

## NIHR patients and the public

Winter 2017

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### Clinical research: 'Better if it's done with patients rather than to them'

"We see patients as a partner that holds our hand throughout the process and actually makes us a better research funder and a better research organisation as a result" says Simon Denegri, NIHR National Director for Patients and the Public in

Research in the latest Business of Discovery Podcast <https://soundcloud.com/allangaw/podcast-15-patient-and-public-involvement-with-mr-simon-denegri>

Twitter: <https://twitter.com/NIHRCRN/status/920979316367937536>

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### Read the latest NIHR blog from Zoe Gray, Director of INVOLVE Climbing the mountain: 21 years of public involvement in health and care research

We've come a long way in two decades.

As we prepare for next week's NIHR INVOLVE Conference the team and I have spent some time looking back down the mountain which we've been scaling in public involvement in health and care research over the last twenty something years.

Our INVOLVE at 21 conference is the latest step on a journey that started at basecamp at the beginning of the 1990's with a growing awareness that patients and the public receiving care or treatments had experiences of disease that were relevant and important to research. The 1991 Research for Health Strategy (NHS research) included a commitment to involve patients and the public at all stages of the research process.

As all mountaineers will tell you, it is crucial to prepare for the terrain, the climate and to know your team. This might help to explain why it took another five years - and numerous unpublished reports - to promote involvement in the original NHS Research and Development programme. Members of their Standing Advisory Group on Consumer Involvement in NHS Research and Development were instrumental in establishing the "Consumers in NHS Research" group who were the pioneers of the INVOLVE we know today.

## Today's journey

Fast-forward to 2017, and undeniably huge progress has been made in scaling the mountain. Not only is public involvement a commitment enshrined (even by Acts of parliament) in many parts of our health and research system, its value is widely understood and demonstrated. Many boulders have been passed, crevasses traversed and bad weather navigated.

The risk of progress is that we begin to take it for granted. Or that we judge our progress more harshly retrospectively because our expectations have grown. Some would argue that we have become complacent, that we have reached a plateau. But, I expect that if we could look down from the search and rescue helicopter and see across the full mountain range we'd be reassured that there is steady progress still being made, even if at times footings may be temporarily lost.

NIHR public involvement today certainly has a navigational aid that was lacking back in 1996; a plan in the form of "Going the Extra Mile". Collaboration and progress towards the challenges set out in that plan are evident both nationally and regionally, not least in the session and posters that will be showcased at our conference. It is also much better equipped with vast and widely shared knowledge about what works in practice; encouraging people at all levels - including researchers, patients and the public, PPI leads, commissioners and other stakeholders - to lead, advocate and champion for involvement. Whilst constant change is ever thus the backdrop for our work and the weather might taunt us from time to time, the climate remains hopeful. The direction of both health and care delivery AND research is unmistakably aligned to a future where, to be viable, patients, carers and public members must be front, back and centre.

## New pathways

If we are to continue or accelerate our progress, we need to take stock and think about our teams and our equipment. Are we ready for this next leg of the journey? Are we brave enough to open up our well-established teams to new people, skills and to act upon new ideas, open up new pathways?

This is something that INVOLVE is working with many of you on as part of our Coproduction leadership challenge to the system over the next few years: Firstly providing a steer (guidance to be published early in the New Year) to research teams, PPI leads and advisors, then going ahead up the mountain to identify and influence others to shift the boulders in the way or build bridges across crevasses - to address the organisational and system challenges in making coproduced research a reality.

Likewise, with the Diversity and Inclusion leadership challenge. As we strive for an inclusive health research system, we are building foundations which will strengthen commitments at all levels to bring new perspectives and knowledge into our teams (a diversity and inclusion policy and statement is currently going through the process for adoption within NIHR). We will provide inspiration, support and facilitate partnerships to reach out and build inclusive teams which best enable research outcomes to be tailored to the needs of all.

As our new vision and mission, and emerging strategy for 2018-22 will suggest, INVOLVE – in collaboration with many colleagues from within NIHR, the charity and industry sectors – might be considered the mountain reconnaissance team. Looking ahead to identify the obstacles and the opportunities currently out of sight, to inform, advise and support across teams and networks about the route options and the tools and skills which might be needed for continued progress.

Ultimately of course, to reach the summit of public involvement will rely on the bravery of many. To push ahead, to challenge the status quo, to blaze a new trail. In the words of Sir Edmund Hillary: "It is not the mountain we conquer, it is ourselves".

## INVOLVEat21 Conference



"INVOLVE at 21" saw over 350 patients, members of the public, public involvement leads, researchers and healthcare professionals from the UK and abroad attend an action packed day at Church House, London. The day was opened by 18 year old Sophie Ainsworth, founder of RAISE

(Raising Awareness of Invisible Illness in Schools and Education) and Zoë Gray, and young people were kept on the agenda with presentations from Simon Stones (young researcher and patient) and YPAG member Laila Xu. Anne MacKenzie (Head, Consumer and Community Health Research Network, Australia) and Louise Wood ended the plenary session. All of these presentations will be put onto the INVOLVE website. There were 24 parallel sessions, whose abstracts alongside those of the posters authors were given the opportunity to have these published in a supplement for Research Involvement and Engagement <https://t.co/ulgdvdFw1l>. The closing plenary session saw Simon Denegri step down from his role as INVOLVE Chair and hand over to Tina Coldham. A full report on the conference, including the standards drop-in session, will be available in the New Year.



