

newsletter

Summer 2014

Welcome to the Summer 2014 issue of the INVOLVE newsletter. This issue has a learning and development theme, beginning with a personal reflection from INVOLVE Advisory Group member, Amander Wellings.

Learning and development for public involvement: a personal reflection

By Amander Wellings

I have been a voluntary member of Norfolk and Suffolk Group, Patient and Public Involvement in Research (PPIRes) for over a decade. I am an INVOLVE Group member and also review for funding bodies and sit on the East of England Research for Patient Benefit Advisory Group. I am a lifelong carer so feel I have a lot of personal experience and common sense which can help researchers create research that patients and carers want. I believe that learning and development is essential for real public involvement; without a certain level



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The INVOLVE conference is taking place at the National Exhibition Centre, Birmingham on 26 and 27 November 2014. Turn to page 6 for more information including the draft timetable.

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.

of understanding no group can work together properly. Learning and development is needed for patients and carers, researchers and those who have public involvement management roles. At the last INVOLVE conference, INVOLVE surveyed delegates and discovered that researchers felt they had not received enough learning and development in public involvement and they wanted more. When I am reviewing applications, it seems that many researchers do not understand public involvement.

Some important questions that I have considered are:

- How do we provide what people need?
- Do people need to be taught, coached or mentored?

We need learning and development that fits all roles and is learner centred, that is it suits how individuals learn and meets their support needs. Diversity can be lost without this.

We need to embrace new technology where possible but always remember those who lack computer literacy or the necessary resources.

There are pockets of good practice in learning and development for public involvement, but also much re-inventing of the wheel, wasting valuable resources.

I have learnt a lot by doing; however, sometimes when thrown in at the deep end you struggle to swim. The whole experience can feel frustrating when you cannot give your best due to lack of support and learning opportunities. It took me three years to really feel confident on a research governance committee.

My learning journey is fuelled by wanting the things I am passionate about to really succeed. If they do not succeed, I aim to learn, from personal reflection and feedback, how things can be done differently next time. Time for feedback and to question is important for all and I sometimes think it is impossible within tight research schedules/budgets, but it needs to be given priority.

Cicero once said: “The authority of those who teach is often an obstacle to those who want to learn.” Involving the public in developing training resources for themselves, researchers and management breaks down some of the barriers between these groups and we all have much to learn from each other. This collaboration is useful for active public involvement; if the seeds are sown in training then we can reap the rewards and develop further.

This issue of the INVOLVE newsletter has a learning and development theme and contains articles from several perspectives showing how learning and development may be different depending on the role/needs you have. It includes an article about the National Institute for Health Research-wide learning and development working group, of which I am a member. For more information about the work of this group see the article on page 10 and the INVOLVE website www.involve.nihr.ac.uk/about-involve/current-work/learning. We do not have all the answers yet – it is a very complex subject – but we have developed recommendations and resources.

Learning should be fun and not a laborious ‘death by PowerPoint’ experience; to quote the great John Cleese: “He who laughs most, learns best.”

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INVOLVE Coordinating Centre news

New INVOLVE publication – NIHR Senior Investigators: Leaders for public involvement in research

The National Institute for Health Research (NIHR) Senior Investigators (www.nihr.ac.uk/our-faculty/senior-investigators.htm) are a network of senior researchers who represent the country's most outstanding leaders of clinical and applied health and social care research. In a new INVOLVE 2014 publication – NIHR Senior Investigators: Leaders for public involvement in research (www.involve.nihr.ac.uk/wp-content/uploads/2014/07/NIHRSeniorInvestigatorsINVOLVE2014.pdf) – five Senior Investigators give an account of how and why they involve patients and the public in their work, featuring:

- Dr John Bradley, Director, NIHR Cambridge Biomedical Research Centre
- Professor David Gunnell, Professor of Epidemiology, School of Social and Community Medicine, University of Bristol
- Professor Elaine Hay, Director, Institute of Primary Care and Health Sciences Centre, Keele University

■ Professor Hywel Williams, Professor of Dermato-Epidemiology and Director, Centre of Evidence-Based Dermatology, University of Nottingham

■ Professor Sue Ziebland, Director, Health Experiences Group, Nuffield Department of Primary Care Health Services, University of Oxford.

