

NIHR patients and the public

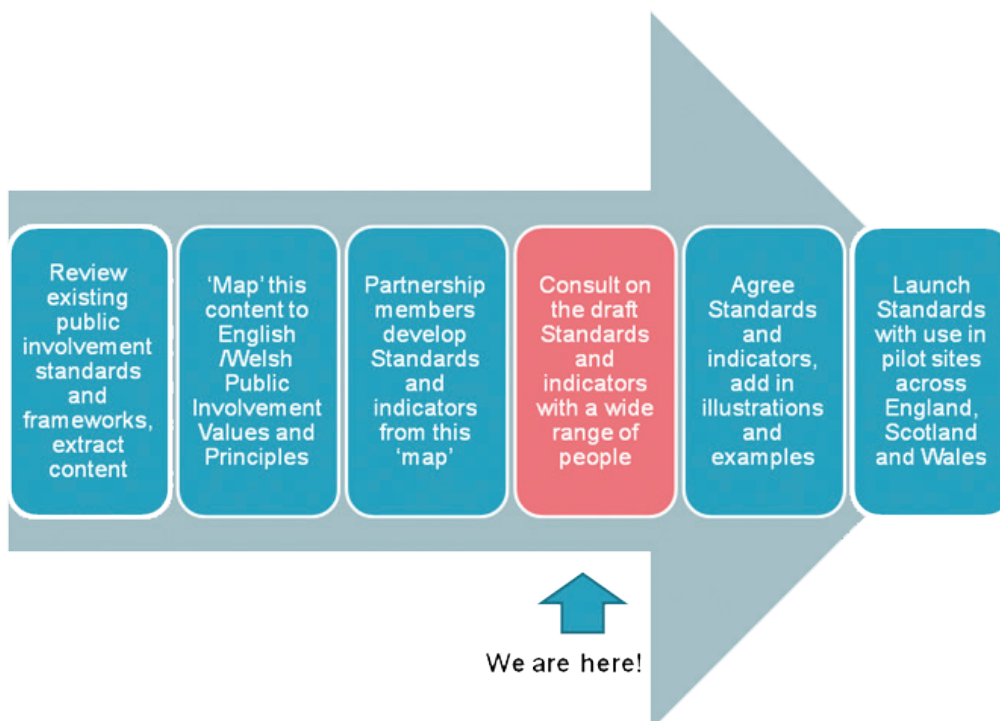
Summer 2017

Improve our draft national standards for public involvement in research

During 2016/17, Health and Care Research Wales, the National Institute for Health Research (NIHR), the Chief Scientist Office in Scotland and the Public Health Agency in Northern Ireland have been working with public contributors as the 'Public Involvement Standards Development Partnership'. The Partnership is developing a set of national standards and indicators for public involvement (PI) in research that can be used by organisations, research projects and individuals to improve the quality and consistency of PI.

For the NIHR, developing PI standards is a commitment made in the Going the Extra Mile report, with implementation mandated and overseen by the NIHR Patient and Public Involvement Senior Leadership Team led by Simon Denegri, the National Director for Patients and the Public.

Here is a summary of the steps we have taken so far and our plans for future work



As you can see, we would like to involve you in reviewing and giving us feedback on the draft standards and indicators. Do they capture what good public involvement in research looks like from your perspective? Will they be of practical use to you? What have we missed out? How can we improve them?

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The consultation is running from Thursday 29 June to Friday 1 September 2017. Please visit the project website for more detailed information about the consultation process and to access all the resources you might need:

<https://sites.google.com/nih.ac.uk/pi-standards/consultation>

If you have any questions or queries about the consultation please contact the PPI team at the NIHR Central Commissioning Facility:

Email: ccfpfi@nih.ac.uk Telephone: 020 8843 8041

We look forward to hearing your views.

Philippa Yeeles, NIHR Central Commissioning Facility

On behalf of the Standards Development Partnership

Alan's Cancer Story

I had a sore throat. It persisted. I thought it would be OK by the time I would be going skiing in 10 days.

