

newsletter

Spring 2014

Welcome

From Sarah Buckland, Director,
INVOLVE Coordinating Centre



Welcome to the Spring issue of the INVOLVE newsletter. In this newsletter there are some interesting articles about different aspects of involvement. You can read about how nine PhD students identified the need and then organised a workshop for fellow researchers within their University to raise awareness of the value of public involvement. You can also read about two research projects where patients and carers were involved from the outset and throughout the projects influencing their design and direction.

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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 Coordinating Centre news

An aspect highlighted by one of the studies – the Beating Anxiety Together study – was the importance of using clear language both within the research team and in describing the project to the young people and parents involved.

Writing clearly is important to every aspect of research and can help all of us to better understand sometimes complicated research. However, it isn't always easy. In this newsletter we report on some work we have been leading on, working with colleagues from across the National Institute for Health Research (NIHR), to produce new guidance for researchers on writing plain English summaries for NIHR funding applications.

Also in this newsletter we update on some of the other activities at INVOLVE. If you would like to know more, then go to the About INVOLVE / Current work section of our website: www.involve.nihr.ac.uk/about-involve/current-work. Here you can read our INVOLVE update, where we give a summary of the different projects we are working on, as well as read about our plans for the coming year.

Please don't miss the opportunity to respond to the National Institute for Health Research strategic review of public involvement in research 'Breaking Boundaries: thinking differently about public involvement in research'. The review is an important chance to contribute your views and influence the future shape of public involvement in research. The deadline for contributing is **12.00 noon on Thursday 26 June**. For further details see the article on page 11 of this newsletter.

The Summer edition of the newsletter will have the theme of learning for involvement. As part of this we will be reporting on work that we have been involved in over the last 12 months with colleagues from across the National Institute for Health Research. We have been exploring issues such as principles and standards for learning and development and different approaches to support involvement.

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 2014 conference update

Our INVOLVE conference 'Changing Landscapes' is being held at the National Exhibition Centre in Birmingham on 26 and 27 November 2014. The conference is an opportunity for people interested in public involvement in NHS, public health and social care research to meet, discuss and debate.

We received a record-breaking response of 218 abstracts to our call for presentations, which has now closed. 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/involve2014

Two new webinars

We have recently held two new webinars in the joint National Institute for Health Research (NIHR) School for Social Care Research and INVOLVE series:

1. End of Life Care research methods and public involvement in End of Life Care on Thursday 1 May 2014, featuring:
 - Claire Goodman, Professor of Health Care Research at the Centre for Research in Primary and Community Care at the University of Hertfordshire, providing an overview of the range of research methods (<http://sscr.nihr.ac.uk/PDF/MR/MR12.pdf>) commonly used in end of life care research and their relevance to social care.
 - Heather Maggs, ex-dementia carer, speaking about her experience of being involved in end of life care research.
 - Sabine Best, Head of Research at Marie Curie Cancer Care, speaking about their Palliative and end of life care Priority Setting Partnership (PeolcPSP).
2. User controlled research on Tuesday 13 May 2014, featuring:
 - Peter Beresford, Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University, speaking about user controlled research (http://sscr.nihr.ac.uk/PDF/ScopingReviews/SSCR-Scoping-Review_5_web.pdf)

- Dr Sarah Carr, Sarah Carr and Associates Ltd, Universities of Birmingham and York and co-Vice Chair, National Survivor User Network (NSUN), talking about her experiences of developing an academic research programme bid that includes user-controlled investigations.

You can view the slides from these webinars on our website: www.involve.nihr.ac.uk/about-involve/current-work/nihr-school-for-social-care-research-and-involve-webinar-series

Welcome to Martin

We are delighted to welcome

Martin

Lodmore to the Coordinating Centre. Martin is our new Senior Public Involvement Advisor, leading on Capacity and Capability. He will have a leading role in updating guidance materials, community development and supporting our work on learning and development. Martin continues to have a role with the National Institute for Health Research (NIHR) Clinical Research Network Coordinating Centre, as patient and public involvement (PPI) lead for the Diabetes, Renal, Metabolic and Endocrine Disorders theme. He has previously worked as a research administrator at Imperial College London, and in adult education, re-training people who were long-term unemployed in business administration.



