Understanding and measuring the effects of patient and public involvement: an ethnographic study

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Abstract

Background In the UK, involving patients and the public in health-care service improvement and research is a policy requirement. Yet, showing the effects of patient and public involvement (PPI) is complicated by an absence of clarity about what involvement or engagement actually is, or what successful PPI might look like. We examined the case of a UK public health-care improvement initiative (Collaborations for Leadership in Applied Health Research and Care for Northwest London [CLAHRC]) to investigate how PPI was put into practice. We focused on how patient and professional roles developed over time and drew lessons from this about key areas for future assessment of PPI effects.

Methods We did a 4-year ethnographic study, using participant observation of PPI activities run by CLAHRC (160 h) and in-depth interviews (n=89), 45 with patient participants (ie, patients and service users involved in CLAHRC improvement projects) and 44 with health-care professionals involved in implementing PPI. Activities reported included monthly meetings in which teams of health-care professionals and patient participants met to work on health-care improvement projects, events run by CLAHRC to facilitate learning about quality improvement methods and PPI, and steering groups in which patients participated in organisation of these events or discussed the overall strategy of the CLAHRC programme. All interviews were audio recorded and transcribed. Findings were recorded in fieldnotes. We used a grounded theory approach that consisted of a process of systematic comparisons across the interview and fieldnote data to generate, review, and refine themes. This approach involved an iterative process of collecting and analysing data by which leads emerging from analysis led to new data collection.

Findings At first, health professionals demanded evidence of PPI effects of the type typical in clinical practice, such as cost-effectiveness data, treating PPI as a discrete intervention to improve a specific health outcome. They often spoke about effect in linear terms, focusing on individual participants; for example, patient input leads to improved clinical knowledge, which in turn leads to better health outcomes. Even so, they also measured their own PPI success using indicators such as successful participant recruitment and retention or tangible non-health outputs (eg, leaflets codesigned with patients), rather than changes in health outcomes. Patients added complexity by acting outside the official remit of their participant role. For instance, they facilitated collaboration within and between clinical teams and engaged powerful decision makers to ensure interventions were sustained. Patients talked about their own contributions in collective and utilitarian terms: they were reluctant to attribute success to individuals, emphasising the role of the team. For them, effect meant timely (and rapid) implementation of incremental changes in health care, which were then sustained and improved upon through collaborative relationships between patients, clinicians, researchers, and others. Staff gradually focused more on creating environments conducive to patient collaboration, and less on calculating the effect of individual contributions as time went on. They increasingly described PPI success in terms of collaborative relationships between diverse patients and professionals, and acknowledged the importance of unpredictable positive effects of patient innovations.

Interpretation The effect of PPI is not captured in simple quantification of PPI elements (eg, patients reached, outcome measures improved). To define and assess the effects of PPI, we should take patient voices into account, and track the dynamic social processes and networks through which PPI contributes to health-care improvement. We present a framework for future assessment of PPI effect: how, whether, and when patient input is integrated into projects; level of sustained and expanded collaborative relationships created via PPI; changes in working relationships between multidisciplinary professionals; presence of new patient-led projects; institutional investment in PPI; and patient engagement in service improvement and self-care.

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Contributors
CM designed the study. AR collected and analysed the data. CM and AR wrote the abstract.

Conflicts of interest
We declare that we have no conflicts of interest.