Launched to mark International Clinical Trials Day, the publication has a foreword from Professor Dame Sally C Davies FRS FMedSci, Chief Medical Officer and Chief Scientific Adviser, Department of Health and an introduction from Simon Denegri, Chair of INVOLVE and NIHR National Director for Public Participation and Engagement in Research. The publication coincided with the launch, in May 2014, of the NIHR's Eighth Senior Investigators Competition.

This was an NIHR-wide project funded by INVOLVE (www.involve.nihr.ac.uk) working with the NIHR Faculty (www.nihr.ac.uk/our-faculty) and the NIHR Central Commissioning Facility (www.nihr.ac.uk/about/central-commissioning-facility.htm).

INVOLVE publications list 2014

Our new publications list highlights a selection of our current guidance and evidence publications (www.involve.nihr.ac.uk/resource-centre/publications-by-involve), as well as the electronic databases (www.involve.nihr.ac.uk/resource-centre) on our website. Ideal for displaying on stands and information tables or putting in delegate packs, you can download the list (www.involve.nihr.ac.uk/wp-content/uploads/2014/06/Publications-list-2014-FINAL.pdf) or contact us at admin@invo.org.uk to order copies.

Research project database improvements

We will shortly complete work on improving the functionality of our research project database to make it easier to upload and search for information. The database is one of the most frequently viewed resources on our website and contains information on over 270 published and unpublished projects with active public involvement in NHS, public health and social care research. Database entries are written by researchers and contact details are available to facilitate shared knowledge and learning. To browse the entries or to submit your own project visit www.involve.nihr.ac.uk/resource-centre/research-project-database

Interesting articles and publications

Enhancing public involvement in assistive technology design research

Tracey Williamson, Laurence Kenney, Anthony T Barker, Glen Cooper, Tim Good, Jamie Healey, Ben Heller, David Howard, Martin Matthews, Sarah Prenton, Julia Ryan and Christine Smith Disability and Rehabilitation Assistive Technology, April 2014, epublication ahead of print

This article reports on the findings from a within-project evaluation of patient involvement in the development of a new mobility aid. The researchers established a lay advisory group who were supported by a public involvement lead. The researchers attended an initial workshop to prepare them for working with the group. The practical details around setting up and supporting the group throughout the project are described in detail. The researchers report positive benefits in terms of improvements to the new device, making it more likely to be useful to patients, as well as improvements to the design of the subsequent clinical trial. This was thought to lead to better recruitment and retention of trial participants. The researchers' attitudes to involvement became more positive after witnessing its potential first-hand. The patients involved reported improved confidence, skills and self-esteem and valued being able to contribute to the care of others.

<http://informahealthcare.com/doi/abs/10.3109/17483107.2014.908247>

Involving Patients in Research: Considering Good Practice

R Goberman-Hill, A Burston, E Clark, E Johnson, S Nolan, V Wells, L Betts and PEP-R Musculoskeletal Care, December 2013, volume 11, issue 4, pages 187–90

This open access editorial highlights some current practice and guidance on involving patients in research. The authors also reflect on the impact of patient involvement activity at the Musculoskeletal Research Unit in Bristol. They seek to involve patients in research design and conduct through a patient forum: Patient Experience Partnership in Research (PEP-R). PEP-R sessions are interactive, training and support is provided,

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and patients are compensated for their time and travel expenses. The authors asked patients and researchers to complete a questionnaire to evaluate the impact of patient involvement. Patients described their interest and learning about the topics and research in general, and how they valued feedback on their input. Researchers identified the benefits of patients' views on the importance, relevance and feasibility of projects and stressed the importance of early involvement. PEP-R has been supported by the National Institute for Health Research.

<http://onlinelibrary.wiley.com/doi/10.1002/msc.1060/pdf>

Patient and public involvement: how much do we spend and what are the benefits?

Elena Pizzo, Cathal Doyle, Rachel Matthews and James Barlow

Health Expectations, April 2014, epublication ahead of print

The aim of this literature review was to assess the potential benefits and costs of involvement and the challenges in carrying out an economic evaluation of patient and public involvement (PPI). The authors found that the benefits of PPI include effects on the design and development of research and new services, on NHS governance and on citizenship and equity but that very few studies have assessed the economic impact. They have developed a framework to help identify the costs associated with PPI, including hidden ones, such as the cost to patients. They suggest that greater clarity about the costs and benefits of different approaches will help make a business case for PPI.

