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Patient and Public Involvement in Healthcare Quality Improvement: How organizations can help patients and professionals to collaborate

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Abstract

Citizens across the world are increasingly called upon to participate in healthcare improvement. It is often unclear how this can be made to work in practice. This 4-year ethnography of a UK healthcare improvement initiative showed that patients used elements of organizational culture as resources to help them collaborate with healthcare professionals. The four elements were: (1) organizational emphasis on non-hierarchical, multidisciplinary collaboration; (2) organizational staff ability to model desired behaviours of recognition and respect; (3) commitment to rapid action, including quick translation of research into practice; and (4) the constant data collection and reflection process facilitated by improvement methods.

Key words

Patient and public involvement (PPI), quality improvement, organizational culture, healthcare, community participation

PATIENT AND PUBLIC INVOLVEMENT IN HEALTHCARE QUALITY IMPROVEMENT

How organizations can help patients and professionals to collaborate

Alicia Renedo, Cicely Alice Marston, Dimitrios Spyridonidis and James Barlow

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INTRODUCTION

Citizens worldwide are increasingly called upon to participate in healthcare quality improvement. Yet how involvement should be facilitated is often unclear. In the United Kingdom, patient and public involvement (PPI) has become a policy requirement and a key official strategy to put patients at the centre of quality care (Department of Health 2008).

Despite the fact that healthcare organizations are crucial in forming the backdrop against which these initiatives are played out, the role of organizational contexts in supporting PPI is rarely analysed (Abelson et al. 2007). Policy and academic discussions of public involvement frequently refer to the need for patients and professionals to collaborate in improvement, and the 'empowerment' that this may require (Department of Health 2008; Mockford et al. 2012; Stevens et al. 2003).

We know that elements of the culture of the organization where PPI takes place (e.g. commitment and attitudes to PPI of key staff, shared constructions of representativeness or of the role of patient participants) are crucial for the success or failure of PPI efforts (Abelson et al. 2007, 2010; Contandriopoulos 2004; Renedo and Marston 2011). Yet the mechanisms through which these or other elements of the organizational culture can become resources for patients in their participatory role – the ways organizational cultures mediate patients' 'empowerment to participate' (Cornish 2006: 301) – remain unexplored.

Bringing together patients and professionals into real collaborative relationships is challenging (Martin and Finn 2011; Rutter et al. 2004). Consultative rather than partnership approaches are common (Rutter et al. 2004), replaying divisions and asymmetries between healthcare professionals and patients (Martin 2008b). A history of negative consultative experiences can leave members of the public feeling mistrustful of official attempts to involve them (Abelson et al. 2007). A growing sense of public disillusionment with PPI initiatives (Beresford 2002) and consultation fatigue (Cook 2002) are key challenges in sustaining collaborative relationships (Rutter et al. 2004). Healthcare professionals are also often wary of PPI: many question the legitimacy of participants' lay knowledge, query whether or not participants are 'representative' of the wider patient population (Martin 2008a; Renedo and Marston 2011), or suggest participants' skills are inadequate (El Enany, Currie, and Lockett 2013).

Efforts to improve public involvement often emphasize the 'technicalities of participation' such as training (Oliver et al. 2001; Thompson et al. 2009), which typically focus on improving participants' skills and technical knowledge so that they can contribute better (e.g. be more articulate, able to 'represent') or on trying to help professionals engage patients and garner public interest in improvement. A large number of guidelines and training programmes have been developed (Gibson, Britten, and Lynch 2012), and healthcare professionals can help educate patients (El Enany, Currie, and Lockett 2013) while patients actively seek legitimacy through such professionalization processes (Thompson et al. 2012).

Yet while we know that organizational culture can be vital (Rose et al. 2002), previous studies have not examined how the elements of organizational culture that are important to patients might work to mediate success.

In this article, we examine the ways patients use specific elements of the organizational culture of PPI as resources for their involvement in quality improvement work (i.e., initiatives that use systematic approaches to make changes in service provision to improve patient outcomes and experience; Øvretveit 2009)). We ask: What elements of organizational culture facilitate PPI, and through what processes does this facilitation occur?

