

From social theory to social practice: understanding patient and public involvement in health services research

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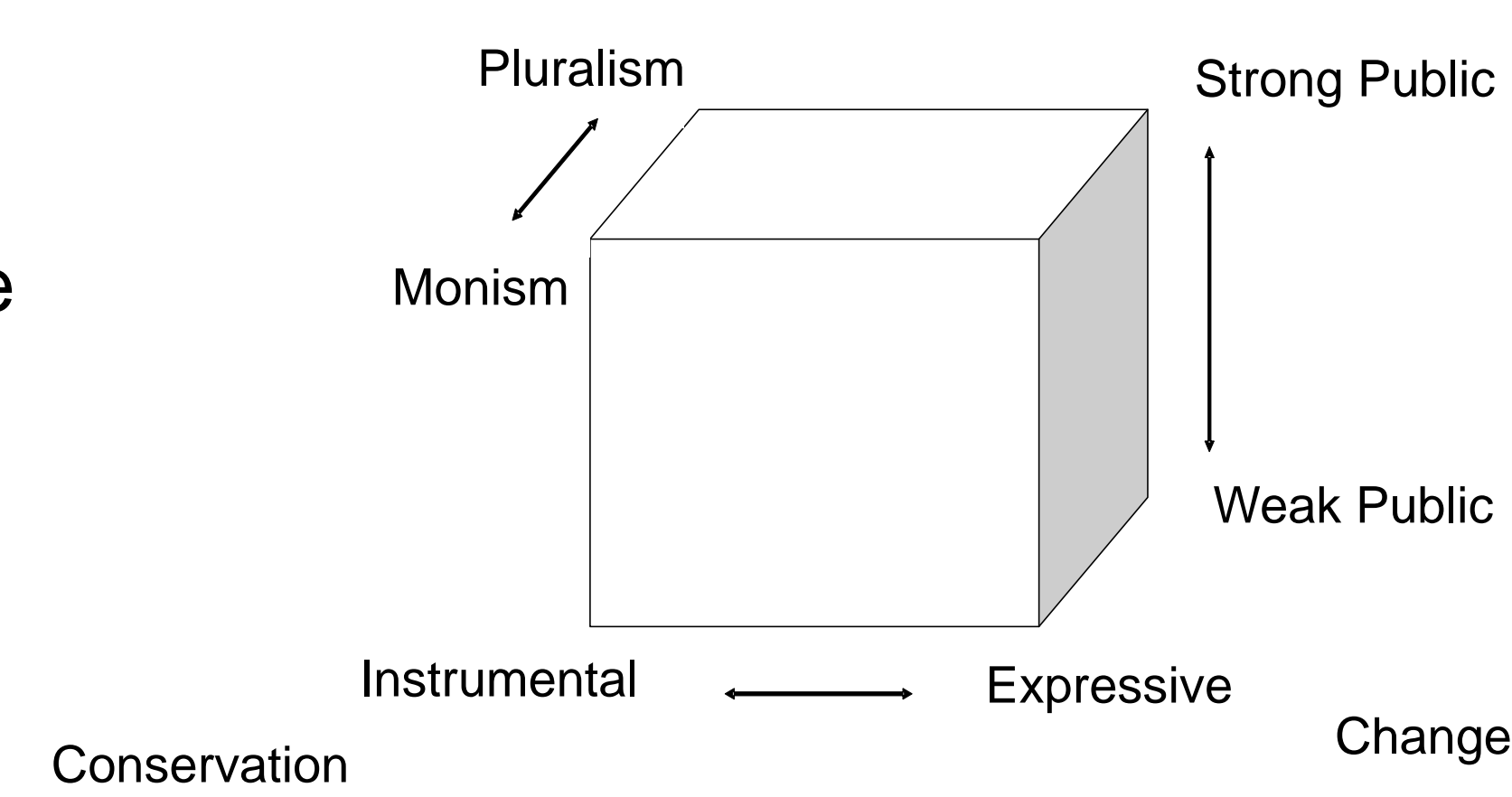
Abstract

Increasingly, citizens are challenging scientific expertise relating to health and medical treatment and are demanding involvement in research processes. In the resulting interactions between academics, clinicians and the public, traditional boundaries of expertise blur and new 'knowledge spaces' are formed. This poster describes how a four dimensional theoretical framework for understanding public involvement in research was turned into a practical workshop to generate visual representations of 'patterns' of public involvement within a knowledge space. These diagrams represent a starting point for conversations between stakeholders about any barriers to public involvement in research and how future involvement might be facilitated.

