

Evaluation of the impact of Patient and Public Involvement on cancer nursing doctoral study exploring cancer survivors' experiences of living with chronic post cancer treatment pain

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Background

Patient and Public Involvement (PPI) can help shape research. It is important to capture the impacts that Public Contributors have on cancer nursing doctoral research.

Methods

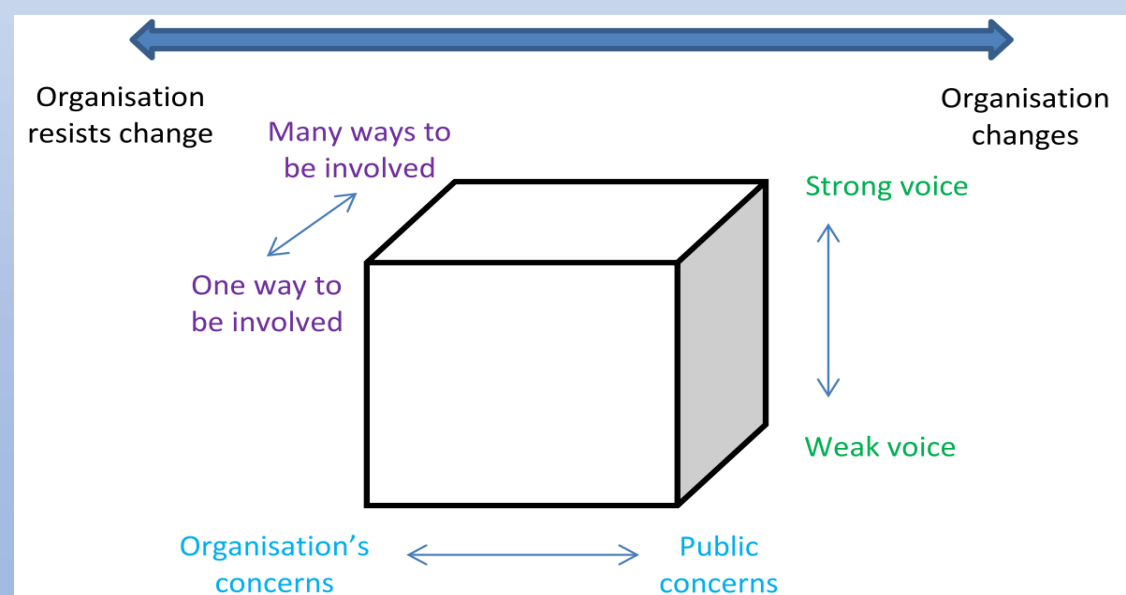
Two Public Contributors, who are cancer survivors living with chronic post cancer treatment pain, worked alongside a doctoral researcher as part of the PhD project team. To capture the impact of their contribution, the full team participated in a 'CUBE' workshop. The 'CUBE' framework uses different forms of knowledge within a 'knowledge space' and incorporates 4 dimensions (table 1). Team members ranked involvement on a continuum for each dimension (figure 1). This was then discussed in a workshop facilitated by a 'CUBE' expert external to the PhD team.



Table 1: The four key dimensions of a knowledge space (Gibson, Welsman and Britten, 2017)

Dimension	Explanation
Weak voice or strong voice	Strong voices discuss issues and influence decision-making. Weak voices may discuss issues, but have little influence on decision-making
One way to be involved or many ways to be involved	Knowledge can take on different forms, which may not be equally valued. A single involvement approach is likely to privilege one social/cultural group over another, thus perpetuating inequality.
Organisation's concerns or public concerns	Public concerns are in the context of social action, e.g. public opinion, norms and values, as well as individual experiences and behaviours. Organisation's concerns are, e.g. bureaucracies and markets.
Organisation changes or organisation resists change	Decision-makers' willingness and ability to respond to issues raised by participants in knowledge spaces depend on contextual factors, e.g. economic resources and national policies

Figure 1: The four dimensional 'cube' depicting a knowledge space (Gibson, Welsman and Britten, 2017)



Findings

- PPI had many impacts on the research including inclusion of GP letters, interview scheduling, wording of patient facing documentation and settling researcher apprehensions regarding term 'cancer survivor'.
- The 'CUBE' evaluation demonstrated consensus among team regarding PPI impact within the dimensions.
- Prior to the workshop, the Public Contributors had not realised the degree of impact they had had on the research and the value attributed to their impact by the researcher.
- The workshop provided opportunity to acknowledge successes and reflect on challenges.

"The way I am treated by professionals and other PPI is very important. If listened to and encouraged, as has been the case here, my voice continues to be strong. If the opposite happens, my voice can definitely be weakened" (Public Contributor)

"Public contributors have been used effectively in shaping the research design and in managing the conduct of studies" (Supervisor)

"(The research) has changed as a result of our input, but more important has always been open to change. This is extremely important. If the professional is resistant to change or appears disinterested, then the PPI engagement and involvement will start to decrease" (Public Contributor)

Conclusions

Evaluating the impact of Public Contributors and PPI on research provides important opportunity to articulate impact and appreciation of Public Contributors and address any challenges or misunderstandings.