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THEORETICAL FRAMEWORK

Public participation in healthcare improvement involves new types of practices and relationships between patients and professionals. Conventional, hierarchical, forms of doctor–patient interactions and communication that characterize clinical encounters need to be adjusted to allow collaborative practices to emerge. Healthcare professionals can be apprehensive of this new way of working as it can require a shift in the balance of power and hierarchy of knowledge (e.g. changing status of professionals' biomedical expertise versus patients' lay/experiential knowledge) (Beresford 2007; Thompson et al. 2009).

According to Zittoun (2006, 6), significant changes in an individual's socio-cultural and relational environment (e.g. war, child leaving home) or a move into a new sphere of experience (e.g. starting a new job) can create 'ruptures' in his or her existing systems of knowledge, habits, and self-definitions. Ruptures create a need to confer meaning on the new experience, redefine identities, and create new understandings, so that new ways of acting can emerge (Zittoun 2006). The process of transition that follows a rupture is facilitated by the use of 'symbolic resources' (Zittoun 2006, 102). 'Symbolic resources' are cultural elements – systems of values and rules, rites, or artefacts such as books and songs – which individuals appropriate from their social environment in order to work through ruptures (Zittoun 2006). These cultural elements become symbolic resources when people actively use them as semiotic (meaning-making) devices that help them make sense of new experiences and respond to the unfamiliar demands of new environments (e.g. manage new relationships) (Zittoun 2006). Zittoun provides the example of a young religious man moving from a rabbinic school to a secular University. This man, Zittoun says, might mobilize non-religious literature to confer meaning to his new situation, using the book's narrative and its characters as metaphors for making sense of his new role (Zittoun 2006). He might also draw upon the meanings contained in the University's institutional ethos to support this process. For this young religious man, the book and institutional discourse can offer him ways to think about his relationship to others in his new field of

experience, and ways to think about forms of conduct that will help him function in the new situation (Zittoun 2006). For Zittoun, symbolic resources are not only employed to facilitate internal changes in the individual (i.e. development) but also to 'act upon his or her interpersonal, material and symbolic surroundings' (Zittoun 2004, 1–2). That is, when these cultural elements are used by the individual to function in the new sphere of practice, they become resources for action and development (Zittoun 2006).

We use Zittoun's ideas in this article to inform our empirical data analysis of how patient participants come to think and act in the new sphere of experience of the organizational culture where PPI takes place. For patients, entering the new sphere of experience of healthcare improvement involves becoming involved in a new culture and requires change: they must make a transition from being mere 'users and choosers' to being 'makers and shapers' (Cornwall and Gaventa 2000, 50) of health services. In this transition, patients adjust to the demands of the new cultural environment, in which they must think and act differently from before. Drawing on new skills or on other behavioural repertoires available to them from experiences from elsewhere becomes crucial. The ways in which cultural elements of this new sphere (e.g. organizational rules, underlying principles and philosophy of the quality improvement culture of the organization and its methods) mediate these changes is our key focus. Our conceptual framework highlights the processes by which patients appropriate elements of organizational culture and mobilize them as symbolic resources to make sense of their role and facilitate their involvement. Using this framework, then, allows us to examine how elements of organizational culture that are important to patients might mediate success of PPI initiatives.

ORGANIZATIONAL CONTEXT OF THE STUDY

We conducted this study within the CLAHRC for Northwest London (CLAHRC NWL), one of nine 'Collaborations for Leadership in Applied Health Research and Care' (CLAHRCs). Worldwide, there have been various 'translational initiatives' to try to ensure research is put into healthcare practice (Currie, Lockett, and El Enany 2013, 27); CLAHRCs, based in England, are one such initiative. CLAHRCs were funded for 5 years by the National Institute for Health Research to build collaborative partnerships between universities and their surrounding NHS organizations in England in order to develop and test innovative ways to improve healthcare. Each CLAHRC developed its own strategy for improving care, according to how each conceived the specific 'translation gap' problem (Currie, Lockett, and El Enany 2013, 27). CLAHRC NWL uses specific quality improvement methods to 'translate' research into practice (e.g. using 'Plan-Do-Study-Act' cycles and sustainability models (Langley 1996) to implement and test changes in care).

