

newsletter

Welcome to the Summer 2012 edition of the INVOLVE newsletter. This issue includes our conference programme and a taster of our new online training and support resource. We begin with a few words from our Director.

Putting our strategy into practice

Welcome to our Summer edition – hopefully you are enjoying some sunshine in between the rain! In the last edition of our newsletter Simon Denegri, our Chair, reported on our new Strategic Plan. Building on this we have now developed our Operational / working plan for 2012-13 which is available on our website. We will be adding further information about our work plans and activities throughout the year, so do look in the About INVOLVE part of our website (www.invo.org.uk/about-involve/) to find out more.

This year is our eighth biennial conference which will be held in Nottingham on 13 and 14 November. Bookings are now open for this and further information is available in this newsletter and on the conference website (www.profbriefings.co.uk/involve2012/)

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Sarah Buckland

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.

If you are interested in attending, do register as soon as you can as places are filling up fast.

We are continuing to add new information and areas to our website. As part of our online Resource for researchers we have just added a new supplement - Strategies for diversity and inclusion in public involvement (www.invo.org.uk/resource-centre/resource-for-researchers/browse/?content=Supplement). Other supplements will follow. We have also just produced a further new publication – Public involvement in research: impact on ethical aspects of research. This document illustrates how public involvement throughout a study can help to make research more ethical (see the publications page on our website www.invo.org.uk/resource-centre/publications-by-involve/). Over the coming months we will be developing an online map providing a directory of local and national networks, groups and organisations that support public involvement activities. We will update you further in future editions of the newsletter.

One of the other key areas of work important to INVOLVE is working with partners to support them in their plans for public involvement. As well as working with colleagues within the National Institute for Health Research (NIHR) we have also been linking with others. For example, we are currently supporting the Economic and Social Research Council (ESRC) in the recently announced ESRC and NIHR initiative to fund social science research on dementia (www.esrc.ac.uk/funding-and-guidance/funding-opportunities/21219/dementia-initiative.aspx).

We are also working closely with the newly established Health Research Authority to help them in developing their patient and public involvement strategy (www.hra.nhs.uk/hra/hra-news-and-announcements/ppi-working-group-ppi-strategy/).

We hope you enjoy reading the newsletter and do let us know of any public involvement activities you are involved with so that we can share them with others.

INVOLVE Coordinating Centre news

New Research Capability Funding

The National Institute for Health Research (NIHR) has a system which rewards research-active NHS organisations by providing them with some additional funds. From April 2012, this scheme is called Research Capability Funding (previously it was known as Flexibility and Sustainability Funding). The main purpose of this fund is to help these research-active NHS organisations to act flexibly and strategically to maintain their research capacity and capability. The main call on this fund is to enable organisations to retain their research active and research support staff.

We are pleased to report that NIHR has clarified that some of these funds may also be used to cover staff time for public involvement, and the costs of working with members of the public (at the organisation's discretion), when this is part of the process of preparing a grant application.

For more information about Research Capability Funding including regulations on using the funding for public involvement go to www.nihr.ac.uk/infrastructure/Pages/research_capability_funding.aspx

Tips sheet: Recruiting members of the public to get involved in research funding and commissioning processes

This new tips sheet aims to offer some practical advice for people who are planning to recruit members of the public to patient and public involvement roles in research funding and commissioning processes, such as reviewing research funding applications or being members of research advisory panels and boards. It has been produced by INVOLVE working with members of the Public Involvement Collaboration Group (PICG), which brings together the patient

and public involvement leads of many of the National Institute for Health Research (NIHR) programmes and others, to work on research funding and commissioning issues of common interest, and to share knowledge, resources and good practice. www.invo.org.uk/posttypepublication/tips-sheet-recruiting-members-of-the-public-to-get-involved-in-research-funding-and-commissioning-processes/

Training and support resource

This new online resource offers advice and guidance to people developing their own training and support packages. The information in the resource has been drawn from the direct experience of members of the public, researchers, trainers and public involvement specialists. Turn to page 10 to find out more. www.invo.org.uk/resource-centre/training-resource/

Interesting articles and publications

**‘But is it a question worth asking?’
A reflective case study describing
how public involvement can lead to
researchers’ ideas being abandoned**

**J Boote, M Dalglish, J Freeman, Z Jones,
M Miles and H Rodgers**

Health Expectations –

published online May 2012

<http://onlinelibrary.wiley.com/doi/10.1111/j.1369-7625.2012.00771.x/abstract>

This case study presents an account of what happened when an academic-led idea for funding was not supported by stroke survivors and carers who were asked to contribute to its development. The lack of patient and carer support led to the research idea being abandoned. Those involved in the research consultation reflect that the resultant public money savings should be seen as an important benefit of public involvement.

