

Patients and the public

March 2020



Tina Coldham, chair of the INVOLVE Advisory Group shares her thoughts on INVOLVE's evolution and the key projects it has recently delivered, including the UK Standards for Public Involvement in Research.

Recently, I was interviewed by a PhD student looking at involvement. It gave me a great opportunity to reflect on how far I had come on my involvement in research journey. One of the constants of that journey has been the presence of INVOLVE. Always encouraging to me as an apprentice/emerging survivor researcher, helpful and a great source of information and inspiration. A real touchstone to those wanting to further the cause of involvement, and its reputation and reach went beyond the research world to a wider health and social care community - to even international recognition and envy. INVOLVE has come a very long way from its beginning as "Consumers in Research" that started in 1996. Things change and develop and INVOLVE has always been able to adapt and be responsive to the needs of the research community.

For the past three years INVOLVE has been ably hosted by the Wessex Institute at Southampton University - Thank you Lynn Kerridge and Matt Westmore! Under their wise wing, INVOLVE has regrouped, and pushed ahead with several of the recommendations arising from the Going the Extra Mile report (2015) on the **strategic review of public involvement in the NIHR**.

Some of the key achievements of INVOLVE in last 3 years have been:

- The development of our understanding and various outputs as to what Co-production is in research.
- Working with NIHR partners we've delivered several Learning and Development outputs/materials.
- A lot of thought and work has gone into the Diversity and Inclusion agenda in involvement, and what needs to happen to strengthen a diverse and inclusive public involvement community.
- A multi-partnership approach was taken to setting up the UK standards for public involvement.

Indeed, the standards work took on board previous iterations of other 'standards' work developed elsewhere in an attempt to finally create some benchmark by which NIHR and its partners can achieve good involvement. Also, people engaging with NIHR organisations can expect a level of service and care, and by which they can hold those institutions to account. People engaging with various health and social care organisations as well as Universities have been crying out for this for many years. The fact that the standards have been developed in partnership with the devolved nations and are being used far and wide is a credit to a really useful piece of work and the people involved. A major achievement!

There is no doubt that INVOLVE staff, INVOLVE Advisory Group members and partner organisations have worked to maximum effect in a partnership way on many projects. More can be achieved together. With this thought in mind we enter into a new era of development with INVOLVE joining forces with the NIHR Dissemination Centre from April 2020. The new Centre will have a refreshed focus and team. So, keep an eye out for exciting job opportunities on the LGC website www.lgcgroup.com who will be hosting the new Centre, as indeed they already host other parts of the NIHR. Change can be difficult but the commitment to the recommendations in the Going the Extra Mile report give us a clear roadmap of travel, and together we can all make great strides forward. Let's carry on doing that!



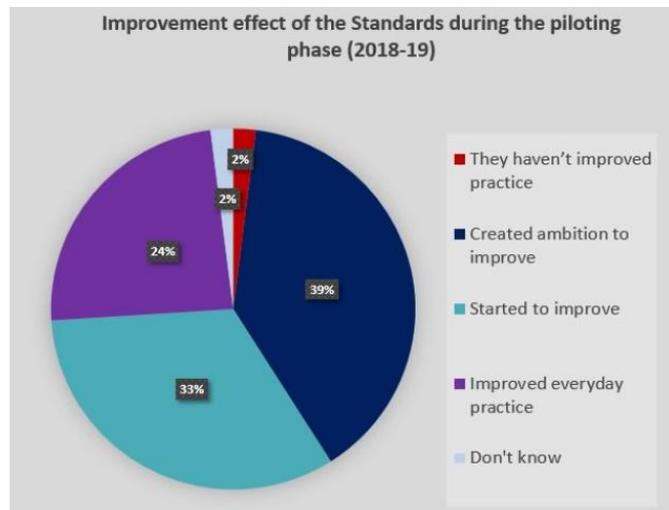
The Standards Partnership share an overview of the development of the UK Standards for Public Involvement in Research. Their reflections and perspectives on the next steps for putting the standards in to practice.

Firstly, on behalf of the partnership we would like to thank you all for your critical role in driving forward the need for standards, shaping their development and adopting them into practice. The original drive for the standards came from the public involvement community, our contributors and practitioners. There was a wish to know what 'good' looked like and a mechanism to build on INVOLVE's Values and Principles Framework.