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CLAHRC NWL's original vision was that PPI in quality improvement should become normal practice across its local healthcare context within its 5-year lifespan. CLAHRC NWL funded, trained, and supported individual project teams of 8–10 multidisciplinary frontline staff from NHS organizations to carry out quality improvement initiatives. Teams had to learn about and use CLAHRC NWL's quality improvement methods to plan and test small changes in care, including involving patients as team members, and generally operate in line with CLAHRC NWL's overall ethos (e.g. translating research into better care, multidisciplinary collaborative team working, routine collection of data to develop and gradually improve on their original ideas).

At the heart of CLAHRC NWL's organizational culture was a model of iterative development. In this approach, learning and reflection run alongside continuous data collection and measurement of the teams' improvement initiatives. CLAHRC NWL modelled these same approaches (i.e. used the same PPI and quality improvement methods it advocated for project teams) to inform and improve its own managerial practices, including involving patients in deciding on strategy, and using quality improvement methods to reflect on and develop its support for projects.

CLAHRC NWL introduced 'Collaborative Learning Events' – a regular training programme – for teams, including patient participants, to learn about quality improvement and PPI, and to exchange experiences. As the programme evolved CLAHRC NWL increasingly emphasized PPI as a key means to achieve improvements in care.

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METHODS

This research is part of a larger ethnographic study examining the PPI activities of CLAHRC NWL. We used an ethnographic approach, examining PPI activity both at CLAHRC NWL programme level and at small project team level. Here we draw on (1) in-depth 60–120 minute individual interviews with twenty 'patient participants' – patients or carers involved in CLAHRC improvement projects – conducted between September 2010 and November 2012; and (2) 132 hours of observation of PPI activities run by CLAHRC to examine how PPI was organized and enacted in practice between September 2010 and January 2013. Observation included, for example, monthly meetings where teams of healthcare professionals, researchers, and patient participants came together to work on their healthcare improvement projects, events run by CLAHRC to facilitate learning about quality improvement methods and PPI, and steering groups where patients participated in discussions about the overall strategy of the CLAHRC NWL programme. Following Emerson, Fretz, and Shaw (1995) our observations focused on processes and practical aspects of participation: What actually happens when people participate? What type of actions do patients engage with as part of their participation? What is the nature of professional–patient interactions?

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All interviews were audio-recorded and transcribed verbatim. Interviews covered general experiences of PPI in healthcare improvement, and interviewees' participatory pathway into CLAHRC (e.g. how they started participating, their PPI experiences in other settings, and how these linked to their involvement in CLAHRC). Observations were recorded in field notes.

We analysed interview transcripts and field notes using iterative thematic analysis (Attride-Stirling 2001) to identify key themes in interviewees' experiences of becoming involved in improvement work. The coding frame reflected our a priori interest in the theoretical concepts of transition and symbolic resources, and was also developed inductively from the entire data set. The frame helped categorize data in terms of the cultural (e.g. PPI-related values), social (e.g. interpersonal relationships, organizational practices), and psychological (e.g. self-understandings as participants) aspects of PPI (e.g. codes included 'learning through participation', 'trusting professionals', 'reflecting upon oneself'). During repeated rounds of coding and 'memo-writing' (Charmaz 2006, 72), we made frequent comparisons across codes and the interview and field note data to develop, review, and refine themes (Braun and Clarke 2006) on the basis of the complementarity, convergence, and dissonance of ideas across data sources (Farmer et al. 2006). This was combined with narrative analysis of each interview (Riessman 1993) orientated towards identifying specific points within interviewees' flow of argument in which they drew on elements of the organizational environment and gave them a personal function, using them as symbolic resources to make sense of their experiences or to help them act within CLAHRC NWL. Narrative analysis enabled us to examine the temporal ordering of events in patients' pathways into healthcare improvement work, understand links between their participatory actions and the consequences of these through time and across different settings.

