, and ii) the 'Strategies for Trials Enrolment & Participation Study' (STEPS), to obtain pertinent trial information to build a picture of factors influencing R&R. From this, we will utilise health economics to build a framework that explains the factors, including PPI, influencing R&R in trials.

Our research examines and quantifies the role that PPI plays in R&R and our financial model will, along with qualitative data (derived from interviews with key stakeholders) be used to develop a PPI strategy and guidelines with the aim of having a positive impact on both trials failing to reach recruitment targets as well as new trials starting out. We propose that PPI can help research to be more 'participant friendly' and more focused on bringing benefits to NHS patient care.

Specifically, PPI can ensure success by ensuring that the research question addresses patients benefits, that the clinical studies pay special attention to educating potential study subjects, both in a general sense of how clinical trials work (education) and specifically how their clinical trial is designed, as well as what is hoped to be



gained by their participation (informed consent). PPI can also have great influence on trial operations, ensuring that risk and unnecessary procedures are minimised to trial participants and that it is designed ethically and with patient consideration at the forefront.

For example, in the dental trial IMPROVDENT – an NIHR funded Research for Patient Benefit grant that looks at improving denture construction for patient benefit – there were two PPI representatives, Shirley Swithenbank and Carol Lee. They gave rich insights that improved both the trial design and also aided the logistics for running the trial to ensure it was focused to maximise patient recruitment and retention.

In brief, the trial involves construction of two sets of dentures for each patient, constructed using different moulding materials. A comparison of the comfort of the two sets of dentures is of paramount importance and necessitates the patients keeping a diary and interchanging their sets of dentures. Initially, the chief investigator had suggested the patients swapping between denture sets in the course of one day and records being made over several days. Carol and Shirley were able to offer a patients' perspective of how uninviting this changing

between dentures would be within a given day and that it was likely to cause real problems with compliance to the research protocol; instead they offered a much simpler regime that was just as likely to still achieve a good final comparison between the sets of dentures.

In addition, as many of the trial participants are likely to be older and perhaps reliant on their senior citizen travel passes, Shirley and Carol again offered useful practical advice that those travelling by public transport are likely to prefer to attend appointments that enabled them to travel to the clinic on their travel passes and outside the afternoon rush hour. As a result, flexibility was built into appointment system and the majority of appointments were made in morning clinics as suggested by Shirley and Carol.

Whilst it is difficult to compare how well the trial would be running without these modifications what we can see is that IMPROVDENT is recruiting to target and that patients are appreciative of clinic appointments that fit in with their preferred travel time – and this has led to very few cancelled or rescheduling requests which can otherwise add to trial delays and costs.

Continued →



**Members of the IMPROVDENT Clinical trial team left to right : Gillian Dukanovic, Paul Hyde, Shirley Swithenbank, Nuria Navarro Coy and Carol Lee**

Shirley and Carol report:

“...we are valued members of the Trial Management Team and our views are well received and appear to make a difference, which is good. We value the importance of this research and we are passionate about the need for this research as well as overcoming the stigma and ridicule experienced by denture users – after all no one laughs at other prosthetic users, do they?”

Similarly, other trials such as ProtecT (prostate testing for cancer treatment) have demonstrated that PPI can significantly turn around trials where R&R is proving problematic.

In recent years there has been a huge growth of PPI but evaluation is problematic. PPI has largely developed in an ad hoc fashion with no consistent framework or model for how it should be done across either the various stages of the research cycle, or different disease areas or indeed to meet the requirements of different stakeholders.

Our evaluation with a novel application of health economics should prove beneficial for future robust trial design, delivery of recruitment and thereby improved efficiency.

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## On The Buses: piloting an innovative reciprocal approach to involving young people in research

**By Anna Goodman and Tabitha Manzuangani**

Since 2006, London's young people have had access to free bus and tram travel. The National Institute for Health Research funded 'On The Buses' (OTB) study is based at the London School of Hygiene and Tropical Medicine (LSHTM), and is examining the public health impacts of this policy. This may include positive effects, such as promoting well-being by increasing young people's access to opportunities in London. There may also be negative effects, such as reducing young people's walking and therefore their exercise levels.

Since starting six months ago, OTB has involved eight young people via work experience and over 40 via school workshops. For example, in March 2010 Tabitha (then in Year 10) was supported by Anna in conducting a survey at her school and concluded that 'free public transport is linked with better mental health in students under 16'. Tabitha also helped deliver one of the On The Buses schools workshops, and has since returned in her holidays to join Anna and colleagues in doing observational field work on buses.