The Going the Extra Mile recommendations set out the need to 'commission the development of a set of values, principles and standards for public involvement. These must be co-produced with the public and other partners.' NIHR Central Commissioning Facility and INVOLVE came together to achieve this and partnered with Health and Care Research Wales as they were embarking on a similar journey. We are grateful for all the devolved nations' support of this initiative making the standards a truly UK wide approach. For the past three years the partnership has:

- Developed a set of draft standards drawn from other contexts and practice.
- Completed a public consultation which received almost 700 responses.
- Changed the draft standards on the basis of the feedback and presented these at the INVOLVE Conference in 2017.
- Completed a year-long piloting phase with 40 groups and individuals.

The piloting phase had 10 formal pilot sites and 30 'freestyle' sites from across the devolved nations. They included public contributors, charities, NIHR organisations and Royal Colleges. No additional resource was provided to the pilot sites, as it was important to understand how they could work within existing budgets and in the real world. The feedback from the pilots was incredibly positive, with the vast majority reporting improvement in practice as a result of implementing some, or all of the standards. The partnership were encouraged and impressed by the different approaches taken by the pilot sites.



Pie chart illustrating pilot responses to the survey question: *'In general, how have the standard(s) improved your/ your organisation's practice?'* (N=40)

Below is a 'Tag cloud', which visually represents the ways the standards were used by the pilots.



A final revision of the standards reflected the information provided by the different groups and individuals who tested them. The most significant revision was the removal of the example indicators and the introduction of reflective questions to give more flexibility for their application in different contexts.

The UK Standards for Public Involvement in Research ( #UKPIStandards) were formally released on the 19th of November 2019 in Belfast, as part of [Involve Fest](#), a week-long celebration of public involvement in Northern Ireland. The partnership is pleased that organisations and people are embedding them in practice.



Following the launch, work has been going on to develop implementation stories from some of the organisations and people that tested the draft standards during 2018 and 2019. They will showcase successful as well as more challenging implementation experiences and will be relatively short with a practical focus. In keeping with the varied experiences and

contexts of public involvement in research we will feature standards implementation done on a 'shoestring', using the standards with experienced teams, in large and small settings and using standards to help with 'first time' public involvement in research.

The partnership wants the examples to show the reflective processes at work, what did testers learn about public involvement, about themselves and about each other whilst implementing the standards? Examples will also reflect the reality of using standards in public involvement, and cover issues such as 'buddies' for public involvement, avoiding tokenism, walking before running in diversity and inclusion in public involvement, auditing for quality involvement, prioritising effort and resource, improving feedback to public contributors and much more.



It was never intended that the standards would become a tick box exercise, rather that they will enable individuals, groups or organisations to reflect on practice and plans to identify areas of achievement or opportunities for improvement. They can provide a framework to audit and monitor your activities not want to set the expectations so high that people or groups embarking on their public involvement journey aren't encouraged to take those first steps. We live and work in a world with limited resources, not least of which is time, but we know that from that first conversation with a patient, carer or member of the public to the innovative arts based schemes, there is a vast spectrum of partnership opportunities and all have the potential to add incredible value to our work and lives.

Our hope for these values based standards is that through reframing of the reflective questions they will work in multiple contexts and be applicable at an individual through to an organisational level. The objective of this work was to provide an adaptive framework that would shape and guide practice to improve outcomes for everyone.

Photographs kindly provided by The Welsh Centre for Aging and Dementia Research.

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Working together

Work together in a way that values all contributions and that builds and sustains mutually respectful and productive relationships.

The Reaching Out project in Yorkshire share their learnings and outcomes of their work with Gypsy and Traveller Communities. This is an inspirational project showing that we can actively engage and involve marginalised communities and support them to achieve their goals.