I skied with the infected throat. On my return, I went to see my GP; it was a Monday morning

My GP said: "it's a very mild infection". I explained I was going back-packing, to Northern Ireland next week, to get my peace dividend. "Can I have some antibiotics, as I don't want to be ill on my travels". She replied, "I'll give you a prescription, but hold off a few days it'll be gone by then". I said "that's what I thought 4 weeks ago". She responded, "You're 61, I'll send you for a blood test. Pick up a form from reception on the way out".

I had a full week's work planned. So the next day I gave a blood sample at Dulwich Hospital at 7:30am and went off to work.

My doctor was right; the sore throat was getting so much better.

On the Friday evening I opened the front door and answered the ringing phone, in the hallway.

It was someone from Kings College Hospital, saying they had arranged an appointment for 09:30 on Monday morning for tests. I explained, I was away by then, and could it wait a week or two.

The person put me through to a professor. I re-explained why I was not going to be there. After some talk, he said, "I think you have Bone Marrow Cancer, and want to take some marrow to check". I said "I think you're wrong, but I'll be there".

On the Monday morning I gave some bone marrow and motor-biked home.

The hospital asked me to bring someone with me for a Wednesday appointment at 09:15. My girlfriend took the morning off work.

We sat in the waiting room for 3 hours. I was very angry.

At 12:15, the professor saw us. He is a small avuncular gentleman. He explained it was very important that he see me, and if any patient had not turned up for their appointment, he would have fitted me in.

I had a Bone Marrow Cancer called Chronic Myeloid Leukaemia (CML). He explained this was a good cancer to get. There had been real breakthroughs in the treatment of CML and I could start my treatment at the weekend. I had switched off after the cancer diagnosis was mentioned. My mind was racing in another direction sorting out my affairs. He was explaining with hand sketches how the drug I was going to take, works.

What happened next was brilliant.

The professor jumped up and led me back to the waiting room. There he introduced me to a fellow patient.

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The professor had asked one of his CML patients to stay after her appointment. He took us, with the fellow patient through some corridors to an empty room. Where she told me she had been diagnosed 8 years ago! She was there explaining the side effects. I was not listening. She was still alive... I loved this lady.

We had a month long holiday booked to Australia, going in 6 weeks.

My Cancer Specialist Nurse checked Melbourne Hospitals. Yes they could do a blood test during the month I was going to be there. On holiday, I was able to think about my meeting, and how that had calmed me down.

I thought it would be so good if when everybody was diagnosed there was a fellow patient to talk to. Someone who was not a clinician. Someone who could explain how it feels; someone who had been there, done that, a survivor who could give tips on what to expect and was living proof that some treatments work.

I joined the new support group for my cancer at Kings College Hospital, and set about trying to get the idea in motion. There were lots of obstacles. CRB Checks, costs, back-up and money needed. I joined the 'South East London Cancer Research Network' (SELCRN)

I love the idea of patients supporting patients (PsP), Old-people supporting Old-people. To this aim, a group of us have been able to get a grant from Macmillan and the NHS to pilot a scheme. In this scheme, the Specialist Nurse gives the newly diagnosed patient a postcard. The card gives information on how they can contact a fellow patient with the same diagnosis.

To find out more, go to <https://tinyurl.com/yd23cmoj>

People Are Messy

As part of the new I Am Research campaign, we are screening 'People are Messy' at events across England. The film engages its audiences in an informed debate around patient and public involvement in health research. The events also feature a research fair where you can find out more about how patients and the public can help shape and deliver improvements in health.

To read more, go to <https://tinyurl.com/ybda8rtt>

Results of a study to improve Patient and Public Involvement in Clinical Trials - Methodical Study



Patients and members of the public are increasingly involved in the design and delivery of clinical trials. Patient and public involvement within trials might involve helping to identify which topics should be prioritised for research, or helping to write trial information materials, such as leaflets and posters.

However, we do not know the best ways to involve patients and members of the public in trials and what impact this involvement has on clinical research.

In the METHODOICAL study we wanted to help resolve uncertainties and improve how we do PPI in clinical trials by identifying the most important topics for future research.

What did the METHODOICAL study do?

Between October 2015 and March 2016 we invited people with at least one year's experience of working within PPI in clinical trials to take part in something called a Delphi survey. A Delphi survey is a type of survey used to find people's opinions on important topics and seek agreement on topics across groups of people who might have different views.

