

newsletter

Welcome to the Spring 2012 edition of the INVOLVE newsletter, which includes articles written by members of the public and researchers on their experiences of active public involvement in research.

Bringing our strategy to life



**By Simon Denegri,
Chair of INVOLVE**

Did you see the recent news item about the research study suggesting that the more meetings we attend, the lower our intelligence quotient (IQ) becomes? It doesn't bode well, does it?

Modern life seems a never-ending train of meetings, planning and strategising. Worse still, I remember a former naval officer telling me that all strategies and plans go out the window as soon as the enemy turns up! 'Best laid plans ...' as the saying goes. **Continued >>**

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But the point is, of course, that strategies and plans do many other things as well: guide, focus energies, make transparent, bring people together and give licence, rather than tell us what, to 'do'.

As I mentioned in my last piece for the newsletter, the INVOLVE group has been busy shaping and agreeing a strategy for the next three years, beginning 1 April 2012. You can find it on our website here:

www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEStrategy2012-15.pdf

It's a good document with a strong vision - 'A dynamic partnership between the public, researchers and others, to advance NHS, public health and social care research and improve the health and well being of the population' - and a bold ethos of challenging ourselves and those we work with, not simply to strengthen and improve public involvement, but actually ensure that it thrives.

I don't know about you but I am of the view that strategies should be living, flexible documents, not left to amass dust on a high shelf somewhere in an office. And I hope you can help us bring our strategy to life. Please do take a look and, in particular, consider our four new objectives and what they mean for you:

- lead on public involvement across the National Institute for Health Research (NIHR)
- build and share the evidence base
- develop capacity and capability for public involvement in research
- influence research policy and practice.

More than that: please also tell us how you think you can help us achieve these objectives. To continue the military reference above: even the best armies need constant reinforcements and re-supply to keep them advancing, fresh and unified.

Our partnership with you and other colleagues is going to play an important part in the way we take forward our strategy over the coming months. Indeed, I hope we can look at different ways in which to engage and

bring with us old friends and new partners on key projects and activities. Our challenge to ourselves is to be transparent about the way we do things and open-minded to new ideas and approaches to how we do them.

One more thing: it is important for people to remember that, while INVOLVE may not be a delivery organisation in the sense of providing services, it has much that it can, indeed must, deliver: leadership, intellectual rigour, solutions to problems, advice as well as guidance and, of course, influence.

The more colleagues I talk to across the immediate public involvement community and beyond, the more excited I become about what we can achieve by working together to put our strategy into practice.

I hope you agree that two minds are better than one.

Now, when shall we meet?

INVOLVE Coordinating Centre news

INVOLVE 2012 conference update

The INVOLVE conference 'Putting people first in research' is being held at the East Midlands Conference Centre, Nottingham on 13 and 14 November 2012. The conference is a unique forum for people interested in public involvement and health and social care research.

We received a fantastic response to our call for presentations, which has now closed, with nearly double the number of applications submitted for 2012 compared to our last conference in 2010. Thank you to all of you who sent in a submission. We are looking forward to reviewing the proposals and putting together an exciting conference programme ready for publication in our Summer newsletter. In the meantime, please visit the conference website for regular updates: www.profbriefings.co.uk/involve2012/

Welcome to new INVOLVE members

Following the successful conclusion of our membership recruitment process, we are delighted to formally welcome 15 new members to INVOLVE.



New INVOLVE members

They are: Lizzie Amis, Jonathan Boote, Pam Carter, Tina Coldham, Lynne Corner, Rosie Davies, Jo Ellins, Linda Laurie, Tara Mistry, Una Rennard, Carol Rhodes, Lesley Roberts, Veronica Swallow, Amander Wellings and Patricia Wilson. Our new members recently attended an introduction day, which gave them the opportunity to meet each other and learn more about INVOLVE. You can read their profiles (together with those of established members) on our website:

www.invo.org.uk/about-involve/who-are-involve/members-information

New briefing notes for researchers: public involvement in NHS, public health and social care research

The new edition of our briefing notes for researchers is now available on our website (www.invo.org.uk/resource-centre/resource-for-researchers), where you can view the ten briefing notes online or download a copy of the publication.