In Yorkshire we have started an exciting project working with the Gypsy and Traveller Community (GTC). Gypsy and Traveller Communities (GTC's) use a variety of health and social care services, and often

face challenges accessing the services they need. Evidence suggests that GTCs have poorer health outcomes in comparison to other socioeconomically disadvantaged or ethnic minority groups (Peters et al 2009). The average life expectancy in Leeds is 78 years, within the Leeds GTCs it is thought to be around 50 years (Baker 2005). GTCs report challenges when accessing services due to issues such as, discrimination, lack of a permanent address and higher than average levels of illiteracy. Despite a clear health need, GTCs are rarely represented within public involvement activities in our region.



The Reaching Out programme, funded through NIHR by INVOLVE and the Research Design Service (RDS), seeks to encourage the development of new public involvement and engagement relationships with those parts of the community who are not usually, or consistently, involved in health, social care and public health research.

What story goes untold?

We want our project to be driven by the community and very much focused on their needs, we attended a GTC fair, here we were able to explore collective problems of families and the community at a local level. Informed by the literature and directed by the York Travellers Trust, we narrowed down questions to explore at the event.

We wanted to know what the focus of our research should be; this was narrowed down to bad nerves (mental health), children and sick and elderly. We conversed with a wide range of community members from small children to elderly pensioners. Although we provided people with options, we also captured other thoughts and interesting topics, which people spoke about. Some amazing inspirational stories and some very upsetting things to hear which provides motivation to do more!

Our objectives

- Start to build trust between community members, researchers and research organisations
- Provide a platform for community members to express their views about health and social care
- Develop, evaluate and share involvement and engagement methods, which others can apply
- Develop and agree a plan for future collaborative working
- Raise profile of Gypsy and Traveller Community



How do we share our work?

Feedback from the GTC is that often research is carried out; we get involved but then hear nothing about it! We wanted to ensure that we do not make this mistake so we asked how best to communicate our findings, research or anything we produce. Again being directed by YTT we provide options which included **Facebook**, **YouTube** or **on paper**. We also captured anything else, which people suggested but found that generally the votes fell into these categories.

The event was truly a community event with everyone supporting each other, we got a real community feel and felt very welcomed.

What's next?

Our consultation at Lee Gap has helped focus the next stage of our project. The community told us they want to challenge negative perceptions of GTCs for example, by **collecting positive stories** about how people **look after sick relatives**. They also talked about **children** and how the project could provide opportunity for **home schooled children** to get valuable experience, **by working with University researchers**.

Next we are holding a Stakeholder workshop on 7th February in Wakefield where we will provide opportunity for members of the community to tell researchers and the NHS what matters most to them and help refine the next stage of the project.

More information and updates

- <https://www.rds-yh.nihr.ac.uk/public-involvement/reaching-out-project/>
- Samaira.khan@sheffield.ac.uk
- <https://www.facebook.com/YorkTravellers/>



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The STADIA project public involvement contributor and researcher share their experiences of working together. It is great to see the benefits of involvement not only to the study but to those involved.



The STADIA study (STANDARDISED Diagnostic Assessment for children and adolescents with emotional difficulties) is investigating the impact of a standardised diagnostic assessment tool, in addition to usual clinical care, on the diagnosis of emotional disorders in children and adolescents who are referred to Child and Adolescent Mental Health Services (CAMHS). The PPI team consists of Colleen Ewart (Parent Co-Applicant and PPI Co-Lead), Alexandra Lang (STADIA PPI Research Co-Investigator) and Ellen Bradley (Research Assistant).

Colleen tells us here about her experience of working with the STADIA team, and Ellen provides an account of how she experienced PPI during her recruitment process. Colleen Ewart - I was involved from the proposal development stage of this project by the lead, Professor Kapil Sayal. It's still easy to forget on a new project that you are there because of 'lived experience' when faced with a new group of academics/clinicians. The appointment of Dr Alex Lang, an experienced PPI co-applicant was 'key' in helping me to navigate the unfamiliar and enable me to flourish in my role.

My first task was to consult a group of young people about a STADIA logo!



This was a significant task creating a visual identity for a 4 year project. I had never done anything like this before. Using my community contacts I set up a workshop to rank the fourteen logo options. I had no budget for this activity so prepared in advance a personalised certificate, thanking them from STADIA for their valuable contribution. These were well received. The shortlisted two logos were voted upon by the Trial Management Group.

