

National Institute for Health Research (NIHR)–wide learning and development for public involvement : working group report and recommendations (2015)

This report makes recommendations for improving learning and development for public involvement in research. It documents the activities of a working group established in 2013 to initiate a discussion around leadership in learning and development for public involvement in research across the National Institute for Health Research (NIHR). The recommendations are aimed at the NIHR on a strategic and organisational level, as well as at researchers and research managers supporting public involvement.

The report and recommendations have been submitted to the Department of Health. Following a response, we will be exploring with others across the NIHR how best to address implementing the recommendations.

**Taking Stock: INVOLVE
Coordinating Centre**

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This report outlines some of our recent activities and achievements in supporting and promoting public involvement, working in partnership with our National Institute for Health Research (NIHR) colleagues and the public. It provides a broad overview and snapshot of some of our recent work (2013-15) and [our reach](#) in 2015. It also reflects on who we are working with and influencing.

No. of pages: 10

A game of science: The gamification of science literacy for hard-to-reach groups

Abstract: In a long-term project partnership between Manchester Metropolitan University and Parkinson's UK, we are developing a distinct kind of engagement activity. Instead of teaching the public about a research topic, we aim to give the public the tools they need to understand any area of science or health research they wish to engage with. By giving the public these tools we are approaching our aim – to develop a more informed audience – from a different direction to traditional public engagement projects.

Our workshops have been running for several years and have evolved in response to feedback. The workshop style allows the presenter to encourage participants to pull back a curtain and reveal how science is done. Through activities, participants are given opportunities to uncover the research cycle, understand peer review and the primary literature, and to have

a go at designing a study for themselves. The skills learnt in these sessions give the audience confidence to find out more about science and engage with research, and may encourage increased patient and public involvement.

Feedback from participants is now directing this project down a new path. We are developing a table-top game – the Game of Science – to teach how science, particularly medical research, is conducted and communicated. Importantly, the table top format of the game makes it suitable for social support groups and those who do not use a computer.

This poster describes the current game prototype and discusses our philosophy for public engagement with research.

[Download poster](#)

The Involvement Portfolio

Abstract: The Involvement Portfolio has been developed by the NHS R&D Forum Service User and Carer Working Group. It is a tool for those using health and social care services who are involved in voluntary or involvement activities such as consultation, committee membership, research and development, to record and provide evidence of their activities.

Many people using health and social care services are involved in a range of involvement and voluntary activities such as research, teaching and training. Much of this involvement goes unrecognised although the participants are gaining valuable skills and experience as well as contributing their experience and expertise. This tool allows people to record the skills and experience gained through involvement and voluntary activity as this can help with applications to undertake new

activity, for educational or vocational courses, or to find employment.

In the portfolio, the portfolio holder has the opportunity to record their employment or other experiences including those gained through voluntary activity, or life experience such as being a carer or a parent, training events and experience of leading or facilitating training, 'involvement activity' and experience including taking part in committees, in consultation events, in NHS or social care research and development, or in curriculum development for educational courses. The portfolio holder has the opportunity to record the involvement activity they have taken part in, the type and level of involvement, the skills learnt, and any qualifications gained.

The portfolio was successfully launched some years ago and has now been refreshed and re-launched taking into account the lessons learnt and experience of its use.

How can we use existing knowledge and evidence to facilitate patient and public involvement in a quality improvement programme?

Abstract: National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Northwest London facilitates a particular approach to healthcare improvement, with Patient and Public

Involvement (PPI) being a core part. We believe involving patients leads to more appropriate and long-lasting improvements. We've observed improvement teams benefit from a facilitated approach to develop patient and public involvement (PPI) practice.

Mechanisms already exist to support this approach, but there is a tendency to create new ones; either because people do not know previous ones exist, or they do not feel they work in a specific context. We were interested in how existing mechanisms can be adapted/adopted to work for healthcare improvement teams.

We introduced three items to these teams to strengthen their PPI practice:

1. an emancipatory framework
2. a set of national standards for involvement
3. a guide to support the assessment of impact in involvement.