Public involvement in research sits in a changing and evolving environment. There is now a greater commitment to the importance and contribution public involvement can make to research and there are far more organisations and individuals supporting

public involvement. There are also many more researchers and research commissioners working alongside the public for the first time. We have restructured some of our thinking about the framework for public involvement in research. In the past we have used the terms consultation, collaboration and user controlled to describe different levels of involving people in research. Over time it has become clear that in practice researchers can use a combination of these three and it is more helpful to describe them as different approaches to public involvement in research rather than levels.

This publication provides an introduction for those new to public involvement in research. However, it will also be of interest to researchers with experience of public involvement who are looking to update and refresh their knowledge and skills and helpful to others interested in public involvement in research. There is information on why members of the public should be involved in research, how to involve members of the public and the different ways people can be involved in the stages of the research cycle.

The briefing notes are part of a larger online resource that will be developed to include more detailed information, examples and templates. We will be constantly updating the resource so sign up for email alerts from our website to be kept up to date with new content (see below).

Receive regular news updates from INVOLVE

Remember that you can receive the latest news and information from INVOLVE by signing up for our mailing list and selecting the 'website news alerts' and 'other information from INVOLVE' options:

www.invo.org.uk/about-involve/keep-in-touch/sign-up-for-mailing-list/

INVOLVE website feature: My clippings

Have you seen the 'My clippings' feature on our new website? This enables you to create your own area for holding information that you have 'clipped' from the website. Simply click 'Add to my clippings' on the website pages that you are interested in and the information will be stored on your own 'My clippings' page: www.invo.org.uk/my-clippings. You can then email items to a friend, download pdfs or Word documents or view and print the items in your collection.

invonet workshop summary

invonet is a network facilitated by INVOLVE. It has a membership of researchers and others interested in the development of the evidence base on the nature, extent and impact of public involvement in research (www.invo.org.uk/invonet/about-invonet/).

The sixth invonet workshop, which was held on Tuesday 21 February 2012 at the Kings Fund in London, focused on researching public involvement in research. Over 50 members attended the workshop, which was chaired by Simon Denegri, Chair of INVOLVE.

In the morning four recently funded studies looking at the impact of public involvement in research presented their work plans and then took part in a chaired discussion on common themes and emerging issues.



invonet workshop participants



invonet workshop presenters

The presenters were:

- Jennie Popay, Lancaster University on 'What are the impacts of user involvement in health and social care research and how can they be measured?'
- Carrol Gamble and Jennie Newman, University of Liverpool on 'An evidence base to optimise methods for involving patients and public representatives in clinical trials: a systematic investigation of a cohort of Health Technology Assessment funded clinical trials'
- David Evans, Rosie Davies and Vito Laterza, University of the West of England on 'Public involvement in research, assessing involvement through a realist evaluation'
- Patricia Wilson, Marion Cowe and Elspeth Mathie, University of Hertfordshire on 'RAPPORT, ReseArch with Patients and Public invOLvement: a RealisT evaluation'.

Jennie Popay's study is funded by the Medical Research Council (MRC) Methodology programme and the other three projects are funded through the National Institute for Health Research (NIHR) joint Health Service Research / INVOLVE funded programme.

In the afternoon there was a wide ranging and enthusiastic discussion on other research underway and the potential areas for further work. Visit our website for further information about invonet and this event, including short audio clips from some of the delegates: www.invo.org.uk/invonet/invonet-2012

Interesting articles and publications

An evaluation of service user involvement in studies adopted by the Mental Health Research Network

Kristina Staley, TwoCan Associates

Published January 2012

www.mhrn.info/data/files/MHRN_PUBLICATIONS/REPORTS/Service_user_involvement_evaluation.pdf

The Mental Health Research Network (MHRN) has published this evaluation which identifies what more they and others could do to promote successful service user involvement in adopted studies. Lead researchers from 45 studies selected at random from the MHRN portfolio were interviewed for the evaluation. Lessons relating to good practice were drawn out in a series of case studies following further in-depth interviews with researchers and service users.