The next task quickly followed; convene a parent/carer consultation to feedback on six documents (questionnaires/information sheets). I returned to the parent/carers of the young people I had consulted about the logo. I had taken the opportunity to deliver a presentation to them on the same day. This group provided insightful and clear feedback in readiness for our ethics submission. This early work enabled me to build trust and rapport with a group steeped in 'lived experience'. I have recruited our 'core' parent/carer advisory panel from this group.



The recruitment of the young person's advisory group has proved to be so much harder. This cohort is more fragile due to their ongoing health challenges. Recruitment has been spread across numerous contacts which has proved to be 'long winded' and not often successful. Time spent building rapport has been 'key' and I am so grateful for their trust, engagement and wisdom.

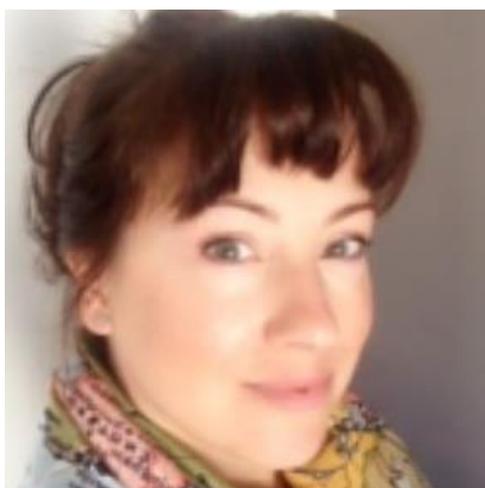
Working in partnership with Alex has led to a number of opportunities. An invitation for us to co-author a book chapter in a volume exploring contemporary issues in Ergonomics. It's been an amazing experience to

translate my involvement and knowledge of PPI activities within STADIA for an international audience. In addition we have now been invited as joint co-investigators to contribute to an international panel session on PPI at the U.S Human Factors & Ergonomics Society Congress 2020.

Ellen Bradley - The STADIA team have been trialling a novel application of Patient and Public Involvement (PPI) in developing and taking part in researcher recruitment. During the process of being recruited onto the study as a Research Assistant, I went through a PPI-led process, which consisted of a role-play scenario being presented at the interview stage. There were a number of scenarios developed for this purpose, and I was tasked with enacting a phone call with an overprotective parent who wanted to complete the questionnaire on the young person's behalf. The parent in this scenario was played by Colleen – I believe that it is vital to have someone who has lived experience to take on this sort of role, and her insights made the role-play much more realistic. From my perspective, this was a very useful activity not only for the recruitment panel, but it also gave me a much clearer sense of what the role would involve, and an opportunity to demonstrate skills that would normally not be assessed in a standard interview process.

These first 18 months of STADIA have seen real integration of PPI throughout multiple work streams of the trial. The coming months will see the PPI leads, research team and advisory panels focussing on a range of communication outputs and knowledge transfer activities.

Authors: Colleen Ewart, Ellen Bradley & Dr Alexandra Lang



Zoe Gray, Director of INVOLVE reflects on the journey of the Standards development and looks towards the next steps.

A summit has been reached, and a metaphorical flag planted, with the launch of the UK Standards for Public Involvement. This has certainly been a long climb for many of us. Starting at the foothills of development of the INVOLVE Values and Principles Framework 2015, the ground soil was richly fertilised by the experience and recommendations from the public involvement community of NIHR and partners, including a meeting in 2016 involving over 100 Public Involvement Leads.

It can be easy to focus on reaching the summit as an end in itself, but looking back down to where we started, it is striking how the co-production approach taken to developing the standards has engendered a subtle but significant cultural shift in the way people work together (as patients, carers, public members, researchers, funders and leaders in involvement, engagement and participation) to collectively nudge forward progress across a dispersed and complex research system.

The Going the Extra Mile strategy 2015-2025 points its compass towards a more co-ordinated and distributed leadership for involvement, engagement and participation, where public, researchers, health professionals and others are “equal partners in creating knowledge and... ensure adoption and diffusion across the health and social care system”. Indeed, the standards deliver one of the strategy's central recommendations; providing an adaptive framework by which anyone group, organisation, leader or

person, can set their ambition and strive towards continuous improvement in their involvement and engagement practice. What is equally noteworthy, though, is that the process of designing and testing out the standards with a such a variety of interests (involvement leaders, charity research funders, regulators, industry networks, patient groups, senior investigators etc.), has invigorated new forms of dispersed leadership across NIHR and its partners; creating a community of standards orienteers who are themselves, and with others, navigating the standards “map”, setting ambitions for continuous improvement, and implementing action to achieve them.