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Seven different groups of people working in PPI were identified which included PPI contributors, lay reviewers, PPI coordinators, researchers, funders, clinicians and PPI advisors.

After the survey we held a face to face meeting with twenty five people to discuss the survey results and make a final decision on the importance of the research topics. Nearly half of the people at the meeting were patients or members of the public involved in designing and running trials.

What did the METHODOICAL study find?

The study identified sixteen critical research priorities for improving PPI in clinical trials. Three topics came equal first:

- Developing strong and productive working relationships between researchers and PPI contributors
- PPI practices in selecting trial outcomes of importance to patients
- A systematic review of PPI activity in improving the accessibility and usefulness of trial leaflets and information sheets for clinical trial participants

The full list of topics and a plain English summary of the study can be viewed at **www.methodicalstudy.uk**

The METHODOICAL results have also been published within the journal Health Expectations (**<http://onlinelibrary.wiley.com/doi/10.1111/hex.12583/full>**)

What next?

The results of the study will help us to know what research is important to help improve PPI. As part of this we are helping connect people who are interested in starting research projects for each topic.

To find out more about the working groups visit **www.methodicalstudy.uk** or email Kerry Woolfall on kwoolfall@liv.ac.uk

This work was supported by the MRC North West Hub for Trials Methodology Research (N62)

Physiotherapy Priority Setting Partnership survey

In partnership with the James Lind Alliance, The Chartered Society of Physiotherapy have launched a 'Physiotherapy Priority Setting Partnership' survey to find out what research is important to patients, carers and health professionals from across the UK. To find out more and to take part in the survey, go to **<https://tinyurl.com/y8ksrpf4>**

RDS SE and INVOLVE partnership event

Research Design Service South East and INVOLVE held a successful event 'Patient and public Involvement in research: Examples of the 'why, where, what, and how' of patient and public involvement in the South East' – to promote and strengthen Patient and Public Involvement (PPI) across the Kent, Sussex and Surrey (KSS) region. The event showcased PPI in research in the South East, explained PPI and why it is important, and highlighted how people can get involved in research. It also provided an opportunity for members of the public to meet National Institute for Health Research (NIHR) staff and researchers and find out more about PPI in health and care research in the region. Regional partners supporting and attending included: NIHR, Clinical Research Network, (CRN) KSS, KSS Academic Health Science Network (ASHN), Sussex Partnership Foundation Trust (SPFT), Centre for Health Services Studies (CHSS) University of Kent and the Jaffa panel, based at Brighton and Sussex University Hospital (BSUH)

Simon Denegri, Chair of INVOLVE and NIHR National Director for Public Participation and Engagement in Research, set the scene by explaining the work of the NIHR, its strategic objectives and its work in encouraging and supporting PPI in research. He stressed the importance of the RDS/ INVOLVE partnership in promulgating PPI networks.

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Gary Hickey, Senior Public Involvement Manager at INVOLVE, outlined a project being undertaken by INVOLVE in partnership with Public Health Agency (Northern Ireland), Chief Scientist Office (Scotland) and Health and Care Social Research Wales to develop standards for public involvement. These standards, building on INVOLVE's values and principles, would provide a framework to improve the consistency and quality public involvement. They could be used by the public, researchers and funding agencies to assess the strengths of weaknesses of the PPI arrangements within projects and organisations.

Paul Seddon then outlined one of the successes of the partnership work in the South East – the securing of funds from the charity Rockinghorse to establish a Children and Young Person's Group (C&YPG). The C&YPG seeks to ensure that health and social care research and services in the South East are informed by the needs and views of children and young people.

Laura Lea and Julia Fountain from SPFT kicked off the afternoon presentations which showcased public engagement and involvement within the South East region. They described the origins and history of the Lived Experience Advisory Forum (LEAF) and their role in all aspects of the research cycle. The challenges encountered by the group were limited resources for research at the design stage and embedding PPI into research practice. They also shared their successes and some of the projects that had been directly impacted by their contribution.