<http://onlinelibrary.wiley.com/doi/10.1111/hex.12204/pdf>

Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research: a modified Delphi study

D Snape, J Kirkham, N Britten, K Froggatt, F Gradinger, F Lobban, J Popay, K Wyatt and A Jacoby

BMJ Open, May 2014, volume 4, issue 6

This Delphi study aimed to explore areas of consensus and conflict in relation to perceived barriers and drivers to public involvement (PI), perceived impacts of PI and ways of evaluating PI in health and social care research. The authors found high levels of consensus about the most important barriers and drivers and an acknowledgement that tokenism in public involvement was common. They found strong support for the view that tokenistic practice

makes it difficult to demonstrate the impact and value of PI as well as clear support for the importance of evaluating impact. Research team cohesion and appropriate resources were considered essential elements for effective public involvement. The study findings have been used in the development of the Public Involvement Impact Assessment Framework (PiiAF) <http://piiaf.org.uk>. <http://bmjopen.bmj.com/content/4/6/e004943.full.pdf+html>

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

Working together to develop public involvement training

By Rosamund Yu

At the National Institute for Health Research (NIHR) Biomedical Research Centre (BRC) at University College London Hospitals (UCLH) NHS Foundation Trust and University College London (UCL) we have just finished running a month's programme of training workshops for researchers on actively involving patients and the public in research. This article explains how we went about it and some of the – very practical – lessons we learnt.

Why we needed this training

Our aim is to make sure that when patients and the public take an active part in biomedical research, their input has a real impact. We want to make sure that patient and public involvement (PPI) in research is a positive experience for everyone – patients, public and researchers.

Many of the researchers who consult our PPI team lack confidence to carry out PPI and many don't even know where to start. So training is a key part of our work and we have for some time been running workshops on topics like setting up a patient group.

In February – thanks to our academic health services centre UCLPartners – we received funds from Health Education North Central and

East London to develop this training into a more intensive programme of workshops for academic clinical researchers right across UCLPartners organisations. The programme had to be delivered by the end of March.

Working together to design training

Even though it was a rush, we met up with patients and members of the public who had helped us in the past and asked them what kind of training researchers needed. We also surveyed one of our PPI panels. People told us they wanted training that broadened researchers' horizons and brought home just how valuable PPI is to research.

We worked with expert PPI trainers, as well as patients, charities, lay people who review funding and ethics applications, UCLPartners and PPI leads, and used results from a training needs assessment of over 100 researchers, to design a programme of nine workshops (see www.uclhospitals.brc.nihr.ac.uk/sites/default/files/Programme_Involving_patient%2C_carers_and_the_public_in_research_workshops.pdf).

Workshops tended to be for a half day and subjects ranged from setting up a patient group and filling in a grant application form to PPI in laboratory research and communications. Some sessions were delivered by expert trainers and others by patients and members of the public. We also made sure that at least one lay person came to each workshop to help us bring home the 'other perspective' to researchers.

In-built evaluation

We set up a system of evaluation, with participants asked to fill in surveys before each workshop and immediately after. We will also be surveying researchers six months down the line. Our aim is to find out exactly how helpful workshops were. It's all very well researchers saying that the workshop was good, but a few months later have they been able to use the skills they acquired?

We advertised the workshops as best we could and the response from the research community was overwhelming. In the end we delivered nine oversubscribed workshops across a range of locations including UCLH, UCL, Moorfields BRC, the Royal London Hospital, London Cancer and City University. Over 120 researchers took part in workshops and 119 of them filled in before and after surveys.

Early analysis of the surveys is promising: the training impacted on researchers' confidence and enthusiasm for research. Before the workshops 50% of researchers were PPI enthusiasts and

most of the rest were interested in PPI but hadn't done it. After the workshops the proportions had changed and 60% were PPI enthusiasts. Surveys also showed steep improvements in confidence and understanding of PPI.

Lessons learned

This programme had to be designed and executed within the space of six weeks, so we had lots of scary moments when we thought things would go hideously wrong.