People in Research website – redesigned

We have recently redesigned the People in Research website to improve its appearance, develop new functions and make it more user friendly. An advisory group was involved in all stages of the project including developing the project brief, contracting the website designers and testing the redesigned site.

The key functions of the website are:

- researchers are able to advertise opportunities for people to get involved in their work
- members of the public can find opportunities to get involved in research
- anyone can sign up to the website or follow us on Twitter to receive an alert whenever a new involvement opportunity is added.

Visit the redesigned website www.peopleinresearch.org and follow us on Twitter [@People_Research](https://twitter.com/People_Research)

invONET roundtable

invONET is a network of people working to build evidence, knowledge and learning about public involvement in NHS, public health and social care research. On 21 March 2014 INVOLVE brought nine experts together in a roundtable discussion that considered how the evidence base on the impact of public involvement in research is evolving and how it should be developed in future. Those invited to the roundtable all had experience in the area and represented a variety of different perspectives. The discussion is currently being written up in a report that will include ideas for researchers, commissioners and invONET. The report will be disseminated via our networks and on the INVOLVE website. In addition to the discussion, attendees have each written a brief reflection piece on the future of the evidence base for public involvement. These reflections will also be included on our website.

INVOLVE response to NHS England Consultation

NHS England recently held a consultation on the draft NHS England Research and Development Strategy www.involve.nihr.ac.uk/wp-content/uploads/2014/02/NHS-England-Research-Strategy-Consultation.pdf. The draft strategy laid out six objectives to be delivered by 2018. Objective 4 specifically mentions public involvement in research: “To ensure the inclusion of patients in setting priorities for research and participation in the design, delivery and dissemination of research.”

An INVOLVE response to the strategy ‘NHS England Draft Research Strategy: A Response from INVOLVE’ can be found on our website: www.involve.nihr.ac.uk/wp-content/uploads/2014/02/INVOLVE-Response-NHS-England-RD-Strategy.pdf

Following the consultation we are continuing to be in discussion with NHS England to assist in the redrafting of the strategy.

Interesting articles and publications

Patient and Public Involvement in Your Research

R Pandya-Wood and A Robinson in D-M Walker (2014) *An Introduction to Health Services Research: A Practical Guide*. London: SAGE. ISBN: 9781446247396 (paperback), 9781446247389 (hardback).

A new book has been published containing a chapter on public involvement in health services research. This chapter, which is about helping to plan appropriate involvement for the research being developed, guides readers through the theory and practice of patient and public involvement. Practical strategies are offered, helping researchers to consider why involvement is needed; who to involve and how to find them; how to involve and what tasks to involve people in; and at what points in the research journey to involve them. A real-life case study about survivors of head and neck cancers is used throughout the chapter to illustrate the theory into practice link. The chapter also offers some insights into reward and recognition of people's involvement; the challenges of involving patients and the public together; and the impact of patient and public involvement.

Adding SUGAR: Service User and Carer Collaboration in Mental Health Nursing Research

Alan Simpson, Julia Jones, Sally Barlow, Leonie Cox, and Service User and Carer Group Advising on Research (SUGAR). *Journal of Psychosocial Nursing and Mental Health Services*, January 2014, volume 52, issue 1, pages 22-30

Service User and Carer Group Advising on Research (SUGAR) is an initiative that has been established to develop collaborative working in mental health nursing research among mental health service users, carers, researchers and practitioners at City University, London. This article, written by staff and members of SUGAR, describes its background, how it operates and some achievements to date. It includes researcher reflections and case studies of how the collaboration is influencing research. The article identifies the benefits and possible limitations of the collaboration, outlines future plans, and considers the findings in relation to literature on involvement and empowerment.