We tested various adaptations of them, observing the impact the items had in supporting PPI become everyday practice in the various teams' specific contexts.

The poster will summarise:

- Why we selected the items
- What they aimed to achieve versus what actually happened in practice
- The extent which items support PPI to become part of everyday practice
- The impact of testing the items on their creators and facilitators
- Evidence that is already available
- Our process of adopting/adapting existing items into practice
- How to rapidly evaluate to improve implementation of PPI.

James Lind Alliance Priority Setting Partnerships: Involving patients to change research

Abstract: This workshop will enable delegates to understand the principles of the James Lind Alliance (JLA) and the ways in which Priority Setting Partnerships (PSPs) are established and conducted in order to influence research agendas.

Presenters will explore the motivation of different organisations for running PSPs. The experience of clinicians and patients in the PSP process will be described and discussed.

1. History and rationale of the JLA
2. Unique features of PSPs and their impact upon participants and sponsors
3. Specific examples of PSPs
 - Hips and knees
 - Mental health
 - Spinal cord injuries
4. Clinician and patient experience of PSPs
5. Using the outputs of PSPs for health research

As a result of attending this workshop delegates will be able to describe accurately to fellow patients and colleagues the opportunities that JLA PSPs offer.

To encourage discussion we will structure the latter part of the workshop by means of:

- small group discussion
 - responding to materials or questions
 - rotation of speakers with delegates
 - posing direct questions to delegates
 - recording questions for the future development of PSPs
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Give us the tools... – A toolkit for PPI designed by, with and for PPI people

Abstract: The cancer Consumer Liaison Group (CLG) is a national network of cancer patients and carers, and is an embedded part of cancer research structures in the UK.

The 13-year history of effective cancer patient and public involvement (PPI) by members of the CLG has challenged the terms “professional” and “lay”, and has prompted new models based upon the concepts of co-production and partnership working.

The core members of the CLG are expected not only to be “expert patients” but to offer a professional contribution to their committee or group. We review regularly the support we need to ensure that our individual and collective experience and expertise continues to have impact on and add value to cancer research.

During 2013 CLG members designed and piloted our own Toolkit to assist us in delivering the role of PPI representative in an effective manner, blending advice and guidance from external sources with our own tried-and-tested consumer-to-consumer tips and suggestions.

The Toolkit covers topics from trial design and development to dissemination and application of the findings. Themes include appraisal of trial applications for funding (relevance and recruitment), national portfolio management, and navigating the external resources that support the role of PPI rep.

The Toolkit is free to access. Designed by PPI reps for PPI reps in cancer, it has many aspects that are useful for anyone working at in any disease or condition at local or national level, and we hope to explore those aspects with our colleagues in other diseases to produce a generic version.

Inspire, encourage, support: Senior Investigators leading PPI in research

Abstract: National Institute for Health Research (NIHR) Senior Investigators are a network of approximately 200 pre-eminent researchers who represent the country's outstanding leaders of clinical and applied health and social care research. They are selected through a process of annual competition with advice from an independent expert panel.

Patient and public involvement (PPI) has been integrated into this selection process since its inception, with on-going support from INVOLVE. Applicants are asked for evidence of their PPI activities, PPI and patient/public benefit are criteria in assessing applications, and there is a public member on the expert panel.

With PPI embedded in this process, and an annual competition, we have a regular opportunity to review:

- What we could improve and why
- How we could deliver this improvement
- How we would know if this had made a difference
- We describe how we have worked together to address these questions.

The heart of our work, this year, is a new publication. Nothing that unusual. But both the content of this publication and its targeted dissemination supports our main ambition:

- To inspire, encourage and support researchers to integrate PPI into their careers – as researchers, capacity builders and ultimately as leaders.

We talk about this process from different perspectives including:

- What we have learned
- What distinguishes research leaders for PPI
- What we hope will change

We'll also invite people to identify PPI activities they are involved in that either have benefitted, or would benefit, from taking a similar approach.