Tabitha's involvement represents part of an innovative, reciprocal approach which Anna has been piloting. All young people taking part in OTB work experience or schools workshops in 2010 were invited to do pilot qualitative

interviews, and around a quarter accepted. It provided a quick and (almost entirely) painless way for Anna to conduct interviews and focus groups with 15 young people of different ages from all across London. By contrast, in a previous qualitative research project it was difficult to 'find' young people or get schools on board.

Moreover, young people not only contributed as participants – they also contributed as scientists. For example, Tabitha's work experience research highlighted the importance of considering mental and social well-being. This was particularly crucial since little routine information is collected on these aspects of health, and researchers can all too easily fall into the trap of thinking that what they can't measure is unimportant. Tabitha also argued strongly that the important thing about free transport is that it is universal. This has become the starting point for a new research question that young people may feel more positively about free transport than about free school meals, which are means tested and so perhaps more stigmatising.

The young people involved have also provided positive feedback about being involved in the research. Describing when she presented her research findings, Tabitha says: "At first, it seemed impossible to convince the LSHTM post-graduate students but, when I started to speak passionately about the issue, my audience was engaged. Passion was the key to engage my audience on the issue. Next time, I will make sure I speak more clearly." Tabitha and other young people have also commented that getting directly involved in this study made scientific research seem less 'serious' and more approachable, and made them realise that health research is not just about the NHS.

We therefore believe this reciprocal approach

has been a success for us, and may also be useful to other groups. For researchers, it can offer a more efficient way of convincing both young people and schools to get involved. For schools and young people, it may increase an understanding of research, improve the relevance of research and increase the number of researchers willing to involve young people. The LSHTM Young Scientist Programme (which Anna organises) usually finds enough volunteer supervisors for work experience projects, but Anna believes more staff would come forward if their research could benefit directly.

We also recognise, however, that these benefits must be balanced against important ethical considerations. In particular, we do not want to undermine the altruism which currently motivates participants to take part in research, and motivates researchers to take part in LSHTM's Young Scientist Programme. For example, we do not want scientists to start offering work experience that is useful for them but less interesting or educational for the young person. Nor do we want schools or young people to feel obliged to participate in research in order to get workshops and work experience (although the modest 25% take-up rate of our invitation to take part in interviews suggests this hasn't been a problem yet).

Anna and Tabitha look forward to discussing these issues more when we present at the INVOLVE conference in November – and hope perhaps to see you then. For more details of LSHTM's Young Scientist's Programme, see: [www.lshtm.ac.uk/aboutus/volunteering/ysp/](http://www.lshtm.ac.uk/aboutus/volunteering/ysp/)

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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.

## James Lind Alliance – Affiliates Programme

The James Lind Alliance (JLA) is a non-profit initiative which brings patients and clinicians together to identify unanswered questions about the effects of treatments, and then prioritise for research those that they agree are the most important. The JLA Affiliates programme is for organisations and individuals who identify strongly with the JLA's mission and who want to express support for, be involved in or simply be kept informed of the JLA's activities. It's quick, easy and free to become a JLA Affiliate. You'll receive a bi-monthly newsletter and will become part of an ever-expanding network of decision-makers, influencers and pioneers committed to involving patients and clinicians in research priority setting. For more information and to apply online, go to:

[www.lindalliance.org/Affiliates-Programme.asp](http://www.lindalliance.org/Affiliates-Programme.asp)

Or contact the JLA at:

Email: [patkinson@lindalliance.org](mailto:patkinson@lindalliance.org)

Tel: 01865 517635.

## The International Journal of Consumer Studies: Consumer, User and Carer Involvement in Health and Social Care

Christine Wilson from the University of Glamorgan has recently guest edited a Special Issue of the International Journal of Consumer Studies, Consumer, User and Carer Involvement in Health and Social Care, September 2010.

Christine is presenting at this year's INVOLVE conference in Nottingham on the 16th and 17th of November. A number of copies of the Special Issue will be available to delegates and Christine is looking forward to meeting up with some of the authors at the INVOLVE Conference. Details of the Special Issue can be found at:

<http://onlinelibrary.wiley.com/doi/10.1111/ijc.2010.34.issue-5/issuetoc>

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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.