<http://tinyurl.com/p7ojxna>

Consumer involvement in health research: a UK scoping and survey

Elsbeth Mathie, Patricia Wilson, Fiona Poland, Elaine McNeilly, Amanda Howe, Sophie Staniszewska, Marion Cowe, Diane Munday and Claire Goodman. *International Journal of Consumer Studies*, January 2014, volume 38, issue 1, pages 35-44

This paper adds to the international evidence base on patient and public involvement (PPI) in research by providing an overview of current trends and impacts. The authors carried out a scoping exercise and survey of selected UK studies in order to understand the current extent and variation of PPI in research. They selected six research topic areas (cystic fibrosis, diabetes, arthritis, dementia, intellectual and developmental disabilities, and public health) and contacted a total of 838 study authors. Key findings from the scoping exercise and survey include: steering committee membership and reviewing patient information leaflets are the most common PPI activities; there appears to be some blurred roles with patients participating as research subjects as well as carrying out PPI activities; and there is a limited amount of available information about PPI in publicly accessible research documents.

<http://onlinelibrary.wiley.com/doi/10.1111/ijcs.12072/full>

Values associated with public involvement in health and social care research: a narrative review

Felix Gradinger, Nicky Britten, Katrina Wyatt, Katherine Froggatt, Andy Gibson, Ann Jacoby, Fiona Lobban, Debbie Mayes, Dee Snape, Tim Rawcliffe and Jennie Popay. *Health Expectations*, December 2013, epublication ahead of print

This narrative review is part of a larger Medical Research Council (MRC) funded study that is producing a framework and related guidance on assessing the impact of public involvement (PI) in health and social care research. This review aimed to identify and characterise the range of values associated with PI that are central elements of the framework. The authors undertook a review and narrative synthesis of diverse literatures of PI in health and social care research and identified three overarching systems/values. The first of these is concerned with ethical and political issues; the second with the consequences of PI in research; and the third with the conduct of PI in research. The authors recommend that research teams should consider

and make explicit the values they attach to PI in research and discuss ways in which potential tensions may be managed in order to maximise the benefits for researchers, lay experts and the research itself.

<http://onlinelibrary.wiley.com/doi/10.1111/hex.12158/full>

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 Marisha Palm at the Coordinating Centre with details: mpalm@invo.org.uk

Inspiring involvement in research

By Nicola McCleary and Brian Power



It is essential for early-career researchers to become aware of the importance of involvement, to gain an understanding of meaningful involvement at all stages of the research process, and to learn how to improve the relevance, quality and impact of their own research through involvement. We delivered a workshop within our University based on these principles.

How was the workshop organised?

The workshop was organised by a group of nine PhD students at the University of Aberdeen, who are enrolled on a leadership training programme funded by the Medical Research Council. We thought that a workshop involving expert speakers would be a good way to gain some initial knowledge of involvement.

We recognised the value of involving experts with different perspectives, such as researchers and people who have been involved in research. We also thought it would be useful to include an interactive element to enhance learning.

What did the training cover?

The event comprised a seminar session, open to PhD students throughout the University, where our speakers covered key topics (for example what involvement is and why it is important, examples of involvement work, and the impact of involvement and how it is assessed). This was followed by an in-depth interactive session led by the nine of us. In this session, we discussed some example research proposals (adapted by materials kindly provided by Dr Jonathan Boote) in the context of involvement. The discussions focused on:

- consolidating understanding of the basic principles of involvement covered in the seminar
- understanding how to incorporate involvement into different stages of the research process
- recognising the relevance of involvement to our own research
- understanding the motivations, practical challenges and barriers to involvement.

How was the workshop rated by attendees?

Fourteen delegates (five PhD students, four research assistants, four early-career researchers and one research nurse) attended and completed evaluation forms. Overall, feedback was very positive, and a key theme arising was the knowledge gained through the diversity of presentations delivered. Attendees also referred to the benefits of being reminded why one is doing research and the usefulness of highlighting the challenges and opportunities of involvement.

When asked what they would take away and implement from the event one delegate commented that they would use contacts made at the event to improve the next stage of their research. A few stated they would investigate the area of involvement further when conducting their research and visit the INVOLVE website for additional resources and information.