Involvement of consumers in studies run by the Medical Research Council (MRC) Clinical Trials Unit: Results of a survey

Claire Vale, Lindsay Thompson, Claire

Murphy, Silvia Forcat and Bec Hanley

Trials, volume 13, issue 9, January 2012

www.trialsjournal.com/content/13/1/9/abstract

This study aimed to establish levels of consumer involvement in randomised controlled trials (RCTs), meta-analyses and other studies carried out by the UK Medical Research Council (MRC) Clinical Trials Unit.

The knowledgeable patient: communication and participation in health

Edited by Sophie Hill

Published 2011, Wiley-Blackwell

ISBN: 9781444337174

This Cochrane handbook is aimed at consumers, healthcare professionals, health

service managers, students and policy makers. It examines communication and participation issues and explores the surrounding evidence base. Practical information on how to access and use evidence is also included. The book is based on a variety of different sources, including consumer stories, evidence found in systematic reviews and examples drawn from the community, health services and policy making.

Towards co-production: taking participation to the next level

Social Care Institute for Excellence

Published February 2012

www.scie.org.uk/publications/reports/report53.asp

This short report details the findings of an independent evaluation of the Social Care Institute for Excellence (SCIE) participation function and describes SCIE's new strategy to work towards co-production.

VOICE: Developing a new measure of service users' perceptions of inpatient care, using a participatory methodology

J Evans, D Rose, C Flach, E Csipke, H

Glossop, P McCrone, T Craig and T Wilkes

Journal of Mental Health, volume 21, issue 1, pages 57-71, February 2012

www.ncbi.nlm.nih.gov/pubmed/22257131

This article reports on the development of a patient-reported outcome measure of perceptions of acute care in mental health. Service user researchers carried out the study and constructed the measure, VOICE, from the qualitative data.

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

The patient inside and ‘outside’ the committee

By Jennifer Bostock

There’s a lesson to be learnt from my first day on the National Institute for Health Research (NIHR) Research for Patient Benefit Programme (RfPB) committee – never carry a cup of coffee if you’re also carrying a large bag and a pair of crutches.

This lesson was unexpected, but it was the first, the worst, and one of many. For on that day I nervously arrived at the RfPB committee meeting as an observer, wearing best suit, carrying thoroughly examined papers and negotiating crutches and coffee. A beautiful building awaited, and with vim and vigour I announced my arrival by falling into the majestic room - coffee, crutches and papers everywhere. The stunned, serious and seemingly less than amused faces stared from around the table – the patient had arrived!

Fortunately it could not get any worse, in fact it got a lot better – the stony faces soon turned to smiles and the stern conversations to light hearted and welcoming chat. I had survived the observation at least. From then on it’s been a pleasure to be a part of the committee. I must say it’s hard work, with tons of papers and lots to get my head around from methodology and statistics to complex medical and surgical research. But such is the stimulation of the committee, the approachability of the ‘experts’, and the value placed upon the patient perspective, that I genuinely feel a valuable and valued member. I have now been given lead assessor duties which means that I introduce studies to the rest of the committee and keep track of and feedback the salient points to the Chair.

I certainly still have lessons to learn in terms of getting my head around the subject matter, for example the differences between feasibility and pilot studies, and what would prevent an

application being recommended at the end of the assessment. I suppose one of the most important lessons for me is to take a more laid-back approach, to realise that I do not have to read and understand every word of every application, nor do I need to comment on every aspect – no one else does.

I feel that as a lay person I am expected to comment more than other people who sit on the committee as they have their own area of expertise, whereas I see the projects as a whole. But it is not expected - and probably not a good use of the short time we have for assessing each application - for me or anyone else to dissect every aspect and critique every word.

So it is still a learning curve for me but I like that, as it keeps the work interesting and challenging. As a patient, I suppose my biggest contribution to the committee is to ask the simple and somewhat naïve questions, for example why is this research, how exactly will patients benefit from this study or can’t the money be better spent elsewhere? I don’t always get an answer, I don’t really expect to, but I’ll keep asking because sometimes I find that others agree with my innocent questions.

