

Submission Id: 5337

Title

Creating and maintaining participatory space to share organisational decision making with patients in family practice

Priority 1 (Research Category)

Participatory research

Presenters

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Abstract

Context: Patient involvement in health care design is recognised as important internationally. Health policy cites the moral rationale for involving patients, but also claims involvement will result in more patient centred services, despite little evidence of the mechanism to achieve this.

Objective: To co-design and evaluate an intervention aiming to strengthen patient involvement in family practice.

Study Design and Analysis: Participatory action research study with a co-research group comprised of seven patients, one family physician, and a researcher. Qualitative analysis of observational notes of six intervention meetings and one-to-three follow up meetings; meeting documents; and semi-structured interviews with eight patients and six staff members. Data co-analysis used both an inductive and deductive approach drawing on normalisation process theory.

Setting: Two English general practices.

Population Studied: Staff and patients volunteering in family practice patient groups.

Intervention: Four facilitated meetings, using participatory methods to address power; a bespoke survey to address demographic legitimacy; training focused on representational legitimacy; and a further facilitated meeting to develop an action plan.

Outcome Measures: The work required to create and maintain participatory space in which shared decision making happened.

Results: All actors worked continuously to understand the space; commit to the space; work in partnership within the space; and appraise the space. The intervention changed the space, providing meaning, a credible and legitimate task to structure the space, and facilitation skills and participatory methods to promote tacit relationship building. However, some changes to the space were not maintained due to the lack of communal appraisal which failed to make the work visible and valuable.

External interconnected spaces, the organisational culture and wider society, influenced actors' agency to create and maintain the participatory space. The participatory space also affected the practice space, opening up possibilities for future patient influence.

Conclusions: Inclusive, equitable, and safe participatory space is a prerequisite for authentic patient involvement in organisational decision making. The skills and resources to support this work are not routinely found in family practice organisations. This needs urgent attention to increase transparency and avoid eroding public trust in family practice.