

### Are PPI strategic documents helpful?



Attempts to bring health and care (medic, public and social) research closer with the public has been on NHS's agenda since early 2000s. Under the 'patient and public involvement' (PPI) initiative, the National Institute for HealthResearch (NIHR), the largest funder of health and care research in the UK, is committed to align research more closely with patients' and the public's needs thus increasing success and cost-effectiveness. To provide the necessary mechanism, numerous strategic documents were (and still are being) developed by the organisations. A recent study looked into how helpful those documents really are and found that there was large area for improvement.

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## The Five Principles of Analysis

In 'How helpful are Patient and Public Involvement strategic documents – Results of a framework analysis using 4Pi National Involvement Standards', Matthews and colleagues (2019) looked into PPI strategic documents from the perspective of openness and transparency they are supposed to bring in the dialogue with the wider community. The authors noted that the absence of documentation itself could be interpreted in a negative way, as an unwillingness of organisations to communicate with the public.

Applying an adapted 4Pi National Involvement Standards framework, the study analysed 15 documents from different healthcare organisations, among which were 4 Acute Care Providers, 6 Clinical Commissioning Groups, 1 Community Healthcare Provider and 4 'Others' (ie ambulance, research and education). The focus was on how those documents were presented and organised against five domains of principles, purpose, presence, process and impact.

In the resulting matrix the comparisons could be performed either across domains or across organisations. Neither had any discernible pattern, although the levels of meeting the criteria varied. Thus, no single document addressed all five domains of 4Pi; only one organisation partially met the criteria for all domains; while 10 were unable to meet the criteria in at least one domain.

### **Identified Complexities**

According to the authors, it would be difficult for a potential reader to find and comprehend the 'why' (strategic aim) and 'how' (plan of action) of involvement. Mostly, dense language and insufficient accessibility of content were behind this complication. Although some of the documents exhibited attempts to use Plain English, managerial and technical language with jargon and acronyms still dominated the sample. Details on who was to be involved were often absent, as was a clear explanation regarding NHS or organisational structures.

It was found that only 8 out of 15 documents fully met the purpose domain of 4Pi, which means that the rest lack a clearly defined purpose. Out of the sample, 6 documents did not meet the impact criteria, while only 2 did fully. The authors pointed out the possible logical interlink between these two domains highlighting that different approaches (eg emancipatory and instrumental) assign different value to these domains.

This lead to conclusion that the ways in which PPI was rationalised were confusing. Strategic aims were not clearly expressed in the documents, while the complexity of language and content made it difficult for a lay stakeholder to be involved. As a result, sharing of generalisable knowledge became elusive and there was still a gap between the theory and practice of involvement. This, according to the authors, "explains a commonly expressed frustration in the field when attempting to answer 'why' we should involve and difficulty in describing 'how' to do it" in order to achieve meaningful results in improving both care and research.

### QI as a Possible Approach

In search for as an alternative, the study turned to <u>quality improvement (QI) approach</u>. Particularly, it looked into the possibilities of programme theory generation and action effect method application. The authors suggested that this would introduce a structured approach to continual testing and learning from practice by better identifying and practically testing the 'why', 'what' and 'how' aspects of PPI.

# Patient and Public Involvement and Engagement Strategy

### The NIHR's strategic aims are to:

- Raise awareness of research and opportunities for involvement.
- Create a pool of interested parties (patients, carers and the public).
- Provide training and resources for all the parties to work together.
- · Reach out to community groups and health services.
- Make patient and public involvement a necessary element of the research.
- Analyse the experiences of the people involved and explore the consequent changes.

#### References

Matthews R, Kaur M, French C et al. (2019) How helpful are Patient and Public Involvement strategic documents – Results of a framework analysis using 4Pi National Involvement Standards. Research Involvement and Engagement, 5:31. Available from <a href="https://www.biomedcentral.com/epdf/10.1186/s40900-019-0164-0">https://www.biomedcentral.com/epdf/10.1186/s40900-019-0164-0</a>

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Published on: Tue, 12 Nov 2019