Melissa Ream and Ursula Clarke from Kent Surrey and Sussex AHSN presented the work that they had started in engaging patients as partners in improving services and redesigning services. Important work has begun to incorporate patient voices and stories with learning exchange days planned. Ursula gave examples of her projects looking at technological advances to help patient care be closer to home.

Julia Simister from the CRN described the Research Ambassadors Initiative, a national initiative that has been rolled out in the region, and the building research partnerships (BRP) programme.

Victoria Hamer from the Jaffa panel based at Brighton brightened up the afternoon by beginning her presentation with a poetry performance. She went to describe how the Jaffa group came into being (a love of the biscuits and no love for acronyms!) and how clinicians in the trust have valued their input at the research design stage.

Ugochi Nwulu and Patricia Wilson finished the presentations by presenting PPI activity at the University of Kent. Ugochi described the engagement work in patient participation groups in primary care practices that belong to the Encompass Vanguard, a new model of multi-provider care being trialled in the community. Patricia described the very active patient group (Opening Doors to Research) that has started to meet and contribute to the research proposals of researchers in Kent.

Looking forward, Simon Denegri noted that 'Following the success around the C&YP I would encourage the region to identify a similar win that might be pursued over the next 12 months.' Attendees expressed support for an annual event, similar to the one attended, which includes information about national PPI developments, learning about good practice and PPI opportunities in the South East and time for networking. Another, subsequent, suggestion from an attendee was to create an online community of interest. We all look forward to discussing and developing plans for the network.

You can see all of the presentations here <https://tinyurl.com/y78to6sp>

Assisted dying - developing the debate

INVOLVE group member, Tina Coldham has had a piece of user led research published on the subject of assisted dying.

To read the article, go to <https://tinyurl.com/y8qucuc9>

Recovery in research: valuing experiential knowledge

By Jo Cairns (Senior Research and Policy Officer, Alcohol Research UK)

On 30th January 2017, I chaired the Voices of Experience event at Changes UK, a substance use treatment service in Birmingham. This event was part of a larger Alcohol Research UK programme of work promoting public involvement in alcohol research, which started in October 2016.

The first event, held at the Wellcome Trust in London, had involved interested stakeholders from academic research, including Martin Lodemore (Senior Public Involvement Advisor, INVOLVE). The purpose of the Birmingham meeting was to learn from those with lived experience of recovering from alcohol harm (directly or indirectly) who were involved in research and/or represented those with lived experience.

We had an exciting and diverse programme. Steven Collier-Ellen, Sarah Willmott and Madge Wilson from the Sheffield Addiction Recovery Research Panel (ShARPP) at the University of Sheffield, Adrian Kelly (a Public and Expert by Experience Researcher - PEER) at Bedfordshire University, and Dave O'Connor a client representative at Changes UK each talked about the journeys that led them to public involvement. In the afternoon, members of the Manchester-based Voicebox Inc. Crew (Amanda Clayson, Keiran Ryan, Amanda Kinsey, Phil Kinsey, Zac Sargent, Ali Brooks and Keith Tucker) and Lucy Webb from Manchester Metropolitan University facilitated a co-productive exploration of their perspective on service-user involvement in substance-use research.

Everyone agreed that real-life experiences were valuable in substance use research, though there was a comment that they may also “get in the way” as describing the experience of recovery could be highly emotional. Some concern was also expressed about managing the relationship between stages of recovery and involvement in research so that there is no risk of relapse - creating a potentially serious ethical dilemma. However, many participants felt that being involved in research can help with moving past shame and guilt and, therefore, may be part of the recovery process itself. Participants also discussed feeling empowered by involvement in research. The “feel good” factor that comes with knowing you have been part of change (as was the case for Dave O'Connor) or attributed to the feeling of inclusion and value (as in Adrian Kelly's case). Public involvement, or research co-production, was also identified by many participants as a way of challenging paternalism: as a practical critique of the assumption that academics “know what is best”.