FINDINGS

By participating in CLAHRC NWL, patients entered a new healthcare environment – the quality improvement sphere. As we will see below, being in this environment for the first time, they experienced new ways of interacting with healthcare professionals (compared with their experiences as patients before the CLAHRC NWL) and new CLAHRC NWL demands on them as 'participants' in the improvement sphere. They had to learn the CLAHRC NWL ways of acting and values characteristic of the CLAHRC NWL organizational culture (e.g. multidisciplinary teams, patients as team members, patients co-designing interventions with healthcare professionals through improvement methods, collaboration). Patient participants had to make sense of what participating in quality improvement meant to them and how to position themselves within this new sphere. We show below how these processes were facilitated by patients' use of elements of CLAHRC NWL's organizational culture as symbolic

resources to help them in their transition into this new domain. All participants also had professional backgrounds and a history of participation in PPI initiatives elsewhere which may have affected the ways they adapted to the improvement sphere, perhaps, for instance, preparing them for interactions with healthcare professionals. Observations and interview accounts suggest that patients became active participants and felt that they were partners in healthcare improvement.

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Entering healthcare improvement culture: Reconfiguring ways of acting as patients

By entering CLAHRC NWL and interacting with its culture, patient participants underwent a process of becoming aware of their position vis-à-vis healthcare improvement. Participation took place in spaces 'owned' by healthcare professionals (CLAHRC NWL staff, project team staff) such as in meeting rooms in their institutions, and within the frameworks and types of social interaction established by them (e.g. monthly meetings during working hours, normative ways of behaving – like sticking to the agenda). Nevertheless, the cultural discourses and practices of the CLAHRC improvement sphere called on participants to develop more active ways of being patients.

There were asymmetries in the relationships between patient participants and healthcare professionals. Professionals retained control over leadership and project management, including budget allocation. There were some hierarchical features, such as the existence of appointed 'clinical leads' and 'project managers'. A small number of patient participants complained about inequalities relating to material resources (e.g. professionals were paid for their time but patients were not).

Nevertheless, patient participants' accounts of their PPI experiences – even those who complained – contained narratives of hope about what patients and healthcare professionals could achieve together, and expressions of trust in healthcare professionals' ways of acting in the improvement sphere. For instance, they said they felt that commitment to understanding healthcare from a patient perspective was 'endemic' (interviewee B, quote 2) and the status conferred on patient participants was embedded in the 'spirit' of the organizational culture (interviewee A, quote 1).

According to some interviewees, participating in CLAHRC NWL had been a turning point for them – a 'rupture' (to use Zittoun's term) – in their ordinary experience as patients and PPI participants.

Entering CLAHRC had involved becoming aware of the symbolic environment of the quality improvement realm (e.g. improvement values and collaborative approach, organizational commitment to PPI). Participants' accounts suggested that this rupture had stimulated them to reflect critically on their previously taken-for-granted, habitual ways of behaving as patients.

This process of reflection marked the beginning of a transition; a process of repositioning, from being passive recipients of healthcare to becoming active participants in service improvement (quote 1).

> That was the start of my discovery of CLAHRC. […] the patient representatives who are involved in [CLAHRC] basically are expected to [be] part of the team. Even though I'm not a medic, I am treated as an equal. […] I feel part of the [team] […]. Certainly, my own behaviour has changed a lot. When I was a patient I was extremely passive. […] I was not a participant. They [doctors] could really have decided to do whatever they wanted to do. […] CLAHRC is different [to PPI in NHS Primary Care], […] I have found that collaboration is not just a word in the acronym of CLAHRC, collaboration is really real, and people work together. […] [CLAHRC] does include a lot of people who really want to progress in terms of healthcare at different levels. They are very genuine […] you're part of the team, you discuss things, you share the lows and the highs and what goes wrong and you email each other at midnight, you call each other at midnight, this is life, this is team work. (Quote 1, interviewee A)