INVOLVE has taken its own turn in piloting the standards, assessing its own effectiveness against each area and implementing improvements. As well as highlighting areas for improvement, this has endorsed the approach in some areas. It has, for example, become a feature of INVOLVE’s working method over the last three years when prioritising work, planning or implementing projects to engage and draw together key stakeholders, including patients and the public, in scoping the issue and developing the response; wherever practicable co-designing solutions. As well as creating higher quality and more effective end products and increasing their reach, it has supported the Working Together standard by ensuring that;

- the purpose of public involvement is clear,
- arrangements for working are negotiated,
- and that ideas and contributions of individuals are recognised and addressed.

On the other hand, it was recognised that the processes for involving the public or patients with opportunities (whether at INVOLVE or via partners) did not always follow fair and transparent processes. As a result of which, INVOLVE and the Advisory Group amended how opportunities were notified and allocated; pushing back to organisations who wanted members of the public involved but who were not addressing barriers to involvement, offering choice or flexibility or using fair processes to select individuals. This has enabled improvements to be made in line with the Inclusive Opportunities standard. Inevitably, there are further hills to climb to embed the standards and build them practically into how people reflect on and evolve their practice at all levels across the system. NIHR and leaders in the UK government administrations and Ireland are fully behind this next ascent. The new NIHR centre which will take on INVOLVE’s public involvement leadership from the 1st April, stand ready to support the journey. But it is the standards orienteers who will ultimately take us there. It is to our next wave of orienteers, and their interested peers, that the system now needs to lend its support, knowledge, development, resources and encouragement.



Join an NIHR Committee

The [National Institute for Health Research \(NIHR\)](#) is seeking patients, carers and members of the public to review research proposals focusing on social care and how to improve it.

The [Research for Patient Benefit \(RfPB\) programme](#) offers social care research funding opportunities via its annual [Research for Social Care \(RfSC\)](#) call. Researchers and practitioners can apply for research funding in any number of areas, for example, transition from children’s to adult care services, health and

social care inequalities, end-of-life care, housing and employment related support, interventions to help tackle loneliness and isolation, etc.

Additionally, the RfPB programme expects research funding applications to demonstrate how people with social care needs, social care service users and carers, and organisations which provide adult social care services will be involved in the proposed research.

All NIHR funded research goes through a rigorous process of assessment by independent experts (such as researchers, clinicians, statisticians, health economists) and public reviewers (such as patients, carers, service users) with similar interests to the topic of the application. These assessments contribute to the work of the decision-making committee that makes a recommendation on which applications should receive funding.

If you have experience in any aspect of social care, either as a service user or carer and would like to review an application, please email: yvonne.anderson@nihr.ac.uk or call for more information on 0208 843 8041.

This is a paid opportunity and the NIHR Payment Guide can be accessed via the link below:

<https://www.nihr.ac.uk/documents/reward-and-recognition-for-public-contributors/21573>



Co-Production: Teasing out the Tensions

The third in a series of highly successful 'co-producing health and social care research' events was held on February 26th at the National Centre for Voluntary Organisations (NCVO) in London. The theme for the day was 'Teasing out the Tensions' in co-production, and built on two previous co-production event themes of 'Co-producing research: how do we do it?' (July 2018) and 'How do we share power?' (March 2019). The event was planned as a collaborative partnership between INVOLVE, the Centre for Public Engagement at Kingston University and St George's University of London, UCL Centre for Co-Production in Health Research, Bridges Self-Management, Department of Design Brunel University and was part sponsored by the journal Frontiers in Sociology.