1. The Theory

Drawing on the work of social theorists, Gibson et al., (2012)** identified three dimensions, conceptualised around a cube (Fig. 1), that might be useful to understand aspects of patient and public involvement. These are illustrated in Fig.1 along with a fourth, overarching dimension which relates to the ability of an organisation to change in response to public concerns.

Fig 1 The original Cube



2. Theory into practice

An initial workshop was run with the PenCLAHRC "in house" patient and public involvement group (PenPIG). Participants used sticky arrows to individually "score" where they felt they sat along each of the four dimensions Fig. 2 illustrates the dimension "weak to strong voice".

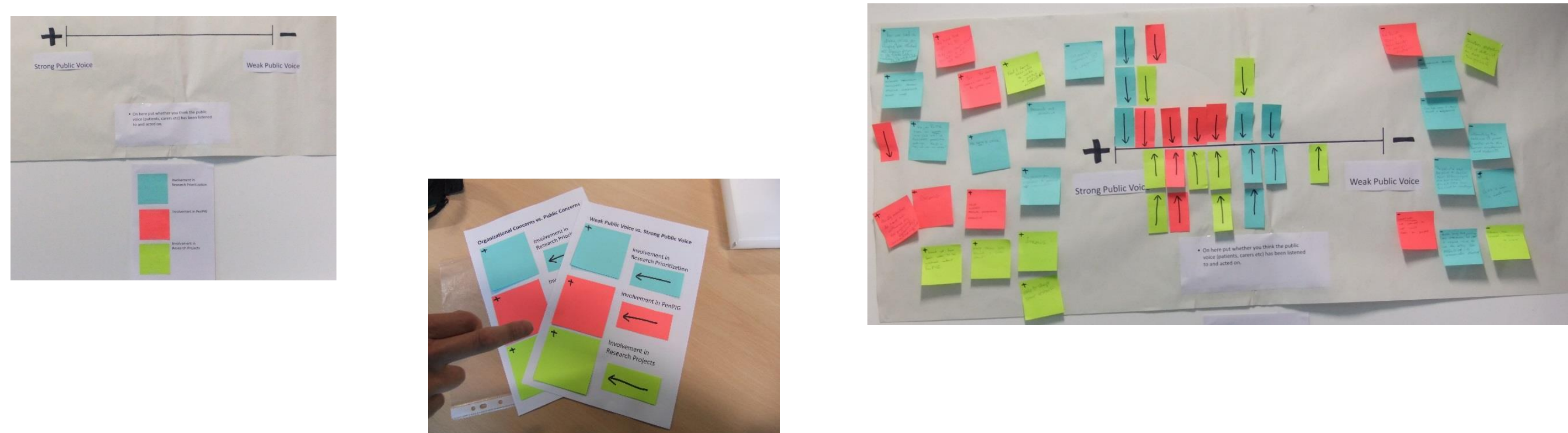


Fig. 2: Materials used to measure participants' ratings along the dimension "weak to strong voice"

Three involvement activities were rated: PenPIG within PenCLAHRC (pink), involvement in research projects (yellow), and involvement in the PenCLAHRC research prioritisation process (blue). Qualitative comments to support ratings were written on sticky notes and grouped according to whether relating to a strong or weak voice.

4. Mapping Involvement

Collating the information collected in the workshops into a single diagram that captured individual responses proved a challenge which was solved using the cross illustrated in Fig. 4. The four dimensions are aligned such that a relatively "weak" group will show responses clustered towards the centre, whereas a "stronger" group will cluster further from the centre. The larger the symbol the more individuals rating at the same point..