What have organisers/attendees done since the workshop to include public involvement in their research?

The attendees have increased patient and public involvement in their research. For example, mother and baby groups were involved as service user co-applicants on a project undertaken within the University. The groups informed the text for participant materials, piloted materials that were used within interview schedules, and contributed to interpreting findings. Further details outlining this work can be found at www.trialsjournal.com/content/14/S1/O35

What challenges were encountered and how were these overcome?

Challenges included how to initiate involvement in the research process. This was overcome by building relationships between researchers and groups relevant to the study. It was suggested at the workshop that a database of patients and members of the public who are interested in becoming involved in research would also be useful to overcome this challenge.

What's next?

To build on the initial knowledge gained at the workshop, the organisers will be looking to develop links with some local patient groups. We also hope to raise awareness of involvement across the University of Aberdeen. We may also run a similar workshop again for new PhD students to the University.

Conclusions

A workshop focusing on patient and public involvement in research was successfully organised **by** PhD students **for** PhD students and other early-career researchers. We provided a forum for speakers to showcase best practice across different parts of the research process, and the workshop was rated favourably by attendees. The organisers would like to thank everyone involved and hope that by sharing our experiences, we can inspire similar events across other institutions.

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The changing face of public involvement in research teams

By Dave Green

In November 2011 my patient and public involvement (PPI) colleague, Sharon Goodchild, and I wrote an article for the INVOLVE newsletter outlining the research project we were involved in as patients. This project is now finished so it is an opportune moment for me to reflect on our contribution to this project.

The research, which was carried out by the Institute of Health and Society at Newcastle University, was part of a wider programme of research looking at how best to involve patients and families in improving patient safety. The ThinkSAFE approach to improving safety was developed following an extensive collaboration and consultation with a broad range of stakeholders – patients, their relatives, and frontline healthcare and ancillary staff.

ThinkSAFE has four components: a video guide to patient safety for patients and their families; a patient-held healthcare logbook linked to the video content including patient question prompts; patients being encouraged to ask questions and to tell staff if things don't seem right; and staff being encouraged to actively foster patient involvement by saying to patients "It's OK to / I want you to ask me questions".

This is a very brief outline of the ThinkSAFE approach. While this was a pioneering study in its own right this article is concerned with an aspect of that study, namely the opportunity offered to extend the role of the patients and to make us an integral part of the research team. It was evident that in order to be fully involved in the project we needed to be brought up to speed on research protocols, terminology and methodology. This was achieved in a series of informal monthly seminars given by a senior research fellow. Without this support neither of us would have been able to partake fully in the activities of the research team.

We negotiated our roles within the team, realising of course that there were activities within the research project that we were not in a position to do. Nevertheless, our activities included observation of focus groups, analysing focus group transcripts, recruiting patients for the project, helping to design patient questionnaires and taking part in a ThinkSAFE video. The opportunity

also arose to present personal experiences of the project and disseminate the results of the project to wider audiences. I have had the pleasure of presenting at conferences, seminars and away days, including a British Science Festival event.

An invitation was extended to get involved in a debate on the role of patients in research. I spoke for the motion that patients could take much more responsibility within the research team and that research was something that was not only carried out by professional researchers. One of the issues raised in the debate was about terminology, and it became clear that patients who are there as part of the research team should not be referred to as 'participants'.

Another concern about patient researchers was the idea that they become too 'professionalised', losing some indefinable 'something' that they bring to the research team. A 'professional patient', if there was ever such a thing, suggests that the more skilled and knowledgeable you become the less effective you are. Only by doing research on the impact of 'lay researchers' will we get a clearer idea of the way forward.

The Institute of Health and Society's project on patient safety has shown that inclusive teamwork arrived at by discussion, negotiation and good humour can enhance the role of patients or 'lay researchers' in research teams. For me this has led to a new concept of the lay researcher as an integral part of the team and not just as a bolt-on extra to obtain funding.

So this research project on patient safety has developed in some very interesting ways and has, I hope, opened up new channels of discussion. We look forward with anticipation to future developments.