These are the things we could have done better:

- Make sure everyone – participants, trainers and administrators – knows who the workshop is for and what it will be giving them. You need to be crystal clear what kind of experience and interest workshop participants need to have. This avoids disappointments and frustration when workshops don't deliver what people expect.
- Workshop attendees like to have an agenda and to know exactly what they will get out of the training – again this avoids frustration and disappointments.
- Unless you are going to line people up in a formal lecture style, allow for plenty of space when identifying and booking rooms. We were often told by facilities management that a room had a certain capacity only to find on the day that it was overcrowded and hot. Check the capacity, go and see for yourself.
- Find a way of discouraging 'do not attends'. We had oversubscribed workshops that were half full because people didn't bother to cancel. A charge for not attending is the best answer in our experience.
- Make sure you have a good system for logging bookings and replying to people. Although no one got missed, we had some close shaves.

But we also learned how much this training was needed and wanted. Indeed we were inundated with people signing up.

We could not have done it without the enthusiasm, commitment and patience of the expert trainers, patients and members of the public, who put up with rushed timetables, squashed rooms and confusion. Without a spirit of 'mucking in' none of us could have pulled such a project off. Special thanks to Bec, Carol, Derek and Jamie, as well as Madeleine, Kavita and Kellie.

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INVOLVE Conference 2014: Changing Landscapes

An opportunity for people interested in public involvement in NHS, public health and social care research to meet, discuss and debate

26 and 27 November 2014 at National Exhibition Centre, Birmingham

www.profbriefings.co.uk/involve2014

INVOLVE's national conferences bring together members of the public, service users, researchers, research commissioners and representatives of voluntary sector organisations who share a common interest in public involvement in NHS, public health and social care research. Our ninth biennial conference is taking place over two days, on Wednesday 26 November and Thursday 27 November 2014.

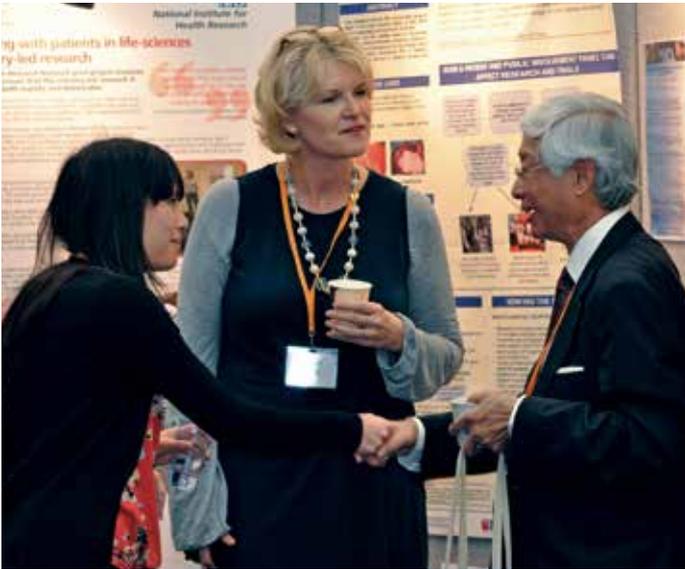
The aim of the conference is to debate and discuss topics such as: how people are involved in research, the need for learning and support, examples of user led research, researching and assessing impact, international perspectives and future directions. There will be opportunities to network, view posters, and visit exhibition stands. As well as presentations and workshops we will be having a 'question time' panel discussion. You can also have your say during our soapbox session.

Below is a draft timetable for the 2014 conference. Please check the conference website www.profbriefings.co.uk/involve2014 for more details.

Day 1: Wednesday 26 November 2014

Registration from 11.00am

11.00am	Practical guide to the INVOLVE conference Optional preconference session for anyone wanting to find out a bit more about our conference or meet other delegates
12.00 noon	Lunch
12.45pm	Welcome to the Conference Simon Denegri, Chair of INVOLVE Keynote speech: Public involvement in the changing landscape, Russell Hamilton, Director of Research and Development, Department of Health
1.30pm	Plenary session – Sharing experiences and impact of public involvement in research Facilitated by Sally Crowe, Director, Crowe Associates Limited
2.10pm	Poster viewing and refreshments Presenters will be standing by their posters ready to answer questions.
2.50pm	Presentations, discussions, workshops and other sessions 1 A choice of nine sessions.
4.00pm	Presentations, discussions, workshops and other sessions 2
5.30pm	Close of day 1
7.30pm	Conference dinner and prizes for poster competition