The practices and social norms of the regular way of acting as patients in clinical encounters (e.g. passivity, compliance) were at odds with the PPI discourses and collaborative practices circulating in the healthcare improvement sphere. Patient participants were not used to the type of interactions with professionals (CLAHRC NWL staff and their teams) they experienced in the improvement sphere. Patients had not imagined professionals would want them to get involved at the level and in the type of activities in which they ended up participating (quote 2). Patients' perceptions that their perspectives were legitimate (e.g. through decision-making processes open to all project team members) contrasted with how they had previously felt about themselves in their previous PPI experiences elsewhere. Interviewees wondered whether CLAHRC NWL staff – by modelling collaborative ways of working – might have provided professionals with a way to learn how to interact with patient participants (quote 3).

> I hadn't expected them to want that type or a level of involvement. And also to be involved at all levels, so to sit in areas that, of not my expertise [e.g. designing a care bundle] […] which are a big thing from a patient perspective, but you don't really consider it. You consider the structure of what you get is, that's what you get […] You're not over in the corner but you're going to contribute whether you want to or not now. You're an adult, come on, let's hear what you've got to say. But actually, they [CLAHRC] want all of that together. I was shocked because I just thought: this actually does mean change on a fundamental level […] CLAHRC's opened up a whole world of difference from my perspective. I'm looking at it and thinking, actually, I can make a change here. I can contribute. I can do all the things I thought maybe that I couldn't do. That's success, that's a change in attitude. (Quote 2, interviewee B)

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> Every time I spoke to [CLAHRC's director] I wondered if he had met the team or if they had taken it just from his attitude, because [...] they were just all equals, there was no sort of snootiness. If you meet [CLAHRC's director, PPI theme lead], any of them, they've got the same manner. (Quote 3, interviewee C)

The emphasis within CLAHRC NWL on collaboration and non-hierarchical multidisciplinarity (e.g. team-working) provided a resource for patient participants to make sense of the types of interpersonal relations that were valued in the improvement sphere (quote 1). Patient participants used the meanings contained in these discourses (e.g. improvement as collaboration between patients and healthcare professionals from different specialities and hierarchies) which they derived from the organizational environment, repurposing them as symbolic resources for themselves, and making sense for themselves of their involvement experience (quote 2, quote 5). These resources helped them work through the transition by helping them develop a sense of belonging to CLAHRC NWL (quote 5). During fieldwork, for example, we observed patient participants praising the organizational values of CLAHRC NWL and trying to spread its ideas about rapid translation of research into changes in care. Staff ability to model the principles of collaboration underlying the organization's PPI and improvement approach such as dialogical relationships of mutual recognition and respect between clinicians and academics also mediated patient participants' social relocation (quote 4) and contributed to developing this new position.

> I was fascinated by the ease with which the 'gods' of medical research were able to talk with each other in a very friendly and yet very frank way, unafraid to express opinions about things, but done with such courtesy and with such respect, that it made me feel that I'd be able to make a contribution as well. And of course, once I started to make my contributions then I realized they were listened to, either accepted or rejected and always with explanations. (Quote 4, interviewee E)

> The team is a team, there is no difference: you turn up, you're part of the team. [...] You're not the patient section, you haven't got the surgical team, you haven't got the medical team like you have normally on a ward and how it's structured. They're the CLAHRC team. They're trying to do something that's outside of that remit. They're multidisciplinary and they're brought together. [...] You had them working together [consultant, surgical team, senior nurses]. I've seen that all work and it works like clockwork, it's brilliant. I didn't expect that team ethos, multidisciplinary. [...] We're all getting this done. […] The same thing is true with CLAHRC [staff]. (Quote 5, interviewee B)

This sense of belonging to CLAHRC NWL allowed patient participants to be assertive and confident in their relationships with healthcare professionals. It also allowed them to 'sketch' an improved personal future and redefine a possible self. Feeling that one was part of the CLAHRC work itself provided a source of symbolic power (quote 6).