As patients, we don’t often feel powerful, but in a strange way being a lay person on a committee like the RfPB allows us to relax and ask all the questions that the ‘experts’ would like to but dare not ask, and that puts us in quite a powerful position.

I did not expect to learn the coffee and crutches lesson at the committee, and the committee certainly did not expect to learn that patients can make just as much noise once inside the committee as they can coming in.

Jennifer Bostock is a member of the National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB) Regional Advisory Committee for London. For further details on the programme and to enquire about joining an RfPB committee, please visit: www.ccf.nihr.ac.uk/Pages/OpportunitiesinRfPB.aspx

Top ten research priorities relating to life after stroke

By Alex Pollock and Bridget St George

A collaborative project, carried out by researchers from the Nursing Midwifery and Allied Health Professionals (NMAHP) Research Unit at Glasgow Caledonian University, has identified the Top Ten shared research priorities of stroke survivors, carers and health professionals relating to life after stroke.

We carried out this two-year project in collaboration with the James Lind Alliance (JLA), a national organisation (funded by the National Institute for Health Research), which aims to ensure meaningful patient involvement in research priority setting. The JLA supports the development of Priority Setting Partnerships (PSPs), which bring together patients, health professionals and their representative groups within equal partnerships. These PSPs identify and prioritise unanswered questions ('treatment uncertainties'). Central to the PSPs is the equal involvement of everyone at all stages of a prioritisation process.

Our 'Life after Stroke' PSP was led by a representative steering group which included a stroke survivor, carer, physician, nurse, allied health professional and researcher. In order to gather our treatment uncertainties, as well as using postal and electronic surveys, we used methods specifically designed to reduce barriers to equal participation. Many stroke survivors have impairments which could prevent or limit ability to get involved, such as difficulties with communication, movement or understanding. Also, we wanted to enable involvement of stroke survivors and health professionals from across the whole of Scotland, including the many remote rural areas and islands. Our specially designed methods included face-to-face visits at stroke

support groups and clubs across Scotland. We also produced information in a variety of formats, including written information, presentations, audio versions and information sheets specifically for people with aphasia (a common communication impairment after stroke). During our visits to stroke survivor groups / clubs the standard presentation was delivered using the most appropriate mode for the venue and group. We were pleased that the methods we used were successful in achieving roughly equal involvement in terms of numbers of stroke survivors / carers and health professionals.



The authors at the UK Stroke Forum

Through this process, we gathered a total of 548 treatment uncertainties, 54% of which were submitted by stroke survivors and carers and 46% of which were submitted by health professionals. After checking and merging similar questions, we involved stroke survivors, carers and health professionals in setting 24 interim priorities. We then held a consensus meeting (of stroke survivors, carers and health professionals), where these priorities were discussed until consensus was reached on a shared Top Ten.

Continued >>

The Top Ten were:

1. What are the best ways to improve cognition after stroke? [Cognition: the function of processing information and applying knowledge. Functions include processes requiring thought and intelligence, such as attention, perception, learning, memory, comprehension, judgment and decision making]
2. What are the best ways of helping people come to terms with the long term consequences of stroke?
3. What are the best ways to help people recover from aphasia?
4. What are the best treatments for arm recovery and function, including visual feedback, virtual reality, bilateral training, repetitive task training, imagery / mental practice, splinting, electromechanical and robot-assisted arm training, and botulinum toxin [a type of injection to relax muscles, commonly known as 'botox']?
5. What are the best ways to treat visual problems after stroke?
6. What are the best ways to manage fatigue?
7. What are the best treatments to improve balance, gait and mobility, including physiotherapy, gait rehabilitation, visual and auditory feedback, electrical stimulation, different types of ankle foot orthoses [splints] and electromechanical assisted gait training?
8. How can stroke survivors and families be helped to cope with speech problems?
9. What are the best ways to improve confidence after stroke, including clubs / groups, offering support, one-to-one input and re-skilling?
10. Are exercise and fitness programmes beneficial at improving function and quality of life and avoiding subsequent stroke?

