

NIHR patients and the public

Winter 2017



Introduction from Simon Denegri, National Director for Patients and the Public in Research

Welcome to the National Institute for Health Research's (NIHR) new patients and the public newsletter. Over the coming months we'll be bringing you public involvement and engagement news, views and good practice from across the NIHR. We hope it will inform and inspire you, as well as stimulate new thinking and ideas across the community.

You may have seen that the NIHR recently launched an exciting and innovative new poster campaign to raise public awareness of the big part the public play in making world-class research happen.

The #twosides campaign shows what can happen when people from different perspectives come together to co-produce an idea from scratch. In this instance the result is a fresh take on the message about public involvement which is simple and effective. If we wish more people to become active in research from across our increasingly diverse population then we need to find new and imaginative ways of communicating our passion so that others want to join us.

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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.

More details about the campaign can be found inside this newsletter and we hope you will display the poster in hospitals and surgeries as well as meetings and events up and down the country; also that you will encourage others to do the same. The spirit of co-production behind the poster and indeed, we hope, this newsletter, is something which the NIHR wishes to encourage and promote more following the 'Going the Extra Mile' report and recommendations published and signed-off by the Chief Medical Officer in 2015. Implementation of the report conclusions is now happening at a cracking pace across the NIHR and we will try and provide regular updates on what's happening through the following pages.

This time around we take a look at learning and development issues and also have a report from an excellent NIHR Voices event in Leeds on diversity and inclusion that I attended last year. These local and regional networks and conversations are going to be very important to developing national strategies and plans. But, more important, will be the impact they have on the ground in ensuring that research is relevant to the needs of the local people who should benefit from it.

As I am sure you will all agree, there are many sides to public involvement and engagement in research not just two. When the review that led to 'Going the Extra Mile' was underway, myself and other review panel members heard a great deal of evidence from people and organisations about the great work that was happening in NIHR facilities, charities and other organisations. But we also heard how this often wasn't co-ordinated or joined-up even when separated by just a few miles of motorway or trainline.

Sometimes the result was duplication and a consequent waste of resources - not least of the public contributors willingly and voluntarily giving their time and energy in good faith. Other times it was distressing to see people struggle long and hard with challenges which others had long since overcome. More often than not, we simply saw missed opportunities to join together and maximise the impact of our work so that everyone could benefit.

If this newsletter can help our community and its partners work more effectively together and open doors to more patients, carers and the public get involved in and help produce brilliant research then it will have played its purpose.

Happy Reading

**Simon Denegri, NIHR National Director for Patients and the Public in Research
Chair, INVOLVE**

INVOLVE's learning and development project group: improving support for public involvement



Author: Dr Adele Horobin on behalf of the Access sub-group

Have you taken part in an activity to develop or reinforce skills, knowledge and insights into public involvement in research? This could be a training day, workshop, networking event or online forum for instance. Have you been involved in developing such an activity? Or are you seeking something to support your learning and have views

on how opportunities should be shared? Whether you are a member of the public, researcher or public involvement manager, we want to hear from you!

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The last two years have certainly been notable for INVOLVE since it was established in 1996 to support public involvement in NHS, public health and social care research. The 'Going the Extra Mile' report was published in 2015. This paper reported on the review of public involvement in the National Institute for Health Research. The year 2015 also saw the final report from the NIHR-wide Learning & Development Working Group. Both reports highlighted that the learning and development needs of all people key to public involvement are not being met. This includes members of the public, research staff and public involvement managers. Taken together, these reports recommend:

- Improving coordination and accessibility of learning and development opportunities, with increasing collaboration in the planning and delivery of opportunities, where these offer benefits.
- Adopting a 'learner-centred' approach to meet the needs of individuals, support an individual's ability to identify their own learning and development needs and evaluate their progress.
- Increasing awareness and knowledge about public involvement and about learning and development for public involvement.
- Sharing learning about engaging and involving diverse and seldom-heard communities.