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Parents advising researchers: Experiences from the 'Beating Anxiety Together' study

By **Deborah Garland, Dave Linsley, Ann Le Couteur and Helen McConachie**

There is increasing recognition that users of services have a great deal to offer to research

that is far more than simply taking part in a study. This article describes our experience as parents advising a research study of group therapy for young people with autism spectrum disorder (ASD).

The study

Beating Anxiety Together (BAT) was funded as a pilot randomised controlled trial by the National Institute for Health Research. It aimed to find out if group cognitive behaviour therapy adapted to suit young people with ASD would be acceptable to them and their parents, and have the potential to reduce their anxiety.

Parents advising researchers

Parents and other service users were involved at all stages of the study, from making sure the right questions were being asked, through to design and management, and publicising the findings.

First, a survey of anxiety in ASD was carried out through Dasl^{ne}, the database of children with ASD living in the North East. Next, parents (again recruited through Dasl^{ne}) were invited to a lunchtime group to discuss their children's anxiety. Examples of what caused anxiety and how children responded were provided by the parents, and some anonymised examples were included in a parent questionnaire.

Discussions with the service user representative in the local mental health trust also informed the study design. The service user representative advised that all families should be offered a chance to attend therapy groups, and that ideally the groups should be held in community settings rather than a clinic.

Once the study was up and running, Deborah (parent of a young person with ASD and Manager of the National Autistic Society (NAS) Resource Centre) and Dave (also a parent of a young person with ASD) joined the BAT Steering Committee. The Steering Committee was responsible for overseeing the running of the study and providing advice to the researchers on a variety of aspects, such as the content of the information sheets given to young people and parents, the wording of new questionnaires, how to ensure that the families who were randomised to 'delayed therapy' understood what the arrangements would be at the end of the study, what to include in the report of the assessments given to individual families, and editing the summary of findings for parents and professionals.

“Shortly after I took up the post of Resource Manager [of the National Autistic Society], I was invited to become an advisor for the BAT study. I was extremely keen to become involved although I knew that I had little experience in this type of work. At the same time I was asked to help identify another parent representative to join the Steering Committee. I spoke with Dave, a parent who had previously contacted me through the NAS, to ask if there were any services in place to help reduce his son’s stress levels at school. Even though his son was too old to be included in the pilot evaluation, I mentioned the BAT study to him and he contacted Helen, the psychologist leading the study. Dave felt that if his son couldn’t be involved directly then he would have first hand experience to give, and he would find out more that could help him and his son.”

Deborah

“Equipped with a personal copy of ‘Exploring Feelings’ [the therapy approach materials used in the study] I sat in Steering Groups, a lost lone voice amongst a sea of academics and at first struggling to come to terms with what they were hoping to achieve and the language they were speaking. But gradually I came to terms with the project and started to take an active role and was never afraid to stop the debate if I didn’t understand the terminology. Initially we discussed the name of the project and a logo. That took two sessions of quite lively debate! We continued to provide a parental perspective and ask questions that we thought the parents of children on the autism spectrum might want answers to, before they volunteered their children onto the pilot study.”

Dave

We were able to ensure that the BAT team used clear language and that the only acronym in any of the documentation was BAT. As parent representatives we also made sure that plans were developed from the start about how best to publicise the study, so that families could hear about the research and its findings. For example, we suggested that recordings could be made of some parents and young people being interviewed about their experiences. This resulted in an edited DVD that can now be used to disseminate the findings of this pilot study and to explain to potential participants in a bigger multi-site study what is involved in the groups. We found having us both on the Steering Committee worked well. We felt supported by the other members of the Steering Group and we were also able to give different perspectives from our own experiences.

Final thoughts

The work involved to get this project up and running has been a real eye opener to us and we feel that the work was rewarding and worthwhile.

“My advice to all parents would be to grab an opportunity like this if you get the chance. It has been challenging, rewarding, educational and I’ve met some great people en route.”

Dave

Acknowledgements

We are grateful to all the young people and parents who took part in the assessments and the groups, and to the group leaders.