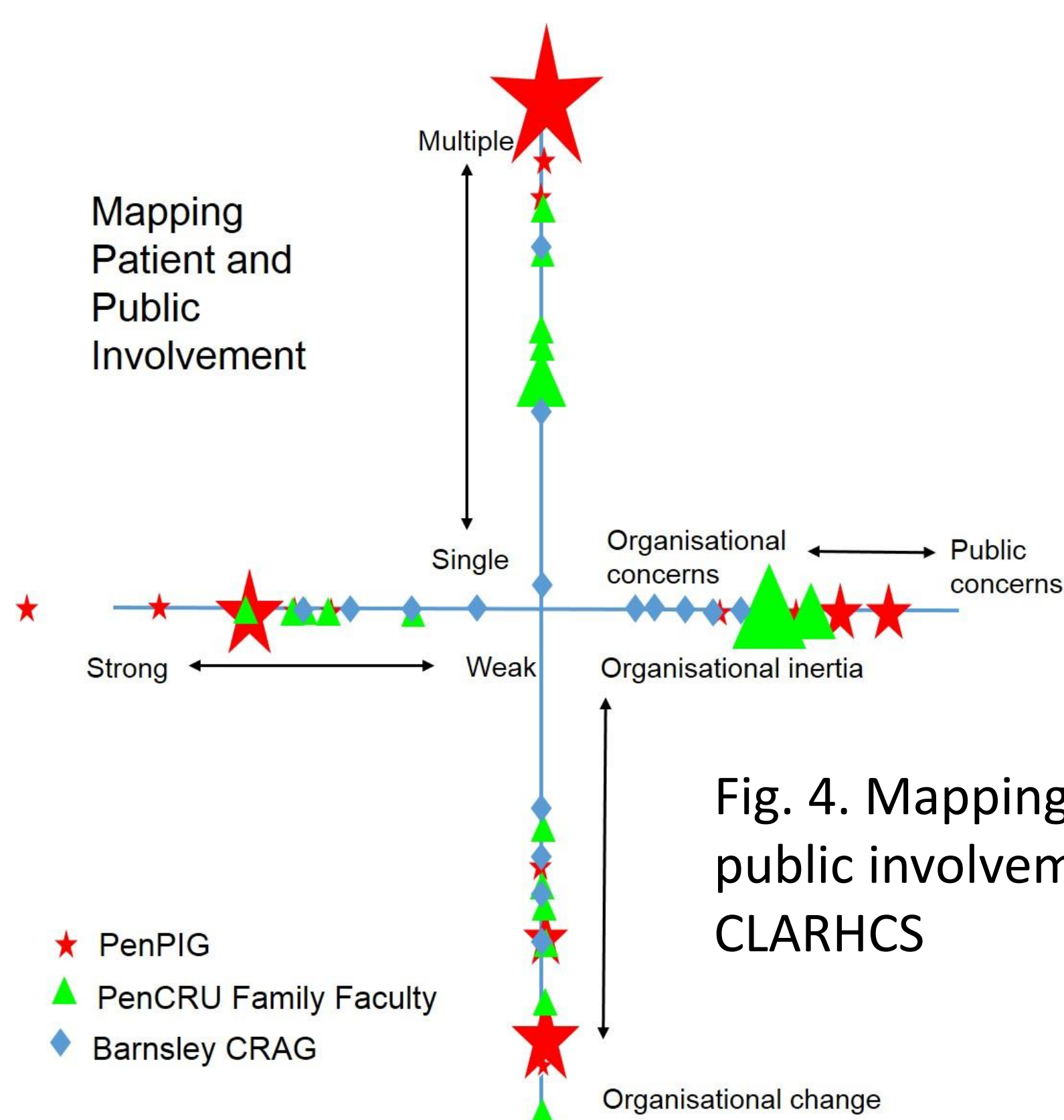


Fig. 4. Mapping the involvement of 3 public involvement groups working with CLARHCS

3. Feedback from participants

The language used on the cube dimensions was simplified for clarity (Fig. 3). For the posters used in the workshops (see Fig 2), tick marks were added to the dimensions to guide responses and positive and negative symbols removed as participants found these confusing.



Feedback!