## INVOLVE launches IN bulletin

An opportunity to share journeys in public involvement

<http://www.invo.org.uk/resource-centre/libraries/publications-by-involve/>

## Understanding Plain English summaries - Research article

A comparison of two approaches to improve the quality of Plain English summaries in research reports - this open access research article originally appeared in Research Involvement and Engagement.

Read more: [https://www.nihr.ac.uk/patients-and-public/documents/Kirkpatrick\\_et\\_al-2017-Research\\_Involvement\\_and\\_Engagement.pdf](https://www.nihr.ac.uk/patients-and-public/documents/Kirkpatrick_et_al-2017-Research_Involvement_and_Engagement.pdf)

- Simple tools to help identify what individuals learning needs might be for their role
- Resources to support inductions for the public, public involvement managers, and researchers and their staff
- A set of Top Tips for key public involvement topics, including learning and development. Read more here: <https://www.nihr.ac.uk/patients-and-public/documents/LD%20reportNov17.pdf>

## **The SHARED study: public co researchers in dementia research**

The SHARED study involved public co-researchers in developing carer and patient-led recommendations for people with dementia or memory loss returning home from hospital. Read more here about the public and academic researchers and their experience of delivering this research together.

<https://www.nihr.ac.uk/news-and-events/features/behind-the-research/the-shared-study-public-co-researchers-in-dementia-research.htm>

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## **Cicely Saunders Institute Open House**

With the support of the Collaboration for Leadership in Applied Health Research and Care South London (CLAHRC South London), the Patient and Public Involvement team of the Cicely Saunders Institute organised an exciting Open House event.

The Cicely Saunders Institute (CSI), King's College London, opened its doors to the general public as part of the London Open House weekend. Over 60 members of the public attended this event. They were able to explore the CSI building in a guided tour, take part in games and quizzes, meet CSI researchers and the artists who contributed to the building, and also pay a visit to the Macmillan information centre. . "Very impressed" was the response of one attendee, and another left feeling "happier to learn more about palliative care."

Read the full article here: <https://www.nihr.ac.uk/patients-and-public/documents/Open%20House%20Research%20Showcase%20September%202017%20final.pdf>

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## **Researchers behind leading children's heart surgery survival launch new patient and public engagement guide**

Researchers from a flagship NIHR-funded study helping parents understand survival data about children's heart surgery have launched a new best practice guide for involving patients and the public and research.

The PRAIS 2 study team had previously been commended for their work in developing the Understanding Children's Heart Surgery Outcomes website to better inform people how the NHS monitors children's heart surgery.

Read more here <https://www.nihr.ac.uk/news/researchers-behind-leading-childrens-heart-surgery-survival-website-launch-new-patient-and-public-engagement-guide/7258>

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## **Supporting Learning and Development**

The INVOLVE Learning and Development Project Group will launched the first set of materials and systems at the INVOLVE at 21 Conference in London on 28th November 2017.

Over the past year, the Project Group coordinated the development of systems and resources that will form a solid foundation for the future of learning and development for public involvement in research.

The materials launched at the conference include:

- Simple tools to help identify what individuals learning needs might be for their role
- Resources to support inductions for the public, public involvement managers, and researchers and their staff
- A set of Top Tips for key public involvement topics, including learning and development.

Read more here <https://www.nihr.ac.uk/patients-and-public/documents/LD%20reportNov17.pdf>

## Visit the Patients and the public section on the NIHR website

More people than ever before are taking part in research studies. New and better treatments and services become available because people take part in our research. Members of the public are also getting involved in advising us about what research should be funded and helping to design research studies.

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## Would you like to apply to become a public reviewer?

Researchers applying for NIHR funding have to complete a form saying what research they want to do and how they want to do it. A range of people including members of the public, clinicians, researchers, health economists and other professionals read and comment on the applications.

<https://www.nihr.ac.uk/patients-and-public/how-to-join-in/review-a-research-application.htm>

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## Join Dementia Research

People with dementia or memory problems, their carers and anyone who is interested can sign up. You can also sign up for someone else, providing that you have their consent. Registering is the first step in becoming involved in supporting vital research studies across the nation.

Read more here: <https://www.joindementiaresearch.nihr.ac.uk/>

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## Hear more about the Patient Research Ambassador Initiative

A Patient Research Ambassador is someone who promotes health research from a patient point of view. They could be a patient, service user, carer or lay person who is enthusiastic about health research and is willing to communicate that to other patients, the public, as well as other healthcare professionals. Read more here: <https://www.nihr.ac.uk/patients-and-public/how-to-join-in/patient-research-ambassadors/>

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## Read News from NIHR

Yorkshire and Humber Join Dementia Research Champion Wendy Mitchell has had her work recognised by two awards over the last month.

Regular takeaways linked to obesity and heart disease in children

New report: Devices for Endovascular Interventions

<https://www.nihr.ac.uk/news-and-events/news/>

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### Zoe's Blog

<https://tinyurl.com/y7s5cq7z>

Join Dementia Research

<https://tinyurl.com/o6esvw3>

New Patient Research Ambassador stories

<https://tinyurl.com/y8odm9xj>

News from NIHR

<https://tinyurl.com/yc58wo68>

Visit the NIHR website

<https://www.nihr.ac.uk/patients-and-public/>

Apply to become a public reviewer

<https://tinyurl.com/yc3p8f6q>

Visit the new INSPIRE Research Portal

<http://www.inspireresearch.org/>

NIHR in your area

<https://www.nihr.ac.uk/nihr-in-your-area/>

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