In light of these reports, INVOLVE is focusing on Learning and Development as one of three National Leadership Areas to work on (the others being Diversity and Inclusion, and Community and Partnerships). In late 2016, a project group was established to turn these recommendations into action. The group shall put in place support for members of the public, researchers and public involvement managers from across the country. This is to help them identify their own learning and development needs in public involvement. Also, to make opportunities to address those needs available and easy to find. Research organisations will be helped to share learning opportunities widely. The project group is led by Martin Lodemore of INVOLVE, and Chaired by Gill Hood as an independent consultant. Members come from across the NIHR, research-active charities and public contributors and are organised into six sub-groups. These are:

- Access and Websites sub-groups. Together, they are charged with establishing the platforms for sharing and advertising information and opportunities relating to learning and development. This is for across NIHR and beyond.
- Learning Needs sub-group. Members are focused on developing tools to support people in identifying their own learning needs and evaluating their progress.
- Inductions and Top Tips sub-groups who shall be producing induction materials and tips on learning and development.
- Diversity sub-group concentrating on creating materials to share knowledge and means for engaging and involving diverse communities.

In completing our work, we are keen to incorporate the lessons that others have learned and to capitalise upon examples of good practice. As such, we would like your help. The Access sub-group, is seeking information on how learning and development opportunities in public involvement (for example training days, forums, networks, mentoring schemes or others) are shared. This includes communications channels used, types of information shared, who shares it and how it is presented. Also, how information is gathered and kept up to date. Likewise, if you have views on how opportunities should be shared, please let us know.

The work of the six sub-groups will be continuing throughout 2017 and we intend to report on progress and share our outputs at the INVOLVE conference on 28 November. We will be seeking to test pilot our developments, so we may be asking for your help again this year. We want to ensure that what we produce is relevant, useful and will be used. Only then will we be able to reap the benefits of a more knowledgeable and skilled workforce and a shared understanding of how learning and development can support the input of public contributors. Let's hope we deliver a fantastic present to celebrate INVOLVE's twenty-first birthday this year!

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NIHR Voices Event 2016

The second NIHR Voices event took place at Weetwood Hotel, Leeds on 10th November 2016. The Voices project is supported by INVOLVE, the Yorkshire and Humber Improvement Academy (AHSN) and NIHR Voices. More information about the organisations which make up the NIHR Voices Group can be found overleaf.

The topic of the day was the **importance of diversity and inclusion in the future of Public Involvement**.



[Simon Denegri](#) (above), the NIHR National Director for Patients and the Public and Chair of INVOLVE opened the event, which was attended by 62 people, with a presentation on the subject of Public Involvement in Research.



"I love how everyone is helpful and willing to listen"

"I find such events heartening—it's time research came out of the closet"



"I have really enjoyed meeting so many like-minded people"

What is Public Involvement in Research?

INVOLVE defines public involvement in research as research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them. This includes, for example, working with research funders to prioritise research, offering as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.

Steps to getting involved

If you are inspired to get involved with what is happening in our region, the group has **five work streams** on various topics which were discussed during the meeting.

You can find out more about the work stream and who is leading it by clicking the links below. Alternatively, Donna Bownes can direct you to more information

1. [Peer Support](#)
2. [Making Involvement Normal](#)
3. [Participatory Methods](#)
4. [Communications](#)
5. [Diversity & Inclusion](#)

Our poems

During the meeting the group worked together to gather the different perspectives and present them as poems to help shape future inclusion in public involvement.

"There is opportunity in the community

To overcome the barriers of inclusion

But race, age, ability and religion offer a solution

It's not the politics, class or sexual orientation

That should affect your participation! "

Click [here](#) to read the other poems written on the day.

During the lunch break there were stalls showcasing work being done across the region. Information was available about other public involvement groups and there were opportunities to explore the current Yorkshire and Humber Public Involvement Community website and give feedback on how it might be more useful.



Lots of networking took place with the exchange of contact details, which attendees found very useful.

The NIHR Voices Group

You can learn more about the organisations which make up the NIHR Voices team below. Please click on any of the links and you will be taken to the website for a particular organisation.