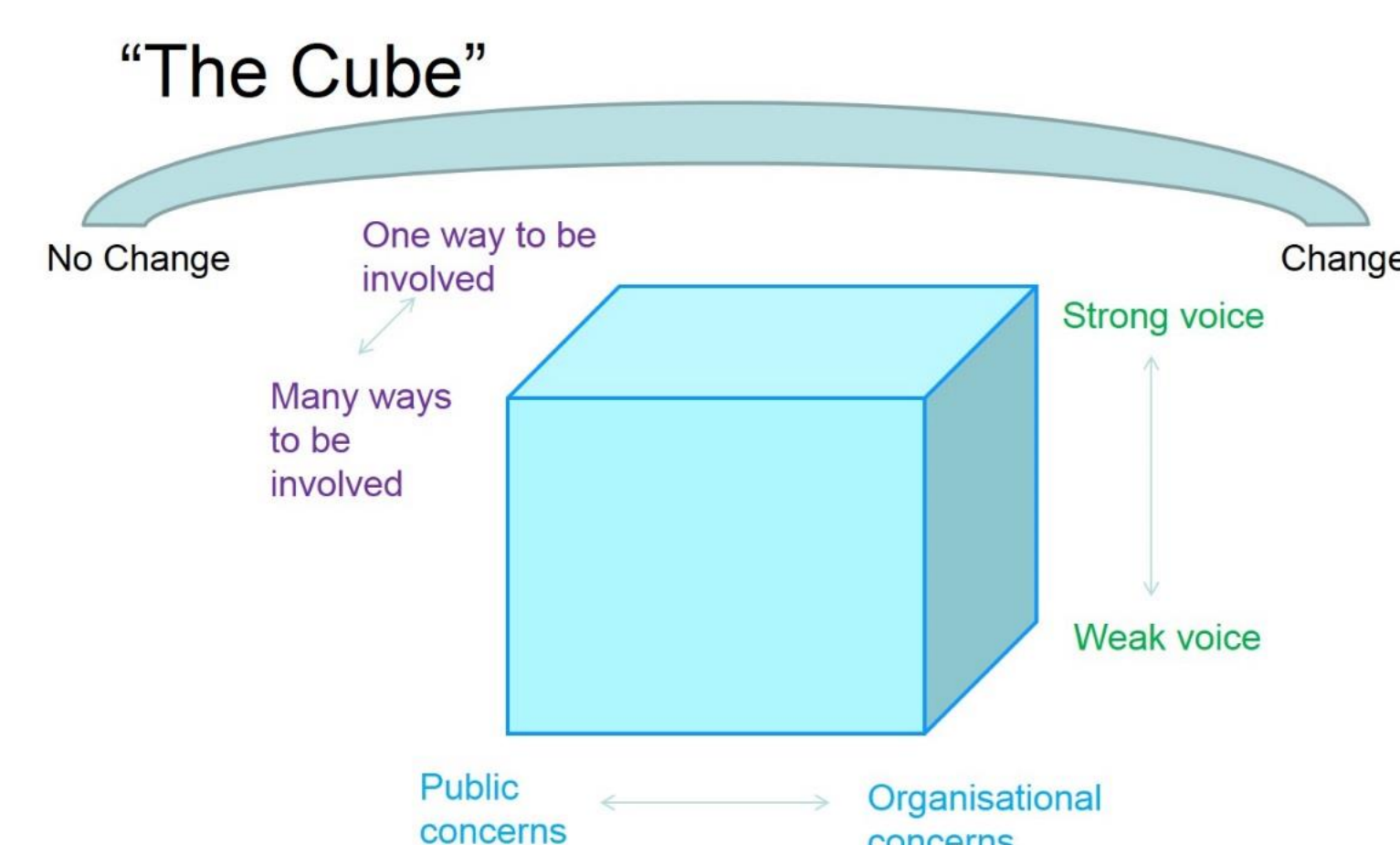


Fig. 3 Modified cube

Subsequently, further workshops were run with two more public involvement groups PenCRU*** family faculty - parents of children with neurological disabilities, and Barnsley Consumer and Research Advisory Group (CRAG) – based at Barnsley Hospital..

5. Results of the workshops

Fig. 4 shows how the three groups mapped their involvement. PenPIG is a well established group, with consistent membership, whose involvement is embedded throughout the work of PenCLARHC. Their responses clustered towards the extremities of the four dimensions. The PenCRU Family Faculty has a larger membership base from which members participate in projects according to availability and relevance. Their responses were more spread across the dimensions with any clustering around the mid points. Barnsley CRAG, the smallest of the groups studied, exists to support the work of the local NHS and, at the time, were co-opted to provide PPI support for South Yorkshire CLAHRC. Of the three groups, their responses were the most diverse and spread along each dimension.

Summary

The theoretical model successfully translated into a practical workshop. Participants particularly liked the immediacy with which group responses could be observed. The discussions around involvement issues the workshops stimulated were valued by both group members and PPI team staff, and provided useful directions for supporting and improving future public involvement opportunities.

*Gibson, A., Britten, N. and Lynch, J. Theoretical directions for an emancipatory concept of patient and public involvement. *Health*, 16:531-547, 2012

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