The article describes independent research commissioned by the UK National Institute for Health Research (NIHR) under the Research for Patient Benefit programme (PB-PG-0408-16069). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

To read more about the BAT study and its findings see McConachie, H, McLaughlin, E, Grahame, V, Taylor, H, Honey, E, Tavernor, L, Rodgers, J, Freeston, M, Hemm, C, Steen, N, and Le Couteur, A. (2013) Group therapy for anxiety in children with autism spectrum disorder. Autism doi 10.1177/1362361313488839

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Plain English summaries in National Institute for Health Research (NIHR) funded research

By Helen Hayes

INVOLVE has been leading on work with the National Institute for Health Research (NIHR) Programmes, the Research Design Service (RDS) and others to review plain English summaries in NIHR funding applications. The final stages of this work are now complete and from **14 May 2014** a good quality plain English summary, submitted as part of the NIHR standard application form, will be a requirement of NIHR funding.

The NIHR is committed to making sure that each funded research study has a clear and concise plain English summary. It is important that this information is easy to read and understand and the NIHR will be encouraging researchers to write better plain English summaries.

What is a good quality plain English summary?

It is a clear, easy to read summary that is as jargon free as possible. It provides an overview of the whole of the research study that readers can understand the first time they read it.

Why is it important?

A plain English summary is used in the following ways:

- reviewers use this summary to inform their review of funding applications
- summaries of funded research will be made publicly available on NIHR and other research websites.

If it is felt that a plain English summary is not clear and of a good quality then the researchers may be required to amend the summary prior to final funding approval.

A good quality summary helps:

- those carrying out the review (reviewers, board and panel members) to have a better understanding of the research proposal
- engage and interest others about the research such as members of the public, health professionals, policy makers and the media
- NIHR Programmes and others to publicise the research
- researchers to have a clear explanation of the research that they can then adapt for different audiences.

What information to include?

When writing a summary consider including the following information where appropriate:

- aim(s) of the research
- background to the research
- design and methods used
- patient and public involvement
- dissemination.

The graphic features the 'make it clear' logo at the top center. Below it are four boxes with the following content:

- A good quality summary**
 - what is it?
 - why is it important?
 - how does it help?
 - how will it be assessed?
- What to include?**
 - aims and background of the research
 - design and methods used
 - patient and public involvement
 - dissemination
- How to write a summary**
 - use common English words
 - use active phrases
 - keep sentences short
 - break up text
- Support and resources**
 - guidance
 - examples
 - resources
 - links

NIHR 'make it clear' web page

How to write one

There are a few simple rules for writing in plain English:

- avoid wherever possible using jargon, abbreviations and technical terms – if you have to use them provide a clear explanation
- avoid complicated English or uncommon words
- use active not passive phrases, for example say 'we will do it' rather than 'it will be done by us'
- keep sentences short
- think about the order and structure
- break up the text, for example use bullet lists
- ask patients / carers / colleagues to read a draft to find out if anything is unclear.

How is it assessed?

The summary will be assessed by NIHR reviewers and board and panel members who will comment on the summary as part of the review process. If it is not considered to be of a good quality then the researchers will be advised through the current feedback processes.

Where to get further information?

For examples and tips visit the NIHR 'make it clear' web page to find out more:
www.involve.nihr.ac.uk/makeitclear

For further support and advice on writing a plain English summary, please contact your local NIHR Research Design Service (RDS) where applicable:
www.rds.nihr.ac.uk

Follow us on Twitter [@OfficialNIHR](https://twitter.com/OfficialNIHR) using [#NIHRmakeitclear](https://twitter.com/NIHRmakeitclear)

"If the plain English summary is well written, somehow the whole application seems easier to assess. It should provide a clear idea of what the research is about."

Public reviewer

Contact: **Helen Hayes**,
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Values, principles and standards for public involvement

By Marisha Palm

Toward the end of last year INVOLVE published a document that reviewed resources, publications and reports that looked at values, principles and standards for public involvement in research. The review identified nine relevant papers and looked at the principles and standards that had been put forward in each.