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> There are certain things that I can learn from them [CLAHRC] in order to improve in my own field, in my own organisation [national charity on whose board he serves] […] meeting health professionals who were top, at the top, the GPs, and even those in charge who were directors …it was good sitting among them […] you learn, you develop from there. CLAHRC is not a small organisation, so just that privilege to be part of a project like that. Now I can put it in my résumé, that I was with CLAHRC, as part of raising my own image or, when you are writing certain things. Take for example, the screening programme. I've been struggling [before CLAHRC] to get the GPs engaged in there, but CLAHRC is able, through our project to get them engaged. […] Now they [GPs] are talking to me, because they want to know how come we did this [...]. (Quote 6, interviewee F)

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The CLAHRC NWL programme discourse referred to patients as equal partners in healthcare improvement. Patient participants used this recognition as a symbolic resource to re-think their social position as receivers of healthcare and to reposition themselves as active participants in their own care (quote 7). Drawing on a narrative of empowerment and responsibility, patient participants at interview often challenged the passive role of patients in their interactions with healthcare professionals. They said patients should take control of their own health and demand the services that they need. Their accounts symbolically relocated patients (including themselves) as active change agents within the context of clinical encounters and healthcare self-management. This was also manifest in their improvement practices: patient participants embraced patient empowerment as one of their (unofficial) duties within their projects and used their existing connections with patient and community groups to try to create a demand for services. They raised awareness about the importance of active self-management of chronic conditions, about timely access to services, and about patient rights to quality healthcare. Interviewee A's experience in the CLAHRC NWL programme, for example, had given him the 'confidence' to start a peer-led self-management group for people with the chronic condition he shared. At the time of the interview he had already submitted a business plan for the group to the NHS Clinical Commissioning Group to obtain their support for the group's activities. Some interviewees said they became more active in managing their own chronic conditions. Interviewee G reported that her involvement in one project had allowed her 'to take ownership of [her chronic condition] and empowered [her] to get the help [she] need[ed] to understand and manage it as well as to help others to do the same'.

> And that's another thing that CLAHRC has done, has actually given me the confidence to say, no actually I do have the right. […] Because of the learning, of the development of this [project] if you like. Of me being able to say, and going to these meetings and talking to other people, no actually I have every right and having every right to say that as part of this [project] group has given me, as far as I'm concerned, the right with my GP to say, no actually I'm sorry, I don't hold with what you're saying. And I did challenge my GP over the use of test strips and he then gave me all the paperwork that the PCT had spent, sent down about you know, £60 per thousand patients is what they should be spending per month on whatever they're called, test strips. I said to him, but that's irrelevant. (Quote 7, interviewee G)

Navigating new territory

Interviewees started their participation with low expectations about the potential of PPI to change healthcare because in their participatory experiences elsewhere (all had had such experiences) they were often unable to see how or even whether their involvement had made a difference. They saw that this need for real influence and impact was recognized in the CLAHRC NWL quality improvement ethos (i.e. working in multidisciplinary teams, implementing small changes evaluated over time, and using real-time data to inform change). This organizational culture of 'getting things done' was regarded as 'the right sort of attitude' and a real effort to 'put things into action' (interviewee H). Such an approach was a novelty for patient participants – they said – because they were used to consultative PPI meetings in other healthcare settings where there was no evidence of input being acted upon or monitored.