The event planning team (comprising of non-professional event organisers!) endeavoured to embody co-production principles in the organisation of the day including having a range of perspectives on the organising committee. A number of free tickets were made available to members of the public to attend and altogether over one hundred people gathered to hear Peter Beresford set the scene in the morning, followed by a choice of 5 parallel sessions (each repeated after lunch) on:

1. Publishing
2. Can we co-produce the commissioning of health and social care research?
3. How do we act ethically in co-production? Does anyone 'own' what we co-produce?
4. Sharing power in a project
5. Evaluation and co-production: Embracing messiness

For a more detailed account of the event including topics that emerged during the sessions, please see event planning team member Sarah Markham's comprehensive blog: <https://blogs.ucl.ac.uk/public-engagement/2020/03/02/tensions/>
Also check out the event hashtag: [#CoProTott](#)

Duncan Barron
[CPE, Kingston & St Georges](#)

Scott Ballard-Ridley
[Bridges Self-Management](#)



Opportunity for patients, service users, carers and members of the public to review research applications into social care

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UK Clinical Research Facility Network: Focussing on the UK Standards

The UK Clinical Research Facility Network ([UKCRF Network](#)) is focussing on the UK Standards for Public Involvement in the Network's 2020/21 work plan.

The UKCRF Network has a [Patient and Public Involvement / Engagement \(PPI/E\) theme](#), which brings together and supports PPI/E Leads from different Clinical Research Facilities. This group will be working together to apply the Standards and reflect on and share learning. The Group aims to develop case studies to illustrate each standard.

The Network collaborates with clinical research facilities and other experimental medicine infrastructure across the UK and Ireland to develop, share and implement excellence in delivering clinical studies, and drive forward initiatives that improve quality of patient experience.

For more information please visit the [UKCRF Network website](#) or email ukcrf.network@nihr.ac.uk



Tell us what you think of this newsletter

We'd love to know what you think of this newsletter, so we can improve it and make it more relevant to you. Please let us know by [filling out the short form](#)



NIHR announces new standards for public involvement in research

The NIHR has released a final and complete set of UK Standards for Public Involvement in research, to help researchers and organisations improve the quality and consistency of public involvement in health and research.

The [UK Standards for Public Involvement](#) are for people and organisations that do health or social care research, support health or social care research and do public involvement. The standards cover six important 'values based' areas:

- Inclusive Opportunities
- Working Together
- Support and Learning
- Communications

- Impact
- Governance

The Standards are a description of what good public involvement looks like and are designed to support self-reflection and learning. Reflective questions accompany each Standard to encourage users to think about their public involvement plans and actions.

The Standards will aim to improve public involvement practice by providing examples of good practice and supporting leadership and accountability for involvement within research organisations - 'public involvement is everyone's job.'

The NIHR has been instrumental in developing the standards over three years through a joint four-nation partnership with Chief Scientist Office (Scotland), Health and Care Research Wales and the Public Health Agency (Northern Ireland). This included hosting and maintaining the standards website and building a standards network of over 400 registered members contributing to the public consultation and piloting phase of the project.

The Standards were tested by over 40 individuals, groups and organisations during a [year-long pilot programme](#). The Standards were used as a framework for public involvement supporting reflective practice and plans for future activities, as an audit tool to identify gaps and areas for improvement and as a way of harmonising public involvement across different settings.

Case studies are currently being developed based on the experience of the pilot sites and covering different elements and challenges of public involvement, which the standards can help improve.

There is no single way of using the Standards. How they are used will be influenced by many issues, such as the purpose of involvement and the amount of resources (money, people, skills) available.

[Find out more](#)



Testing the UK Standards for Public Involvement

The UK Standards for Public Involvement aim to help researchers and organisations climb to lofty heights in patient and public involvement and engagement in research. Bella Starling outlines her experience in testing the draft standards – how the standards informed practice in Manchester, and how practice in Manchester informed the standards.

I'm not a big fan of cable cars – which is strange for someone who loves to be in the mountains – so it's always good to glimpse the heart-shaped kitemark symbol of the cable car glass, as I peer down the ravine. I am instantly reassured that I am in a good quality, reliable and safe environment.

What would a kitemark look like for public involvement in research? This is what the [UK Standards for Public Involvement](#) set out to find out.

The UK Standards for Public Involvement are a framework for what good public involvement in health and care research looks like. The standards, which cover six areas, include questions to help people and organisations identify what they are doing well, and what needs improving.