Consumer involvement in systematic reviews of comparative effectiveness research

**J Kreis, M Puhan, H Schünemann
and K Dickersin**

Health Expectations –

published online March 2012

<http://onlinelibrary.wiley.com/doi/10.1111/j.1369-7625.2011.00722.x/abstract>

This study aimed to explore current approaches to involving consumers in United States-based and key international organisations and groups conducting or commissioning systematic reviews. Through a series of interviews and a review of organisations’ websites, the study found that organisations involve consumers in a variety of ways and for various reasons. It also identified instances of training in research methods but noted that little formal evaluation of the effects of involvement is currently carried out.

Good practice guidance for involving carers, family members and close friends of service users in research

Mental Health Research Network

www.mhrn.info/data/files/MHRN_PUBLICATIONS/REPORTS/Carer_good_practice_guidance_-_complete.pdf

The National Institute for Health Research (NIHR) Mental Health Research Network has published guidance that aims to provide practical, accessible guidance for researchers who seek to involve carers in mental health research. Severe mental health problems impact on the individual and also the people who spend the most time with them, their family members and close friends.

Drawing on a number of case studies, the guidance sets out how carers should be included in research, at what stages of the research process carers can be involved and identifies the core principles for the inclusion of carers.

The VIPER Project: involving young disabled people in research

By Pamela Shaw



A young disabled person designed the project logo

VIPER is a three-year research project funded by the Big Lottery Fund to explore the most effective ways of enabling young disabled people's participation in the development of services in England. The project is delivered by a partnership consisting of the National Children's Bureau (NCB) Research Centre, the Council for Disabled Children, the Alliance for Inclusive Education, and the Children's Society.

VIPER aims to:

- explore the ways in which young disabled people are currently involved in decisions about services
- explore the impacts and benefits of young disabled people's participation
- identify good practice and understand what works in supporting participation
- develop tools and guidance to support young disabled people's participation in decisions about services.

At the heart of the project is a group of 16 young disabled people, aged 12 to 22, from across England. They meet regularly to develop their research skills and to advise the project team. As well as this, they participate directly in the research, for example through conducting fieldwork interviews and focus groups,

developing surveys and analysing data. They have also attended workshops on identity, the social model of disability and disability rights.

VIPER stands for Voice, Inclusion, Participation, Empowerment, Research – a name chosen by the young researchers to reflect what they hope the project will achieve. The young researchers are passionate about the importance of their involvement in the project:

“By getting involved it's showing people that we are able to do what other people can do. Also, by helping to plan the services it's getting [young disabled people] involved in what essentially will affect us.”

“I think it's important to ask young disabled people about their views on services because services need to be accessible to all people... so everyone can use those services.”

“Young people have a voice too. It's really important that they give us a say.”

A key area of learning for the project team has been how to make research relevant and accessible to the young researchers. This has involved developing skills in translating research processes and concepts and adopting a flexible approach to research design in order to meet the needs of the group and ensure meaningful participation, for example building in training on key research concepts and postponing decisions about certain activities to enable the young researchers to be involved.



VIPER Project group

Young people's participation in this project has also increased project partners' knowledge and understanding of participatory research, and developed capacity in making research accessible. It has also led to valuable learning about maintaining rigour in research whilst at the same time ensuring meaningful participation.

While making research language, processes and analysis accessible has of course been a key challenge, other challenges have been of a more practical nature, for example fitting VIPER activities around young people's other commitments, not to mention the logistics associated with ensuring all young researchers were able to participate in fieldwork when case study sites (and young researchers) were scattered across the country.

Initially there was some scepticism from the young researchers about the extent to which they would actually be involved. This has been overcome by keeping them informed of project developments, ensuring they can see progress and understand the impact of their participation in the project, and by responding to requests about their skills development.

However, project successes such as young researchers' full involvement in the fieldwork have far outweighed the challenges. The young people have identified a range of new skills and experiences that they have gained, including disability rights, critically assessing participation work, interview skills, group work, communication, and independence skills:

"The project and the opportunity has broadened our minds about what participation is and how people can be included and what disabled people can do."

"... has given us an understanding of the need to speak to more people to get the full picture and that there will be multiple viewpoints on the same issue."

There has been a high level of external interest in the project, reflected in the number of people signed up to the project newsletter and the emergence of unexpected opportunities, both for the young researchers to develop skills and experiences, and to promote the project at events, for example at an NCB conference on children and young people's participation and to students at University College London.