[Research Design Service Yorkshire & the Humber](#)

[Improvement Academy \(AHSN\)](#)

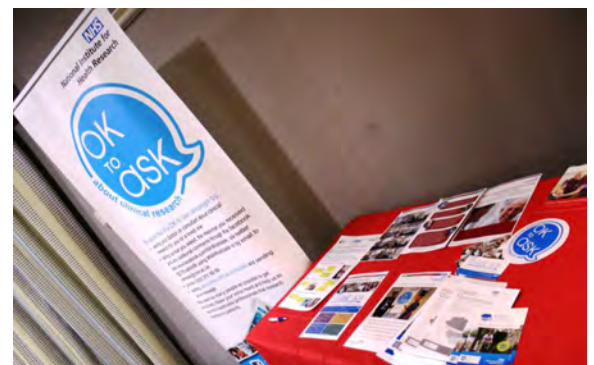
[Leeds Musculoskeletal Biomedical Research Unit](#)

[Clinical Research Network](#)

[CLAHRC Yorkshire and Humber](#)

[Clinical Research Facility—Leeds](#)

[Clinical Research Facility—Sheffield Diagnostic Evidence Cooperative](#)



A short questionnaire was circulated about how people thought it would be best to communicate with people who want to be involved in Research. The findings from this will form the basis of the [Communications Group](#).



**Save the date for the 2017 event -
9 November 2017 We look forward to seeing you there!**

#twosides campaign

The NIHR has launched a striking new campaign urging patients and the public to get actively involved in health and social care research which affects the lives of millions of people. Featuring an iconic split face image, the #twosides campaign highlights ways for people who aren't medical or academic professionals to play an important part in shaping research and helping researchers and healthcare staff make life-changing differences. We have commissioned three posters combining the faces of a diverse range of people in public and professional research roles.

Our campaign calls for people make their voices heard by sharing their patient and carer experiences and their ideas for making a difference to the health and wellbeing of their families, friends, colleagues and communities.

The campaign webpage will signpost people to opportunities to get involved with suggesting research topics, participating in studies, serving on study groups and ethics committees and providing comments on research applications.

Visitors can also download and print A4 and A3 or order free A2 versions of the posters to display in their community centres, schools, workplaces, GP surgeries, and other public places to spread the word. You can join the Twitter and social media campaign using #twosides. During February the NIHR blog will feature stories from patients and members of the public who are involved in research.



To read more about this campaign, go to <http://www.nihr.ac.uk/twosides>

'Going the Extra Mile': Impact and Data Workshop

What does the 'impact' of public involvement in research mean to you? In December 2016, the Central Commissioning Facility hosted a workshop that began to explore this in relation to the NIHR's 10 year vision and ambitions for public involvement, as set out in Going the Extra Mile.

The workshop report:

- outlines the focus of the day
- highlights some of the issues raised in discussion
- provides links to access all the slide sets and reports from the day.

To access the report: http://www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/nihr-central-commissioning-facility/ccf-ppi/PPI%20impact%20workshop/NIHRPPI_Impact_Wshop_161216.pdf

Guidance for Embedding Patient and Public Involvement Champions within Applied Health Research Programmes

CLAHRC Wessex have developed guidance to help in developing PPI roles. This guidance has been produced with PPI Champions to help others create similar roles. This Guidance includes working documents and reflections from the PPI Champions and researchers.

To read the report in full, go to <http://tinyurl.com/hs3rg3p>

Involvement Opportunities



Central Commissioning Facility (CCF) is currently looking for members of the public to join a number of national and regional advisory panels. To read more and to apply, go to <http://www.nihr.ac.uk/ppirecruitment>

Trainees Coordinating Centre (TCC) Review Panel Public Members wanted! For more information go to <http://tinyurl.com/hhmjrgy>

Understanding the challenges of health research: Young people's perspectives

University Technical Colleges are state funded specialist schools across the UK set up to deliver high quality teaching in science and technology based subjects. A core part of their curriculum are challenge projects which involve working with local employers to provide students with an opportunity to develop their subject knowledge in real work environments.