Testing the standards in practice

Here, in the Public Programmes Team at Manchester University NHS Foundation Trust, we were privileged to be chosen as a testbed for the standards, helping the UK partnership to test, challenge and refine the standards for public involvement in research.

As a team, we lead patient and public involvement and engagement (PPIE) with research across a large patch of clinical research, experimental and translational medicine in Greater Manchester including as part of the [NIHR Manchester Biomedical Research Centre](#) (BRC) and the [NIHR Manchester Clinical Research Facility](#) (CRF).

As such, we support a wide variety of researchers and public contributors, with different backgrounds, skills, experience and expertise in PPIE ([as elaborated in our strategy](#)). This presented us with a unique and diverse setting within which to test the standards. We reflected on how the standards helped appraise our work; and how our work could inform the standards.

We applied the standards across three different PPIE contexts:

- First Steps: contexts in which researchers and public contributors are perhaps more inexperienced, or first-timers. Like those starting on the nursery ski-slopes of the mountain.
- Everyday Practice: those undertaking PPIE 'business as usual' with good groundings and levels of competency. Those navigating the blue and red runs of the mountain, not without the occasional bump and tumble.
- Aiming High: the well-versed PPIE partners (researchers and public contributors alike). The black run enthusiasts, with perhaps an appetite for some off-piste.

We're really glad to see that these contexts are reflected in the final standards. Public involvement does not come in 'one size fits all', so appreciating context and difference, we feel, is really important.

Read the blog post from Bella Starling [here](#).



Where did I put my glasses?

How the public provide expert vision for health and social care researchers and how you can help. Jennifer Bostock reflects on her experiences as a public contributor, helping shape research over the last decade, and encourages others to get involved by applying to join an NIHR committee.

It seems like five minutes ago, but it was actually over 10 years ago, when I saw an advert for my local hospital urging patients to attend a meeting to share experiences of having surgery.

Eager to have my say, I went along to the session - which aimed to help the hospital improve their surgical services. I shared a few positive and a few not so positive encounters I'd had as a patient who has frequent surgery. So it began, me 'having my say', which I've been having ever since - mainly in the health research arena.

I've spent eight of those years serving as a public member on NIHR funding committees having my say on research applications in a variety of areas of healthcare.

From cold to warmer feet

When I dipped my toe into funding committee membership, I did so with rather 'cold feet', worried that I wouldn't have anything valuable to say, that my questions would be silly and my remarks irrelevant but as you can tell eight years on, my feet have warmed up considerably.

My experience with the NIHR has been great, I've learned loads, contributed loads (not all of it useful I'm sure) and seen the NIHR grow and develop in more ways than I have words to mention.

As a reviewer, I've sat on more than four funding committees. They are all interesting in their own ways but one that stands out is the NIHR's [Invention for Innovation \(i4i\) Programme](#), where incredibly clever inventors present their amazing inventions. I liken it to a sort of health research Dragons' Den without the cash or the Dragons!

The incredible 'talking spectacles'

I recall someone coming along with a brilliant idea to help blind people see by some innovative things that I naively refer to as 'glasses'. The panel quizzed the applicant on all manner of things relating to science, medicine and patent laws. During this, I had a nagging voice in my head urging me to ask a very elementary question, but one I felt confident was important. At the time, my father was going blind and as I sat listening to the presentation and the wonder of modern science, I wondered "how will they be used in practice at home?"

So I simply asked, "If my father is in the kitchen and the 'glasses' are upstairs in the bathroom, how will he find them - bearing in mind he is blind?" A pause entered proceedings quickly and then came a recognition from the inventor that actually he had not considered this. I urged him to find a method of alerting the blind person to where they had left the 'glasses'.

I sat back relieved that my question was not laughed out of the room, relieved that most people appeared to recognise the importance of the question and very grateful that the inventor had the confidence to admit in a room full of people that he had not considered such an elementary question. I need say no more than this example to say why I feel PPI is important.

Simple questions - transforming answers

My advice for anyone thinking about joining a funding committee is just go for it: the fact that you are thinking about it means you must be interested in research and your experience as a patient, carer, or member of the public is just what the committees need. My very top tip is always remember that no question is too simple, no comment too naïve, and no experience is good, bad or indifferent without value.