As Adrian Kelly eloquently argued: research is not simply a specialist activity, it arises wherever we are motivated by a sense of curiosity. To illustrate his own perspective on research involvement Adrian used the analogy of a child. He said we are all born with, and retain through life, the ability to conduct research (purposeful curiosity) as can be illustrated by a child confronted with the candle on their first birthday cake. Keen to understand the flickering yellow flame the child uses all five senses to conduct the essential practical steps of a research project. Firstly, they make observations. Sight informs them that something is there; smell, taste and hearing reveal nothing. With the only remaining sense, they reach out ... and touch. When the crying has stopped, the process may be repeated for reason of reproducibility/confirmation. All observations are recorded (in memory). Now, with two sets of data, analysis (thinking) takes place and arrives at an inference (touching flickering yellow things will probably be painful). What might be regarded as the conclusion of the research, which follows immediately or later, is a change in behaviour. In more advanced research, resulting change (or not) may depend on cooperation of others, e.g. policy makers, politicians, mum even! Younger children at the table will learn from their observation of the unfolding event but they will lack the experiential knowledge held by the expert by experience (i.e. what exactly was it that caused the distress? Was it extreme cold, extreme heat, electric shock, pins & needles etc.) The expert by experience knows what it felt like, emphasising the importance of experiential knowledge.

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The meeting discussed principles of public involvement in substance-use research, but also practical approaches to co-production. Various techniques that can be used to conduct co-produced research, and there are particular challenges in research around substance use and recovery. Through an interactive game they called 'The R Factor', Voicebox Inc. set out some key principles:

1. **Risk**: everyone takes a risk
2. **Reciprocity**: give and take (mutual benefit)
3. **Reward**: everyone gets something out of it (both academic and expert by experience)
4. **Rub (friction)**: clash points are learning opportunities
5. **Recognition**: understanding each other's gifts and needs
6. **Rolling**: adaptability (rolling with the flow in research)
7. **Recovery**: can taking part in research be part of recovery journey?
8. **Reach**: making sure the research speaks to a broader audience (non-academic)

These R's then extended through discussion with participants to include other things such as resonance, respect and rapport. This interactive activity was a striking example of two worlds (academic research and journeys of recovery) colliding: and it illustrated how, through that dialogue, co-produced insights can be achieved.

Feedback from the participants identified the most useful aspects of the event as the diversity of the programme, the opportunity to witness passion and enthusiasm, hearing different experiences of groups and individuals, experiencing how others focus on research, and exploring different communication methods. Various suggestions were put forward in terms of how ARUK can directly involve people with lived experience in the grant decision-making process, which we are currently exploring. These included having organised patient and public involvement panels, such as ShARPP, meeting to discuss research proposals on a regular and sustainable basis, rather than ad-hoc involvement, having service user representatives involved in research funding decisions (whether that be in house or outsourced to existing groups) and in early stages of research process (i.e. this time and commitment in early research to inform proposals could be funded retrospectively).

My organisation is at the early stages of embedding public involvement in their work, but we are committed to promoting peer research and continuing to explore public involvement in alcohol research through further exploratory events. We are also committed to a series of exciting forthcoming opportunities for both researchers and experts by experience.

Jo Cairns

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Evaluating the extent and impact of young people's involvement in National Institute for Health Research (NIHR) studies: an assessment of feasibility

A report of a project commissioned by the James Lind Alliance by Louca-Mai Brady and Jennifer Preston

To read the report in full (33 pages), please go to <https://tinyurl.com/yalez3tw>

New reports from the NIHR Central Commissioning Facility (CCF)

2016/17 PPIE Highlights Report
<https://tinyurl.com/y84oolwe>

2016/17 PPIE Annual Report (23 pages)
<https://tinyurl.com/y8p594jp>

2016/18 Revised PPIE Plan (17 pages)
<https://tinyurl.com/y942oe28>



Examples of how public contributors worked with CCF during 2016/17

INVOLVE Conference 2017 - update



The INVOLVE conference is taking place on 28th November 2017 at Church House, Westminster. See the INVOLVE website and the #INVOLVEat21 on Twitter for tweets about the conference.

Andy and Janet's story
<https://tinyurl.com/ycyhyag6>

Join Dementia Research
<https://tinyurl.com/o6esvw3>

I AM RESEARCH - our latest campaign
<https://tinyurl.com/ycvm5mle>

New Patient Research Ambassador stories
<https://tinyurl.com/yb8sjmng>

News from NIHR <https://tinyurl.com/yc58wo68>

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