> I saw it was actually a network of programmes [CLAHRC] systemically, all in the NHS, all trying to do things, which I felt was a really good way of doing things [improvement approach]. In engineering they call it rapid prototyping, they get the idea, get the concept, it's half baked, doesn't matter, let's get it out there, try and get some feedback […] That's, in this CLAHRC team and that was really refreshing […] That really enthused me. That made me want to stay. […] All right, they're small changes [improvements tested over time], they're little things, but again that's what I believe makes a change […] I saw the value of what the team was doing […] The biggest payoff is seeing […] something the team has worked on and that it has changed something, concrete, for the better […] I wanted to see if, if I could help, if I could make a contribution, no matter how small. That's what I wanted to do. And it's been enabled […] it seems natural to do within that environment […] It's quite intoxicating [...] because you feel that we can do stuff. (Quote 8, interviewee B)

Patient participants nevertheless argued that these measured impacts were inadequate because improvements were only implemented in the specific area served by the healthcare institution that hosted the project. Patient participants often called for more inter-organizational collaboration to spread improvement interventions to other areas more rapidly.

The CLAHRC NWL improvement culture acquired a new function beyond its immediate instrumental role when patient participants started drawing upon quality improvement discourse as a symbolic resource to think about their collaboration with professionals (quote 9) and to act upon team processes. 'Learning together' became the narrative used by patient participants to make sense of the process of working with professionals (quote 9). Here they were using aspects of quality improvement (the constant and iterative process of learning that characterizes the model of improvement) as a semiotic resource to redefine the interpersonal relationships (unity and collaboration) that characterized their engagement in this sphere (e.g. talking about 'getting into the PDSA [Plan-Do-Study-Act cycle] mode', quote 10). Quality improvement methods

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had enabled interviewee G (quote 9) to navigate this new territory with her team. She described how at first she had not seen the point of improvement methods, but later discovered how they helped in 'moving us [the team] forward' and 'helping us to develop and grow' so that 'we have a bigger part to play'. Quality improvement methods became symbolic resources that enabled team members to orientate themselves towards the aims of the project and to help them coalesce around a collective identity as change agents.

CLAHRC had made the healthcare professionals within project teams accountable for implementation of quality improvement methods. Although patient participants were involved in team discussions and attended sessions at Collaborative Learning Events, professionals retained control over how the methods were used. Weekly project data were entered via a bespoke web application, but patients only participated in the PPI data input (and rarely even this) with all other data entry controlled by professionals.

> CLAHRC isn't just somebody, or something that has got a project to fulfil and is ticking boxes, but they are actually interested in the out comings [sic] because they want to move us from here to there, but taking us a whole package and putting us up a little bit higher so that we've all grown in importance […] We've all grown, and we all have a bigger part to play, and they're helping us to develop and grow […] through all the various – I hate using the word tools because that's their word – but the [improvement] tools that they have given us for learning and for actually keeping track of what we're doing. And as much as I didn't think there was much point to that at the very beginning I really can see there is a point to knowing where, where you started and which road you've gone up. (Quote 9, interviewee G)

> My [CLAHRC] experience of involvement has been very good, very rich in terms of being involved in projects where you can actually see the benefit, you can see the outcome for patients. My experience in the primary care sector is exactly the opposite.[…] [Plan-Do-Study-Act cycles] are very simple, so that to show people […] how to get together and say, hey guys, what if we were to do this? And then get into the PDSA mode. It's very supportive, one always knows where one is going. There is a clear aim and very simple. (Quote 10, interviewee I)

Elements of the improvement culture (e.g. learning from routine collection of data and acting on the learning) also became resources for action in this new sphere. At observed team meetings and interviews, patient participants often drew on quality improvement discourses (e.g. asserting the need to monitor intervention progress or to gather outcome data). They used this discourse to frame their input about the overall direction of the project. They often talked about the 'spread' and 'sustainability' of interventions (both lying at the core of CLAHRC NWL's improvement approach and ethos of intervention 'transferability' to other settings) as key indicators of success. Patient participants (rather than team staff) demanded more 'evidence' and impact 'data' to monitor progress, or called for the intervention to be expanded to outside the

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hospital (resonating with CLAHRC NWL's 'whole system' improvement approach). Patient participants often referred to 'us' and 'our(s)', 'we' expressing their collective identity as team members and their commitment to the project. They appeared to be using a quality improvement discourse as a resource to mobilize the collective actions of team members to achieve project goals. For instance, at team meetings interviewee J often said data should be gathered on what patients had gained through the intervention rather than simply how many patients had received the intervention. J's advocacy may have contributed to the eventual inclusion of additional measures of intervention impact (e.g. collecting outcome data). Generally, however, professionals decided how interventions were measured.