For more information, to sign up to receive e-bulletins and to access a range of project partner resources, visit www.councilfordisabledchildren.org.uk/viper

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Deadline for contributions
for our next newsletter:
3 September 2012

If you have any questions on
contributing to the newsletter,
please contact Paula Davis
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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

INVOLVE 2012 Conference: Putting people first in research

A unique forum for people interested in public involvement in health and social care research

13 and 14 November 2012 at East Midlands Conference Centre, Nottingham

www.profbriefings.co.uk/involve2012/

INVOLVE's national conferences bring together people with a common interest in public involvement in NHS, public health and social care research. This includes members of the public, service users, researchers, research commissioners, advisers and representatives of voluntary sector organisations. Our eighth biennial conference is taking place over two days, starting at 12.00 noon on Tuesday 13 November and finishing at 4.00pm on Wednesday 14 November 2012.

The aim of the conference is to debate and discuss topics such as: how people are involved in research, the need for learning and support, examples of user led research, researching impact, and future directions. There will be opportunities to network, view posters, performances, DVDs and photographs and visit exhibition stands. You can also have your say during our soapbox session.

Below is a summary timetable for the 2012 conference. Please check the conference website www.profbriefings.co.uk/involve2012 for more details.

Day 1: Tuesday 13 November 2012

Registration from 11.30am and light lunch from 12.00 noon

1.00–1.45pm	Welcome to the Conference Stuart Eglin, Chair of INVOLVE's 2012 Conference Planning Group Simon Denegri, Chair of INVOLVE Keynote speech: Adding value to research: the role of public involvement (working title) Sir Iain Chalmers, DSc. James Lind Initiative
1.45–2.45pm	Papers, workshops and other sessions 1 A choice of eight sessions. Each of these includes two presentations with discussion, a workshop, debate or other approach.
2.45–3.45pm	Poster viewing and refreshments Presenters will be standing by their posters ready to answer questions. Refreshments available
3.45–5.15pm	Papers, workshops and other sessions 2
5.15–5.40pm	Break for refreshments
5.40–6.40pm	Papers, making links and other sessions 3 A choice of eight sessions including opportunities for people to network with others involved in public involvement in research, make links on specific topics, and view films and electronic posters about public involvement in research.
6.40pm onwards	Refreshments and buffet dinner
8.00pm onwards	Shuttle bus service Free transport from the conference centre to designated hotels



INVOLVE 2010 conference delegates



Presenters at the INVOLVE 2010 conference

Day 2: Wednesday 14 November 2012

- 8.30–9.30am** Free shuttle bus service, registration and poster viewing
- 9.30–11.00am** Papers, workshops and discussions 4
- 11.00–11.45am** Poster viewing and refreshments
Presenters will be standing by their posters ready to answer questions.
Refreshments available
- 11.45am–12.45pm** Papers, workshops and other sessions 5
-
- 12.45–1.45pm** Lunch
-
- 1.30–2.00pm** Soapbox – hosted by **Lester Firkin OBE, James Lind Alliance**
‘The Soapbox’ is our own version of Speakers’ Corner. You have a maximum of **two minutes** to tell the audience exactly what is on your mind.
- 2.00–3.00pm** Papers, workshops and other approaches 6
- 3.00–4.00pm** Final discussion: **Alison Faulkner, Service User Researcher and member of INVOLVE’s Conference Planning Group**
- Endnote speech: Simon Denegri, Chair of INVOLVE and National Institute for Health Research (NIHR) National Director for Public Participation and Engagement in Research**
- 4.00pm** Free shuttle bus service to Nottingham train station

How to book for the INVOLVE 2012 Conference

You can book for the conference by going to the conference website

www.profbriefings.co.uk/involve2012

We expect a high demand for places, so please register as soon as you can.

International Collaboration on Participatory Health Research

**By Jonathan Boote, Tina Cook
and Janet Harris**

The International Collaboration on Participatory Health Research (ICPHR) was established in 2009, to strengthen the role of participatory health research (PHR) in intervention design and decision-making on health issues. The Collaboration currently has 79 endorsing members drawn from 16 countries across Asia, Europe, Australasia, and North and South America. Following the principles of open access and network building, membership of the ICPHR is open to any person or organisation with an interest in its aims, and there are no membership charges. The work of the members is undertaken on a voluntary basis and is dependent on the support of the organisations they represent and on project-related grants.

