

Editorial briefing

Positive reporting? Is there a bias in reporting of patient and public involvement and engagement?

Welcome to this edition of Health Expectations. As we have stated in earlier editorial briefings (e.g. 18.6), we are paying much more attention to the role played by patients and the public in selecting and agreeing the research question, study design and methods, interpretation and discussion of study findings, and in dissemination of results. So this edition of HEX particularly reflects this.

In the UK, the National Institute for Health Research suggests that patients or service users can be involved in research in three ways, which are not mutually exclusive¹:

1. *Consultation* – the study is researcher-led but consultation with patients occurs about one or more elements of research development
2. *Collaboration* – patients and professionals occupying equal but different roles in all aspects of project work
3. *Patient/service user-led* – patients or service users lead research design and implementation of the research.

In *Going the Extra Mile*,² a series of key recommendations are made, with plans for implementation, to further develop patient and public involvement in research. The report draws on the ‘strengths of the models of public involvement developed in Canada and the USA include their focus on communities and their assiduous attention to maintaining a clear line of sight from research design and delivery to patient outcomes and experience’. A key phrase in the report is on page 2: ‘Public Involvement should be so embedded in the culture (of NIHR) that new staff or new researchers coming into

the field, would naturally take on the values and practices of effective public involvement’.

Shippee *et al.*³ describe a model for the stages of patient and service user involvement and engagement: preparatory, execution and translational, and propose a framework which provides a standard structure and language for reporting and indexing to support comparative effectiveness and optimize patient and service user involvement.

Tierney *et al.*, in this edition of HEX, report their review of service user involvement in research and service development highlight that most studies only reported positive outcomes, raising questions about the balance or completeness of the published appraisals. They conclude that ‘to improve normalization of meaningful involvement in primary care, it is necessary to encourage explicit reporting of definitions, methodological innovation to enhance cogovernance and dissemination of research processes and findings’. Tierney *et al.* remind us of the PIRICOM Review⁴ which reported negative impacts on patients involved in research, in terms of personal impact, skill levels and knowledge levels, and users feeling overburdened, not listened to and marginalized.

Fairbrother *et al.*, in this edition of HEX, describe involving patients in a feasibility study using a ‘patient panel’ approach, but refer to their consideration of the word ‘scrutiny’ to describe the function of their panel. They report that involvement in the panel was considered a positive experience by participants, although ‘challenges were identified in terms of the time and cost implications of undertaking patient involvement’.

Jinks *et al.*⁵ describe an on-going project which aims to describe and understand what the costs and consequences of patient and public involvement (PPI) in primary care research. This study has yet to report its findings, but a conference abstract indicates challenges in data collection.⁶ Boaz *et al.*, in this edition of HEX, report a qualitative study exploring researchers' attitudes to PPI and patient involvement in science (PES). They state that 'while participants demonstrated a range of attitudes to these practices, they shared a resistance to sharing power and control of the research process with the public and patients'. This resonates with the difficulty Jinks *et al.*⁵ report in asking researchers to identify patient/service users and inviting them to complete questionnaires to generate data for their study.

In a very recent article, Jinks *et al.*⁷ describe about how to sustain genuine PPI involvement, beyond time-limited commitment to a single research project. They stress the need for institutional support and suggest that the following are needed:

1. Strong and genuine academic leadership, alongside patient/service user representation within the governance structure of the research institution, to ensure that lay people are fully supported and feel valued, and to maintain awareness amongst researchers of the importance of PPI in their work.
2. Clear organizational commitment in terms of appropriate resourcing of PPI through core funding and including realistic costings in all research proposals.
3. Creating a PPI infrastructure with dedicated staff to support lay people and to work with researchers in order to optimize effective relationships with those individuals.

In conclusion, patient involvement and engagement is advocated, and indeed, most funding bodies demand it.^{1,2} Attempts have been made to describe frameworks or models to conceptualize PPI; and while there is an increasing

awareness of the challenges of PPI in high-quality research, as Tierney reports, there remains a positive bias in that most studies report positive outcomes for their PPI activities.

We would like to encourage authors to report impact of PPI on studies in their submissions to HEX – and tell it how it is.

Carolyn Chew-Graham*†

*Professor of General Practice Research, Research Institute, Primary Care and Health Sciences, Keele University, Staffordshire, UK and †Honorary Professor of Primary Care Mental Health, South Staffordshire and Shropshire Healthcare NHS Foundation Trust, Staffordshire, UK

References

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- 2 <http://www.nihr.ac.uk/documents/about-NIHR/NIHR-Publications/Extra%20Mile2.pdf>, accessed 04 April 2016.
- 3 Shippee N, Garces JPD, Lopez GJP *et al.* Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expectations*, 2013; **18**: 1151–1166.
- 4 Brett J, Staniszewska S, Mockford C, Seers K, Herron-Marx S, Bayliss H. *The PIRICOM Study: A Systematic Review of the Conceptualisation, Measurement, Impact and Outcomes of Patients and Public Involvement in Health and Social Care Research*. Royal College of Nursing Research Institute (RCNRI), 2010. <http://www.ukrcr.org/wp-content/uploads/2014/03/Piricom+Review+Final+2010.pdf>, accessed 16 April 2016.
- 5 <http://www.spcr.nihr.ac.uk/PPI/rp/case-studies-final-November-website.pdf>, accessed 04 April 2016.
- 6 <https://sapc.conference-services.net/reports/template/onetextabstract.xml?xsl=template/onetextabstract.xml&conferenceID=3890&abstractID=854975>, accessed 04 April 2016.
- 7 Jinks C, Carter P, Rhodes C *et al.* Patient and public involvement in primary care research – an example of ensuring its sustainability. *BMC Research Involvement and Engagement*, 2016; **2**: 1.