INVOLVE 2012 conference delegates



A presentation at the INVOLVE 2012 conference

Day 2: Thursday 27 November 2014

Registration and refreshments from 8.30am

- 9.00am** **Keynote speech: NIHR Strategic Review of Public Involvement in Research – “Breaking Boundaries”, Simon Denegri, Chair of INVOLVE, NIHR National Director for Public Participation and Engagement**
- 9.30am** **Question time panel session**
Facilitated by Tina Coldham, INVOLVE Group member
- 10.20am** **Poster viewing and refreshments**
- 11.00am** **Presentations, discussions, workshops and other sessions 3**

- 12.00 noon** **Lunch**

- 12.45pm** **Soapbox**
'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.
- 1.15pm** **Presentations, discussions, workshops and other sessions 4**
- 2.20pm** **Plenary session – to be confirmed**
- 3.00pm** **Practical sessions and workshops**
- 4.00pm** **Close**

How to book for the INVOLVE 2014 Conference

You can book for the conference by going to the conference website
www.profbriefings.co.uk/involve2014

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



Building Research Partnerships workshop in Belfast

Building Research Partnerships

By Jack Nunn and Margaret Grayson

Building Research Partnerships is an internationally recognised way of working that has been developed by Macmillan, the National Institute for Health Research Cancer Research Network (NCRN, England), the Public Health Agency (Northern Ireland) and the National Institute for Social Care and Health Research Clinical Research Centre (Wales).

It is a free one-day learning event for the public and professionals involved in health and social care research and helps support public involvement in every stage of the research cycle by using interactive activities and facilitated discussions. We have worked with partner organisations across three countries in the UK to train facilitators to use our resources to run events, and we want to share our resources and let others build on our work.

We recently conducted an impact survey and over 98% of participants said that involving the

public in their research had made a difference or had an impact, 93% of professionals said that as a result of attending their understanding of how to involve the public in research had increased, and 73% of the public who attended said their involvement in research had increased since attending the course.

The National Institute for Health Research (NIHR) Clinical Research Network will be building on this and adopting Macmillan's Building Research Partnerships approach, which has been supporting public involvement in research across the UK since 2007. The Clinical Research Network will be using this successful model to support public involvement across the Network, with programme resources relevant to any type of health and social research. To find out more about this work please contact Tom Newbound: thomas.newbound@nihr.ac.uk

You can learn more about Building Research Partnerships and download the free resources here: www.macmillan.org.uk/researchlearning

In the meantime, here are some words from Margaret, who attended an event in 2012 and is now training other facilitators.

Building Research Partnerships – a personal reflection

In August 2012, as a public involvement representative, I attended the first Building Research Partnerships Workshop held in Northern Ireland under the auspices of Public Health Agency Research and Development, Northern Ireland Cancer Trials Centre and Macmillan. At the start of the day I was not sure what to expect; at the end of the day my conclusion was that it was a brilliant workshop facilitated by Derek Stewart and Jack Nunn. The day was an interactive learning experience (it was fun!) for myself as a lay person, meeting with professional researchers and exploring how we can partner and work together at every stage of the research cycle, making public involvement more than a tick box exercise.

At the close of the workshop the opportunity was offered to consider being trained as a facilitator. I took up this opportunity as I believe the course is of immense value as a starting point for public / professional partnership in research – bringing the unique patient / carer experience of a disease together with the researcher's expertise to ensure that research is of value to both patients and the NHS. During my training as an associate facilitator my first experience of being responsible for a session was a bit daunting but really enjoyable through the support and encouragement of Derek and Jack. My training finished in 2013 and I am now involved with training two more facilitators. As a facilitator I look forward to Building Research Partnerships events, as each brings together a unique group of lay people and professionals.

If you are a lay person interested in being involved in research or a researcher within any area of health or social care please take the opportunity to be part of a workshop. You will find it a good and valuable use of your time!