Each year, the ICPHR holds a three-day working meeting to review progress against its objectives and to plan the next year's initiatives. The inaugural meeting of the ICPHR was held in Berlin in 2010, and last year, the meeting took place in Toronto. This May, 21 ICPHR members - from Brazil, Mexico, France, Canada, the UK, Germany and Portugal - met in the beautiful university town of Coimbra, Portugal. On the first day of the meeting, after a group warm-up exercise, in which we had to collectively transport a raw egg down a flight of stairs and along a corridor without touching it, a world cafe enabled delegates to update each other about the various exciting PHR initiatives in which they are involved. We heard about a recently-published realist review of the impact of PHR relationships; an ongoing systematic review of the PHR literature published in Portuguese; an international course on PHR currently in development; a protocol for reaching

consensus on how the quality of PHR studies could be determined; and a project to establish a database or repository of good-quality examples of PHR.

On the second day of the meeting, delegates split into smaller groups to discuss specific projects and to brainstorm research and paper ideas which could benefit from a cross-cultural or multi-country approach. For example, it was agreed that a comparative paper examining the policy contexts, and the facilitators and barriers impacting on PHR in different countries should be developed by Collaboration members. Ideas developed in the small group sessions were then presented to the main group, which considered how Google Documents, with its various translation facilities, could be used to develop papers by ICPHR members who speak and write in different languages.

The late afternoon of the second day was set aside for sightseeing, and delegates took full advantage of this to explore the famous old University of Coimbra, with its sumptuous baroque library and graduation chamber. The second day was rounded off in style by a lovely meal in the old town, which showcased Portuguese cuisine and wine at its finest.

On the final day of the meeting, we agreed on the work plan for the Collaboration for the next year. Delegates departed feeling energised, and looking forward to the next meeting of the ICPHR, which will take place in the UK in June 2013, hosted by the University of Northumbria.

If you would like to contribute to the work of the ICPHR, please visit www.icphr.org/en/mission

About the authors

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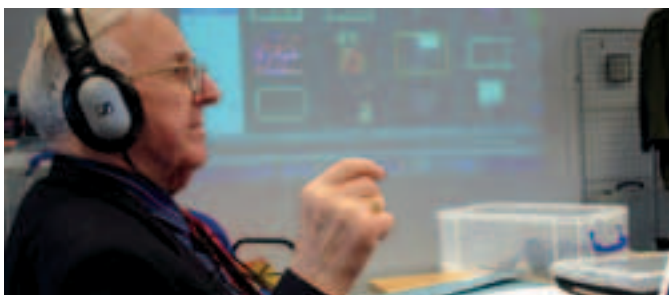
The Past Caring Project: a carer-led narrative research project about carer bereavement

By Wendy Rickard and Victoria Jones

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. There are about six million carers in the UK who are simply ‘getting on with it’ and taking a huge strain, some for many years of their lives. In the Past Caring Project, carers got together to develop research around carer bereavement from the people who quietly experience it. The Past Caring Project collected stories of people who have spent a long time (three to 30 years) caring for a person before they died or for a person lost to dementia. The project was about what comes next, how we feel and what we experience.

This developmental research project took a group of nine bereaved carers through two sets of intensive four-day courses where we each made a digistory (digital story) or short film. Victoria said: “I called my digital story ‘Every Picture Tells a Story’, and based it on the first photo where I could see my husband was ‘gone’ from me into dementia. It was taken for our silver wedding anniversary, before we had a diagnosis, and where others see a happy family portrait, I see only the blankness in his eyes.” Our digistories are on YouTube for everyone to see:

www.youtube.com/folkusuk



Past Caring Project participant



Post Caring Project film editing group

As part of the research design, we also each did an extended interview about our experience of caring and of losing the cared for person. Two from our group had interviewing skills from their past work experience and received some additional specific training on interviewing before undertaking interviews themselves in partnership with the researcher. Three from the group received training in qualitative analysis techniques and Grounded Theory (a systematic generation of theory through the analysis of data). We spent a year working together to gather these interviews, and analyse and examine what we found. Intensive support was provided and there was also counselling support for everyone who wanted it throughout the project period.

The project design was participatory and emancipatory – the project (which was endorsed by The Princess Royal Trust for Carers) was originated and managed by carers, with carer involvement at every stage. One of our participants said: “It recognised my carer experience as valuable. It restored identity and confidence I’d lost, enabling me to use dormant skills, and to learn new ones. It felt safe for me to acknowledge my grief in the group. We were all there because of our losses.”