Interestingly, the views of stroke survivors appear to have had slightly greater impact on the final Top Ten than the views of health professionals. Stroke survivors and carers made eloquent and convincing arguments in support of some key questions that appear in the Top Ten, including several that health professionals would not have placed there independently. The consensus meeting provided an opportunity for both stroke survivors and health professionals to debate their opinions on research priorities, to reach understanding of the opinions of others, and to successfully reach consensus on the shared top priorities.

We feel that we achieved equal involvement of stroke survivors, carers and health professionals at all stages of this process. These Top Ten shared research priorities should ensure that future research targets the issues which are most important to those directly affected by stroke.

www.lindalliance.org/StrokeinScotlandaJLAPrioritySettingPartnership.asp

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Deadline for contributions for our next newsletter: **28 May 2012**

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Consumers take the initiative in patient and public involvement (PPI) training

By Peter Rainey and Carolyn Morris

In this article we report on how we, as two consumers, conceived, designed and delivered a training event aimed at improving the quality and effectiveness of patient and public involvement (PPI) by research teams.

COMPASS was one of two Supportive and Palliative Care Research Collaboratives funded by the National Cancer Research Institute (NCRI). It brought together research groups from 12 UK universities.

We were recruited as consumer members of the COMPASS Advisory Group, which provided guidance to the board on governance, strategy and consumer involvement. We also provided consumer input at COMPASS conferences and other regular meetings with research teams and, through membership of trial steering committees, contributed to individual studies.

While there were good examples of consumer involvement within COMPASS and a general awareness that PPI was a 'good thing to do', it became clear that there was no consistent approach and a lack of confidence and knowledge about how best to involve patients, carers and members of the public in COMPASS research studies.

Our goals

With the approval of the COMPASS board, we decided to take the initiative and design our own training event, to provide researchers with practical ideas and tools for involving consumers effectively. We had three critical design goals: firstly, training should be practical and based on real-life

settings; secondly, it should stimulate action; and thirdly, it should lead to consumer involvement, which improves the quality of the research through collaboration.

'It was about what's in it for them, rather than a moral imperative'

Crucially, we wanted to position PPI as 'part of the solution' to many of the problems research teams encounter as they navigate their way around the research cycle: generating ideas, refining the research question, ethics approval, securing funding, accrual to trials, and dissemination of results – all common hurdles faced by the research community.

'Make collaboration your default setting'

We designed and delivered an interactive workshop called 'Collaborate and Succeed'. The key message was that early engagement with consumers at every stage of the research cycle is the best way to ensure effective involvement and to add value to the research process. The workshop encouraged attendees to participate in practical problem-solving exercises based on their own real-life settings, to view challenges from a different perspective and to learn from each other. We hoped to show how a more collaborative approach with consumers could offer solutions and lead to better results. One significant benefit was that delegates left the workshop with an action plan.

We ran the workshop four times across three COMPASS locations and the feedback from research teams was very positive. Researchers liked the practical approach and the fact that consumers were the workshop facilitators. A good mix of researchers at every level attended the workshop with even the most senior staff learning something new. We could see confidence growing. Our researcher colleague, Marilyn Kendall, joined us for most of the workshops, so we were modeling collaboration as well as advocating it.

Evaluating the training

After the final workshop, COMPASS commissioned a study to assess the impact of the training. Structured interviews were conducted with many of those who attended the event and with others within the COMPASS hierarchy. The findings were broadly consistent with the idea that a practical and action-oriented approach to PPI training is more effective as a means of learning. Most attendees learned something and were able to implement it immediately. Many felt that this form of training could become part of the curriculum for those building their careers in research and that perhaps major funders could provide this training as a means of ensuring there is good quality consumer input to the research proposals they receive.

One major conclusion which emerged from the study is that PPI training needs a champion at a senior level in research groups. We agree, and believe strongly that PPI provides an opportunity for leadership qualities to shine. We also believe that consumers should take a more active and prominent role in developing and designing PPI training for researchers and in actively marketing such training events. The evaluation showed us how important our role in the workshops was: 'They helped to demystify consumer involvement. They normalised it all and made it all OK.' Our backgrounds helped, but we can't be the only consumers with these skills.