Planting the public involvement seed early in researchers' careers

By Peter Thompson

The National Institute for Health Research (NIHR) invests over £100m a year in providing training awards to early career researchers to help establish their academic careers. Six programmes encompassing 24 award schemes provide support for researchers from Masters level all the way to a Research Professorship, and these are managed by the NIHR Trainees Coordinating Centre (TCC) www.nihr.ac.uk/about/about-the-trainees-coordinating-centre.htm. NIHR trainees represent the research leaders of the future and instilling in them the importance of public involvement and how to do it well highlights the commitment the NIHR has to helping people become involved at all stages of the research it funds.

In July 2013 NIHR TCC asked Bec Hanley and Derek Stewart (www.becandderek.co.uk) to run a workshop for 25 NIHR doctoral award holders to introduce them to public involvement and help enable them to explore ways they could build public involvement into their research. Providing this workshop to NIHR trainees on an annual basis is a key part of NIHR TCC's patient and public involvement (PPI) strategy (www.nihr.ac.uk/documents/get-involved/TCC-PPI-Strategy-2013.pdf). The specific aims of this workshop were to:

- build understanding of patient and public involvement in research
- start involving patients and public in the trainee's research, or develop their involvement activities if they were already active in this area
- learn from other participants about what might work in specific contexts.

Feedback from the attendees was overwhelmingly positive, with 19 out of 20 respondents saying the workshop improved their understanding of public involvement. All 20 respondents said the workshop enabled them to think about involving the public in their own research and allowed them to learn from other participants. Several NIHR TCC programme managers also attended the workshop and participated in the activities alongside the trainees and this was a very effective learning experience for them too.

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NIHR TCC has plans to repeat the workshop for doctoral trainees in July 2014 and is also considering expanding the provision of NIHR public involvement workshops to include a 'master class' version for trainees with more experience in involving patients and the public in their research.

Workshop attendee Elaine Cloutman-Green, a NIHR / Health Education England (HEE) Healthcare Science Doctoral Research Fellow, reflects on her experience of the workshop and how it has influenced her since:

“Working within infectious diseases and infection control can sometimes make it difficult to involve the public in your work. My research is funded by Health Education England (HEE) and most of it takes place in a lab filled with agar plates and black boxes that print graphs. Usually it’s just me on my own with some cheesy music for company. When I thought about the idea of patient and public involvement, I couldn’t really see how it would work. I needed guidance about what public involvement (PPI) really was and how I could do it in my field. When I saw a workshop advertised I jumped at the chance to attend.

The workshop itself was a mixture of practical exercises and lectures, led by facilitators called Bec and Derek. They had experience of being involved in research as members of the public and everyone there came from different areas of research. I found this invaluable as everyone had different barriers to implementing PPI and different ideas about how to overcome these problems.

For me, the workshop accomplished two things. Firstly it helped me understand that there are different types of PPI, some of which would be more possible for my type of research than others. Most of what I had done to date had been outreach and was about engaging people in my research by talking to them about what I do. However, there was another level that I could undertake, involvement. Involvement meant that I could include people in parts of my research like grant applications without them having to be participants in the research itself, as would be the case in clinical trials. Not only did

the workshop make me realise that I could extend what I was currently doing but it also gave me new ideas about how to do it. Secondly, it really helped me to understand who the relevant public was for me; this was something with which I had always struggled.

The big question is: has the workshop changed what I do? The answer is a clear yes. The biggest change is that I have recruited 14 people through social media and set up a clinical research group. These people have all had contact with the NHS in the last 12 months and are involved in writing grant applications with me. I hope that we will expand their involvement as the research progresses. The benefits of having them involved have far outweighed any time taken to administer the group and I for one will never look back.”

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The NIHR-wide learning and development group – a member’s view

By Alison Ford

As the Patient and Public Involvement (PPI) lead for the National Institute for Health Research (NIHR) Evaluations, Trials and Studies Coordinating Centre (NETSCC) – one of the NIHR funding centres – I have a strong interest in learning and development for patient and public involvement. On joining the learning and development group I was delighted that there was so much expertise and experience to draw on, both within the NIHR and the wider learning world.

This time-limited group was established by INVOLVE in April 2013, following a stakeholder workshop on learning and development for public involvement in research. The aim of the group was to develop and initiate a plan and recommendations for a NIHR-wide approach to learning and development.

