

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.
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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

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.

Co-producing not just involving: The lessons learned from an emancipatory action research project into mental health recovery

Abstract: In the past ten years new policy drivers have emerged which extol the virtues of wider public and patient involvement in health research. It's been suggested that it has the potential to enhance the quality of research whilst also reducing waste of both time and money. This paper draws on the lessons learned from such a research project funded by the National Institute for Health Research to look at if there is a pathway to mental health recovery through care coordination.

The project sets out to explore not only this research question, but additionally the challenges and opportunities for mental health service users and carers to go beyond straightforward involvement to actively co-producing research with academics and other professionals. They have all worked and learned together within the project to design the questionnaires and interviews used, collected the data,

analysed the findings and disseminated the emerging themes. Along the way practical issues such as gaining ethical approval, obtaining honorary contracts, arranging researcher and participant payments have proved challenging. In particular how to recognise and value different expertise within the research group has been a focus for on-going discussion.

This paper will facilitate an honest exploration of this co produced work through the lived experience of those mental health service users and carers who became researchers within the project. The work will also offer a series of suggestions and principles for good research practice in this area.

Getting the ducks in line: Public involvement in research and organisational development

Abstract: The Quality and Outcomes of person-centred care Research Unit (QORU) is a Policy Research Unit funded by the Department of Health formally launched in January 2011. QORU aims to improve the health and social care of people with long-term conditions through research.

This paper describes the journey so far in ensuring that public involvement is embedded in the work of the Unit. The means developed to deliver this was through the establishment of a Public Involvement Implementation Group (PIIG) to develop, oversee and monitor the implementation of public involvement and the setting up of a group of lay research

advisors to support individual research projects. This initiative combines an over-arching planning function with practical elements to help move involvement forward. There are a number of key features. The PIIG is made up of researchers and the public working side by side to come up with solutions to issues. The Group has identified and piloted different ways to pro-actively connect with researchers. Twenty-five research advisors support a varied collection of research studies including economic evaluation, which has been considered a more challenging area to involve the public. It has been a mutually beneficial experience to share and learn from this public/researcher collaboration which was introduced across three universities where no existing systems for involvement were in place.

This exciting work is on-going and raises multiple issues for discussion including monitoring the consistency and representation of involvement, measuring impact and the resource implications of establishing a fully effective public involvement programme.

Memories on film: Using creative methods with seldom heard groups

Abstract: This presentation revolves around a screening of a short film produced during the course of research involving working alongside people with dementia to co-produce films about their lives and experiences. There will be discussion in the presentation focused on the use of creative methods with groups that are often less heard, with a particular focus on

the use of film, pictures, and song. All examples used are taken from the same project where we worked with people living with dementia, using an approach called Participatory Video. This approach concentrates on including people as much as possible in the research process, carrying out research with, rather than 'on', people. We want to show how pictures and film helped us to connect with the people with dementia we worked with, and how the chance to be involved in co-creating films gave them a sense of power and control – something that is often eroded following a dementia diagnosis.

During the presentation we will play audio clips from our work and one of the films produced during this project will be shown. 'Tally's Story' tells the story of a young woman brought up in care, who sprung into independence as soon as she could, powering into adult life on her bicycle.

In total, 10 films were made during the course of this project, and we will refer to several of the participants, including 'Tally', as we discuss our work.

Taking the pulse: An interactive workshop using the example of the National Cancer Patient Experience Survey (NCPES) to encourage

fairer access to research for all patients

Abstract: Our consumer-led project introduced questions about research to the annual surveys of 120,000 recently diagnosed cancer patients in England.

We will outline some of the findings from that work

- 33% report having had a discussion about taking part in research
- 95% of those asked were glad to have been asked
- 57% of those not asked would like to have been

We will summarise our analyses of patients' responses which point up

- inequalities in who gets asked
- variations in research awareness

We will debate and capture some of the questions that have emerged for us as a group of patients, researchers and policy staff working together on the findings and on the issues they raise for us.

Is 33% "good" in terms of access to research? How do we know? What's the benchmark? Should there be an ambition or target?

Participants in our consumer-led workshop will learn how PPI helped generate data to tackle inequalities and make for fairer access to cancer research.

Patients may have one view, clinicians and researchers another. We know the picture for cancer patients, but what is it for patients with other illness and conditions? We encourage participants to bring issues of their own – we want to introduce this agenda, not control it.

We will draw upon the key messages from our discussions to influence policy makers and those delivering services across the changing research landscape.

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