More on what we did, what we learned and the evaluation's recommendations for consumer involvement training at:
www.ncri.org.uk/default.asp?s=1&p=16

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Involving patients and the public in talking about medical research

By Sara Ellis

Information about health and medical research may be more readily available than ever before, but this does not always help patients or the public make sense of scientific research.

In 'Patients Participate!' – a collaborative project between the British Library, UKOLN (formerly known as the United Kingdom Office for Library and Information Networking) at the University of Bath, and the Association of Medical Research Charities (AMRC) - we wanted to find out about the potential for involving the public and researchers in making sense of scientific literature. We set out to look for ways to bridge the gap between access to health research information and actually understanding that information.

Thanks to initiatives such as UK PubMed Central (UKPMC), anyone with a computer and an internet connection can read the latest biomedical research findings. But access is not the same as understanding, as medical research charities and other patient groups are aware. Charities play a particularly significant part in funding medical and health research in the UK. Last year UK charities invested over £1 billion in health research – about a third of all public spending on medical research. Their supporters want to know more about the difference their money makes and many charities employ people to write about research in lay-friendly terms.

'Patients Participate!' kicked off with a consultation workshop, involving patients, academics, charities and other funders. We wanted to explore views on engaging patients and the public in writing lay summaries of

biomedical research papers, using citizen science-like models (when members of the public, who may not have scientific training, conduct scientific research, for example Galaxy Zoo) and crowd sourcing (when tasks are outsourced to a large community of people, usually via the internet, for example Wikipedia). We were encouraged by the consensus that emerged at the workshop, with overwhelming backing for the idea that every UKPMC article should have a lay summary.

There was strong endorsement for guidelines and templates to make it easier for writers, and mechanisms for gathering feedback from the intended audiences. But when it came to who should write these summaries, the preference was for researchers or other professionals, rather than patients themselves, and a clear recommendation that researchers need support to write well for lay audiences.

AMRC brought our experience from an earlier project, 'Natural Ground', where we examined how our member charities involve patients and the public in research. So we were keen to go back to our members and find out how patient and public involvement in medical research had evolved.

We found a good deal of enthusiasm for the aims of 'Patients Participate!', and over the course of the project we spoke to around 40 charities about how they communicate about medical research with patients, supporters and other interested parties. They told us their priorities were:

- to be able to find out about and access publications that result from the research they fund – many find it difficult to get timely information on published research
- better lay summaries – many employ people to write about research in lay terms
- a way to get feedback on the information they provide for lay audiences – is it useful, interesting and pitched at the right level?

- better training for researchers in communicating with lay audiences.

Almost all charities ask researchers to summarise their research in lay terms when applying for funding and at the end of their projects. Yet one in three told us they have difficulties using the summaries for their intended purposes, and often have to rewrite them.

With so much expertise and good practice in writing for lay audiences amongst charities, one key output of the project was to share and signpost to existing resources. Several charities, funders and publishers gave up their time to take part in in-depth interviews, which were written up as case studies. And our charities generously shared their guidelines and style guides, which we used to compile guidance for researchers on writing for lay audiences.

Our lasting learning from 'Patients Participate!' is that research findings must be accessible if patient involvement is to continue to grow. In March 2012, AMRC brought together people from across medical research charities who work on research communications, patient and public involvement and engagement to share creative ideas for talking about research.

For more about the resources mentioned in this article please visit: www.amrc.org.uk/our-members_patients-participate

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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.

Launch of clinical trials online resources

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

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

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

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

New accessibility resource

The Social Care Institute for Excellence (SCIE) has launched a new online resource for anyone who is organising an event and wants to make it accessible and inclusive. The resource is based directly on the views and experiences of people who use services and is split into three main sections:

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

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

'Research People' videos

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

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

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Friendly disclaimer: The views expressed in this newsletter and in any enclosures are those of the authors and not necessarily those of INVOLVE or the National Institute for Health Research. Articles are selected for the sole purpose of stimulating ideas and debate on public involvement in research.