Jennifer Bostock, NIHR Public Contributor

Jennifer has been a member of committees for NIHR's Research for Patient Benefit (RfPB), Public Health Research (PHR) and Health Services and Delivery Research (HS&DR) programmes and TCC (now NIHR Academy) Post-Doc Fellowship.

NIHR is currently recruiting for patients, carers and members of the public to join committees. More information is available on the [NIHR website](#).

The views and opinions expressed in this blog are those of the authors and do not necessarily reflect those of the NIHR, NHS or the Department of Health and Social Care.

Read her blog [here](#).



What is Health Research? Free online course.

Learning about health research has never been easier, [What is Health Research?](#) is a free three week online course aimed at patients, public, carers and anyone keen to explore the world of health research. Learners can complete the course at their own pace.

Bust the common myths surrounding health research, find out what's involved, discover how research is improving health care and explore ways to get involved. Hear from people who have taken part in research, learn why they volunteered and the difference it can make.

[Sign up today](#). Course started Monday 16th March 2020.



New CASE STUDY : Translating intention into action

Read about how NIHR collaborated with Pfizer Ltd. clinicians patients to successfully design and pilot a new patient involvement service for the life sciences industry.

In the UK the NIHR defines public involvement (also referred to as patient engagement) in research as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.” It is a definition that we have become familiar with and the research community, including the life sciences industry, now accept that patient engagement should be a feature of any high quality research proposal.

There is also general agreement that well executed patient engagement activities can lead to better designed research, better recruitment and better retention. This is based on the simple principle that patients are the experts of their conditions; only they can truly tell us if we are achieving the right balance between the ‘ask’ of the research and the burden of the disease.

To achieve this balance it is crucial that patient engagement happens early in the clinical development process.

In October 2018 a small team based within the NIHR Clinical Research Network decided to embrace this concept and began developing the NIHR Patient Engagement in Clinical Development Service.

The primary aim of the service is to bring patients and life science companies together before a study protocol is finalised. By focussing on facilitating patient engagement activities at this point in the clinical trial process it provides an opportunity for patients to help make trial designs as patient-friendly as they can be.

The NIHR is in a unique position to be able to broker this relationship as a neutral, public sector organisation, working in close partnership with the NHS, with a long history and track record of supporting the life science industry to deliver clinical research in the NHS. Throughout 2018 and early 2019 we collaborated with patients, clinicians and a global pharmaceutical company, Pfizer Ltd, to design and pilot the new service.

The pilot involved two Pfizer studies looking at a new treatment for eczema which were both paediatric and adult studies. We facilitated two meetings at Alder Hey Children's Hospital NHS Foundation Trust, Liverpool, firstly with a group of young people and then with a group of parents/carers.

Sophie Evett, Feasibility Lead for Pfizer UK, who led Pfizer’s participation in the pilot, reflects on her experience of the pilot:

Read about it [here](#).



Stroke Priority Setting Partnership: Have your say

In partnership with the Stroke Association, we are supporting the Stroke Priority Setting Partnership (PSP), which will identify and prioritise unanswered questions about stroke. We're inviting patients and the public to complete the Stroke PSP survey to have their say on what the research priorities should be. Complete the survey [here](#).



NIHR Be Part of Research. What is Research?

Research helps us to increase our knowledge about human beings and wellbeing. This is so we can:

- provide life changing treatments
- diagnose diseases earlier or more accurately
- prevent people from developing conditions
- improve health and care for generations to come
- ensure everyone has a better quality of life

Overall, the aim is to find out whether what is being tested is better than what is currently available. This can include therapies, medicines and services. See the website [here](#)



People in Research

'Find opportunities' for members of the public who would like to get involved in research. 'Add opportunity' for researchers who want to find members of the public to get involved in their research.

Public involvement in research is when the research is 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 advice as members of a project steering group, commenting on and developing research materials and undertaking research with research participants.

Follow @People_Research

See website [here](#).

Co-Production in Action Resources



See 'Co-Production in Action Number One' [here](#).

See 'Co-Production in Action Number Two' [here](#).



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Guidance on
co-producing a research project



See 'Guidance on Co-producing a research project' [here](#).