The learning and development group met every couple of months with staff and public members drawn from all corners of the NIHR. The NIHR is a 'distributed' organisation with a huge geographical spread so it was clear at the outset that we would not be able to create a 'standard curriculum' for the NIHR staff, public contributors and researchers who need to learn the skills and knowledge for effective involvement. Instead, we formed small project groups to develop a variety of ways of changing how people learn about public involvement and develop their skills in it. All the projects set out to be 'learner-centred', that is to work on the basis that people are good at identifying their own learning needs and the best way to help them is to provide information and support in ways that best suit the learner. The group will produce its report and recommendations this summer.

In addition to the report, the main outputs from the project groups will be as follows:

- A document outlining principles and indicators for learning and development which we hope will become essential reading for all in the NIHR who have responsibility for people who are learning about public involvement. These principles and indicators could be used by individuals and organisations to both assist them in establishing good practice and in assessing themselves and their organisations against the learning and development support they provide.
- Examples of practical tools/resources that can be used by organisations and individuals to assist in assessing their learning needs.
- A pilot online forum for members of the public who review commissioning briefs, research funding applications and other documents for the NIHR. Reviewers can feel isolated as they rarely meet the NIHR staff or each other face-to-face. An online survey among these folk has led to the development of a 'Google+ community', facilitated by NIHR staff, which will be tested as a way of providing mutual support. This has proved a technological challenge! We are persisting and initially will invite a small number of public reviewers to join and test the forum.

I think I can speak for all the public involvement 'experts' who contributed to the working group when I say we found it a fascinating process but a huge challenge to devise some really useful changes that will make a difference to the quality of public involvement. We know it is important that someone in each centre has clearly-identified responsibility for the quality of public involvement

and takes up the resources emerging from this group to ensure that public contributors, researchers and other NIHR staff all develop their understanding of and skills in public involvement.

For further information on the work of the group see www.involve.nihr.ac.uk/about-involve/current-work/learning

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What I wish I'd known before going into public involvement research

At an INVOLVE Group meeting, members reflected on what they wished they had known before getting involved or involving the public in research. Responses included:

- "How much help and support is out there already, that a passion shared is a change in the making..."
- "What matters is finding others who share your enthusiasm and commitment to making it happen."
- "You'll never get it completely right, inevitably make mistakes and get criticised, but you need not worry too much, learn from it and do it better next time."
- "That public involvement needs dedicated, long term resource and support – but when this is in place the strength and benefit to our research from patients and the public is immense."

For more information about the learning and development group, see the article above and visit the learning for involvement page on the INVOLVE website: www.involve.nihr.ac.uk/about-involve/current-work/learning

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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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.

Four Nations Conference report

Involving People and Marie Curie Palliative Care Research Centre Cardiff hosted the Four Nations Conference on 9 May 2014. The day provided an exciting opportunity to share examples of public involvement in health research, with speakers from across the UK. A Conference report has been produced giving an overview of each presentation and workshop, together with a summary of delegate feedback.

[www.wales.nhs.uk/sites3/documents/1023/Four Nations Conference Report May 2014 Final.pdf](http://www.wales.nhs.uk/sites3/documents/1023/Four+Nations+Conference+Report+May+2014+Final.pdf)

Booklet celebrating 15 years of Alzheimer's Society's Research Network

In 1999 Alzheimer's Society created its pioneering Research Network of people with dementia, carers and former carers. The Research Network has played an active role in setting the dementia research agenda, through the Society's own research programme and in a growing portfolio of research funded elsewhere. Two founding members, Barbara Woodward Carlton and Shirley Nurock, worked with current staff to collect the thoughts of researchers, Research Network volunteers, external organisations and current/former staff to celebrate this landmark anniversary in this new publication.

www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2261

Research Design Service launch new website

The National Institute for Health Research (NIHR) Research Design Service (RDS) has recently launched its new website (www.rds.nihr.ac.uk). The RDS advises and supports research teams in developing high quality applied health and social care grant applications to NIHR and other national peer-reviewed funding programmes. It does this through a regionally-delivered service across England. The new website includes information on patient and public involvement written for researchers (www.rds.nihr.ac.uk/patient-and-public-involvement/for-researchers) and members of the public (www.rds.nihr.ac.uk/patient-and-public-involvement/for-patients-and-the-public).

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