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NIHR launches new national standards for research

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A set of national standards in order to improve the quality and consistency of public involvement in research was launched at the 2018 Patients First Conference which was jointly hosted by the AMRC and the ABPI – and at the Involving People Network Annual Meeting 2018.

Una Rennard, NIHR INVOLVE Advisory Group member said:

"Patients and the public bring a unique perspective to research, improving accessibility, quality and relevance by, for example, helping to ensure the language and content of study information is appropriate. As a public contributor I want to ensure proposed research is asking questions that are important to patients and is acceptable to potential participants."

The standards aim to provide people with clear, concise benchmarks for effective public involvement alongside indicators against which improvement can be monitored. They are intended to encourage approaches and behaviours that will support this.

They have been developed through a UK-wide partnership over the last 18 months building on previous work in this area. The partnership brings together members of the public with representatives from the National Institute for Health Research (England), the Chief Scientist Office (Scotland), Health and Care Research Wales and the Public Health Agency (Northern Ireland), working with an independent expert.

Dr Dan Venables, Head of Public Involvement & Engagement, Health and Care Research Wales said:

"We know that the quality of public involvement varies greatly across research projects and organisations. The national standards clearly describe a vision for excellent public involvement that we expect all research to aspire to, whilst also enabling us to identify and celebrate existing good practice"

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Simon Denegri, NIHR Director of Patients, Carers and The Public said:

"I am absolutely delighted to see the Public Involvement Standards reach the next milestone in their development at the Patients First conference today. My congratulations and thanks to those organisations who will be 'test beds' for the standards over the next 12 months. They will be playing a really important role in making them roadworthy for future users.

"In the future, we want the standards to be seen by groups and organisations large and small; public, private and charitable as an essential tool in guiding their public involvement. I firmly believe the pioneering partnership that has been at the heart of these standards all along can only strengthen their case in this regard."

The focus is on testing these standards in the coming year. The partnership will be working with ten pilot sites across the UK as they put the standards to practical use in their own working environment. These sites will be based at the Asthma UK Centre for Applied Research, Sheffield Teaching Hospitals NHS Foundation Trust, Keele University, the Kidney Patient Involvement Network, Queen's University Belfast, the University of Glasgow, the Royal College of Obstetricians and Gynaecologists Women's Network, the Royal College of Speech and Language Therapists, Manchester University NHS Foundation Trust and the Wales School for Social Care Research and CADR (The Centre for Ageing and Dementia Research).

Beyond this the partnership is encouraging as many groups and organisations as possible to use the standards in their workplace and share learning and experiences. With over 50 organisations applying to be pilot sites it is clear that, across the entire UK health research system, there is now a real commitment to involve patients, carers and the public so that research is done with their interests and priorities in mind.

Mike Thompson, chief executive of the Association of the British Pharmaceutical Industry (ABPI) said:

"Researching and developing new, life-changing medicines is best when done collaboratively. Today's announcement from the NIHR sets out clear standards for how the pharmaceutical industry should work with patients to develop better vaccines and medicines.

"With 7000 new medicines in development by our members, the future of medicine is exciting. These standards will help ensure patients are at the heart of cutting-edge clinical research for much-needed diseases like cancers, diabetes and Alzheimer's."

Aisling Burnand MBE, Chief Executive, Association of Medical Research Charities said:

"We welcome the addition of these standards for public involvement in research. They provide a degree of consistency across different R&D sectors and articulate the responsibilities on all of us to strive towards meeting them. I particularly welcome the fact that they accentuate what good public involvement looks like.

"Until relatively recently, public involvement was still unheard of as a concept in many fields of research. I am proud that AMRC members are now leading the charge in this area. Patients First provides us with an opportunity to become advocates for pioneering partnerships that put patients at the centre of all we do. These standards are a helpful framework allowing us to do that."

In a recent NIHR-funded feasibility study to help patients manage their epilepsy, involving a group of people with learning disabilities was key to success, reports NIHR website.

Epilepsy is hard to control with drugs and 60-70% of people with learning disabilities will continue to have seizures despite medication. With very few alternatives available, Books Beyond Words - which provides books, services and training for people who find pictures easier to understand than words - became the focus of a Hertfordshire Partnership University NHS Foundation Trust study, as the team set out to evaluate the resources for people with epilepsy.

The team involved the public and patients from the beginning, at which point they presented to groups and gathered input into the study design. This process led to a number of changes in the initial plans and this was just the start. During the study, the team really began to reap the rewards of involving patients and the public in their project. They found patients and the public added a pragmatic element that enabled the team to make changes throughout the study.

Dr Silvana Mengoni, researcher on the study said:

"Patients have a valuable voice that often isn't heard in research. Often patient and public involvement happens at the beginning of a study to help design it, and then at the end for disseminating results but it can be largely overlooked during the running of a study. This was a crucial time for us to be engaging with our reference group and our study changed in a number of ways as a result of their input."