The nine papers described principles and standards for public involvement in different ways, but the descriptions were underpinned by a set of similar values. We grouped similar descriptions and identified the values underlying these as respect, support, transparency, responsiveness, diversity and accountability. We paired the values with summary principles that were based on the descriptions given in the papers we reviewed.

The papers we reviewed also highlighted some key challenges to developing principles and standards for public involvement in research. One challenge is that the term 'public involvement' encompasses such a wide variety of activity that it is difficult to agree principles that are transferable across this activity. Another challenge is operationalising these principles into standards that make sense and are useful to researchers and the public.

There is currently a lot of interest in developing principles and standards for public involvement, and other groups are also looking at this in the context of their own organisations. The challenge for INVOLVE is to look at how to develop general principles and standards that can be applied across the diverse range of public involvement activity which takes place in health and social care research.

Following the publication of our review, we held discussion sessions with INVOLVE Advisory Group members at our symposium, and consulted with the INVOLVE Learning and Development Advisory Group and a National

Institute for Health Research (NIHR) Strategy Group looking at public involvement across the NIHR.

Discussions and consultations led us to bring together a Standards Advisory Group to take forward the idea of developing a reflective framework. This framework will include principles for public involvement and examples of what these principles might look like in practice. It will be a tool for critical reflection and will acknowledge that there is continuous room for improvement and development.

The Standards Advisory Group will be meeting over the next six months to guide the development of this framework, which will be populated by examples of good practice that are brief but useful. The Group has recognised that it is necessary to create a framework that is useful across different contexts, and care will be taken to ensure the examples cover a range of different areas of health and social care.

If you have any comments or questions about this work please contact

Marisha Palm

at mpalm@invo.org.uk

or on **023 8065 1088**

To read the full standards report see:

www.involve.nihr.ac.uk/wp-content/uploads/2013/12/INVOLVE-Principles-and-standards-for-public-involvement-1-November-2013.pdf

To read the summary report see:

www.involve.nihr.ac.uk/wp-content/uploads/2014/01/INVOLVE-PrinciplesandstandardsSummaryDec2013.pdf

We are always interested to hear about your experiences of active public involvement in research, whether you are a member of the public, a researcher or from a research organisation.

If you would like to contribute an article, news item or event notice for our newsletter please contact Paula Davis.

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The National Institute for Health Research (NIHR) strategic review of public involvement in research

The National Institute for Health Research (NIHR) has recently announced a strategic review of public involvement in research entitled 'Breaking Boundaries: thinking differently about public involvement in research'.

Patients and the public, researchers and clinicians, the NIHR and other research organisations are being asked to contribute their views with a particular focus on the innovations and new approaches that will help the NIHR break new ground plus the barriers and challenges to be overcome in this important area. The 'Breaking Boundaries' strategic review is being steered by a panel of service users, researchers, clinicians and staff from across the NIHR and the wider research community, chaired by Simon Denegri, Chair of INVOLVE and National Director for Public Participation and Engagement in Research.

Professor Dame Sally Davies, FRS, Chief Medical Officer and Chief Scientific Adviser at the Department of Health, said: "This is going to be an incredibly important piece of work. NIHR has a great track record of involving the patients, carers and the public in our research. In fact, this partnership has been critical to our success as a research funder. But we want to build on this success and get closer to our goal of public involvement in research being the rule and not the exception."

Go to the National Institute for Health website where you can read more about the review and the terms of reference, as well as submit your views via an online survey, through downloading and completing a Word document or submitting an audio or video file. The deadline for responding to the survey is **midday on 26 June 2014**. www.nihr.ac.uk/awareness/Pages/StrategicReviewofPublicInvolvement.aspx

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.

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

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

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

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

<http://tinyurl.com/map5bzy>

Focus on Stroke

The National Institute for Health Research (NIHR) has launched 'Focus on Stroke' (www.crn.nihr.ac.uk/focus_on/stroke), a new online resource aimed at raising public awareness about developments in stroke research. The resource highlights some of the

work the NIHR is doing in this area and includes experiences of some people who are living with stroke and contributing to research.

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

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.

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