The team at the Addenbrooke's Clinical Research Facility (CRF) and the University of Cambridge Clinical Informatics Department worked together to create a 9 week challenge project in Clinical and Qualitative Research with year 13 students (age 16+). They wanted to assess what the students' views were on being consented into health research, find out what they thought of being research participants, and give them an opportunity to take part in a healthy volunteer metabolic reference study at the CRF.

The study at the CRF involved an overnight stay on the unit, and provided the students with an opportunity to experience how research is conducted in healthy volunteers. They took part in body composition measurements such as a DXA scan to measure regional and whole-body bone mass, lean mass and fat mass and air displacement plethysmography to assess body volume and estimate fat and lean mass. Overnight, the students slept in a room calorimeter that assesses sleeping metabolic rate by measuring oxygen consumption and carbon-dioxide production, and a resting metabolic measurement upon waking to estimate the basis of energy requirements. Finally they underwent a blood test for metabolites such as lipids and thyroid function.

As well as taking part in research the students also received seminars in research ethics, qualitative and quantitative research methods and patient and public involvement in research. The students were then tasked with undertaking some qualitative research and run focus groups with their peers. They investigated what students thought about the consent process and whether they felt ready at 16 to make those decisions alone. (Under the age of 16 you need your parent or guardian's consent to take part in health research or receive medical treatment. Under 16 you give assent. On turning 16 you can make the consenting choice as an adult.)

Karen Hlaba, Research Assistant and PPI Coordinator, was instrumental in setting up and delivering most of the teaching for the project, reflects on what she learnt. *'I found coordinating and teaching on this project both challenging and rewarding. I have learnt a lot from the students about how they learn, and what they want to learn, and I am impressed with how they handled the diverse and challenging workload in the space of time they were given.'*¹

A key feature of a challenge project is the real life work experience. In this project the students were asked to produce a scientific poster and give a presentation, and work as a team to create this, exactly as you would in a research team. The posters and oral presentations were judged and a prize awarded for the best poster and best team.

'Science is such a diverse subject, of which schools can only really scratch the surface. Having the opportunity to take part in a project like this is hugely exciting and developmental for students as it really helps them to understand what science is like and experience aspects of it that they would not normally be aware of. We have been incredibly lucky to work with such a great team at the

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Addenbrooke's CRF and the University of Cambridge Clinical Informatics Department and are very grateful for their support in the project.' **Dr Alistair Easterfield, Director of Science, University Technical College, Cambridge**

What the students had to say;

'Overall our group found the experience interesting and we learnt a huge amount about research.'
'We struggled with delegating the work throughout the group but I feel like it was useful for people who would like to go into research.'

This challenge project provided a real insight into conducting health research for all involved not just the students. We were able to collect metabolic reference data on this age group, and we now understand the questions young people have about research and how we might approach them about taking part. This is of huge importance to us as we want to encourage and support participation, involvement and interest in careers in health research with young people.

I am greatly appreciative of the daily assistance and advice of Laura Atkin of UTC in particular, and the overall supervision by Dr Lydia Drumright. I thank Joann Leeding and Dr Alistair Easterfield of UTC for creating this opportunity, and Stewart Fuller for the partnership with the CRF.

Joann Leeding, February 2017

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INVOLVE Conference 2017



We are busy planning the next INVOLVE Conference, which will be held on 28 November 2017, at Church House, Westminster, London.

We will keep you informed through our dedicated conference page on the INVOLVE website, www.invo.org.uk and will be using the hashtag **#INVOLVEat21** on Twitter for any tweets about the conference.

News from NIHR <http://tinyurl.com/hc2g3jz>

Tell us what you think of the new Patient and Public pages on our website. Take our short survey <http://tinyurl.com/z5qfb39>

Apply to become a public reviewer
<http://tinyurl.com/zxl8hov>

New Patient Research Ambassador resource

<http://tinyurl.com/zeh8rel>

Learn Zone <http://tinyurl.com/jjcd9on>

Events <http://tinyurl.com/jpe7zzz>

Research Changed my life

<http://tinyurl.com/zcoj4ax>

Read the latest NIHR blogs

<http://tinyurl.com/zh6bnby>

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