The draft research findings are grouped around six key emergent themes: stress, death stories, positive perceptions of caring, experience to care, social world and money matters. We are just completing **Continued >>**

the write up of a full research report. We feel we have a powerful and adaptable carer-led research model that we can use to support and enable a larger group of bereaved carers. As a start, we were generously awarded funding by Devon Virtual Carers to run a social evening and film show for carers at Exeter's newly refurbished Royal Albert Memorial Museum & Art Gallery on 1 June 2012. We want to share with other carers what one small group of Devon carers did when dealing with change linked to the end of a caring role. We are also interested in creating a platform to explore the best ways for carers to bring about change in their communities through their own research.



Past Caring Project group

The current group of Past Caring carers and ex-carers has been trained to teach most aspects of the digital storytelling course and to undertake interviewing and analysis. Support from our technical experts will gradually taper off, hopefully leaving the project more affordable, flexible, self-directed and sustainable at the local level. During the next year, we plan to experiment with offering flexible short courses utilising iPad technology and split into accessible chunks of time (one to two day sessions).

Do get in touch if you are interested in our work or would like to share your own experiences of developing service-user led research opportunities.

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Developing training and support for public involvement in research

By Lucy Simons with Kristina Staley, Bec Hanley and Alison Faulkner

A common question we get asked at INVOLVE is: "Where can I access training for public involvement?" Sometimes, this is a researcher or member of the public wanting to develop their skills or knowledge. But often it's a researcher or public involvement manager wanting to offer training to other people – either to researchers across their 'patch' or to members of the public getting involved in their research / organisation.

While it is great that people recognise the value of developing knowledge and skills around involvement, unfortunately the answer to this question is not always what they would like to hear. This is because:

- at present there are few open-access training opportunities for public involvement - most courses or learning events are internal to a particular organisation or integrated into individual research projects
- the evidence from people's experience is that the best approach is to tailor training and support to each individual situation – suggesting that accessing a generic or off-the-shelf course may not be the best approach.

Therefore, our advice is to offer training and support tailored to the situation and matched to the needs of the individuals involved. So the next question is: "How can I find out how to offer good quality training and support?"

Now we can help! We have been working on a new resource to provide information and guidance to people planning training and support packages. All the information in the new resource is grounded in real life

experiences, drawn from the knowledge of members of the public, researchers, trainers and public involvement specialists.

The resource includes our definitions of the terms ‘training’ and ‘support’ and some guiding principles to inform any approach. We give an overview of training and support for researchers and members of the public, look at carrying out a needs assessment and then look in detail at five common involvement roles. Throughout the resource we include short case studies to give examples of how these ideas have been put into practice. These examples include one-day workshops, Master’s level modules, how training has been integrated into involvement, how to assess training needs and, importantly, a wide range of approaches for supporting researchers and members of the public once involvement is underway. To whet your appetite, two of these examples are highlighted here.

Case study: Raising awareness of public involvement with researchers

This one-day workshop was designed to target early career researchers undertaking their PhD. The content for the workshop was designed by a collaborative group including National Institute for Health Research patient and public involvement managers, PhD students and a member of the public. The workshop aimed to meet the needs of researchers by demonstrating how public involvement could contribute to the conduct of their research and help them fulfil the expectations of funders and sponsors, and by identifying a range of resources and practical approaches to developing involvement in their own projects. An innovative aspect of this workshop was using postcards to complete short action plans and mailing them back to participants three months later to remind them of their ideas.

www.invo.org.uk/resource-centre/training-resource/

Case study: Preparing for involvement with the Patient Learning Journey Model

Before people with experience of pressure ulcers started contributing to research at the Leeds Clinical Trial Unit, the Patient and Public Involvement Officer, Delia Muir, brought them together for facilitated workshops. The aim was to prepare them for involvement in research. However, instead of focusing on research, this workshop focused on helping people to understand the value of their personal experience, expertise and skills and how this can contribute to research. The participants worked to identify learning points from their personal experiences and how to communicate these to others. They were also helped to think about how much of their personal experiences they were willing to disclose when working with a research team. As Delia explains in the case study, this approach is valuable as it starts with people and their stories, rather than the other things they need to know.

www.invo.org.uk/resource-centre/training-resource/

To explore the whole training and support resource go to www.invo.org.uk/resource-centre/training-resource/

We would like to thank everyone who has contributed their knowledge and experience to this project – they are all listed in the ‘About this resource’ section on the website.

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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 item on our noticeboard please contact the Coordinating Centre.

UK Clinical Trials Gateway survey

The UK Clinical Trials Gateway (UKCTG) www.ukctg.nihr.ac.uk/default.aspx 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 at www.guardian.co.uk/healthcare-network-nihr-clinical-research-zone/engaging-patients-research-live-discussion

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/>

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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.