Patient participants' use of quality improvement principles as symbolic resources led to the emergence of new participatory practices. For example, some patients gathered data to demonstrate impact (e.g. by doing informal interviews with patients), aiming to use evidence of impact to ensure the spread and sustainability of the project (e.g. project recognition and financial support from stakeholders). For instance, interviewee K promoted a patient medication review tool designed by the team and also monitored its usage through patient feedback. Other patient participants embraced sustainability as one of their core responsibilities and used their existing networks of associations with healthcare organizations such as Clinical Commissioning Groups to raise awareness of the project. Their hope was that by doing this they would obtain funding to maintain and expand the intervention.

Patient participants also used outputs of quality improvement processes in new ways. For instance, interviewee L encouraged her team to develop a not-for-profit organization to ensure project sustainability (quote 11). L had previously expressed resistance to CLAHRC NWL's emphasis on improvement methodologies and technical jargon. For instance, she refused to attend the CLAHRC NWL's Collaborative Learning Events and did not actively participate in team discussions about improvement methods. The outcome measures of the intervention ('statistics'), however, had reminded her that the project was not simply research for its own sake, but to 'sell' it to improve services (quote 11).

> There seems to be this sort of huge, academic ivory tower, into which people are invited up, right? You can mount the steps and join us. All you need to do is, blah, blah [CLAHRC's improvement approach] [...] The most interesting moment was when I saw the first set of statistics that had been gathered. I was reasonably amazed that we had gathered as much information as we had. […] There is no way, and then we get all back into the lovely sustainability words, but there is no way we want to run this as a project and then have it fizzle out. So the great thing about the research bit is that if the statistical information comes up with the right information we will then have a very strong tool to sell this idea broadly […] That's what excites me most: […] having trialled something that works and then making it available to a much larger group of people is something that also really stimulates me. (Quote 11, interviewee L)

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Quality improvement became an opportunity for personal development. Four patient participants were awarded CLAHRC NWL Quality Improvement Fellowships. During fieldwork, interviewee F explained that he had applied for the fellowship because of his desire to improve his longstanding participation in diverse healthcare organizations and his role as a board member of a national patient organization. He now wanted to transfer the quality improvement principles of the project to other domains of activity to be more 'effective'. The fellowship could help him focus his efforts to improve the healthcare of the group of patients he represented. Patient participant M saw the fellowship as an opportunity 'finally' (after a lengthy experience as a participant) to do something to improve wider aspects of his life and to achieve something for himself.

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DISCUSSION

We have shown how organizational cultures can become enabling resources for active and meaningful patient participation in healthcare improvement. Patients can appropriate cultural elements they find within the organizational context of involvement and use them in novel ways to support their participation and collaboration with healthcare professionals.

We found four key elements in the organizational culture that contributed to successful PPI: (1) emphasis on non-hierarchical, multidisciplinary collaboration between and among healthcare professionals and patients; (2) organizational staff ability to model desired improvement and PPI behaviours of mutual recognition and respect; (3) commitment to rapid improvement, which ensured that research was quickly translated into implementation; and (4) the constant and iterative process of data collection and reflection facilitated by the use of quality improvement methods and the commitment to act on that learning. Our framework views patient involvement in healthcare as a transitional and developmental process facilitated through patient participants' active use of cultural elements available to them. This framework allows us to take into account the dynamic interplay between individual/psychological and social/organizational aspects of patient involvement, and we have shown how certain elements of the organizational culture of improvement can mediate patient involvement: patients use these elements as resources to re-organize their patient identity and master their 'participant' role to increase their influence and simultaneously contribute to the creation of cultural conditions conductive to collaboration.

The hierarchy of the clinical encounter was to some extent maintained in project teams, with professionals retaining control over project management and leadership and use of quality improvement methods. Yet patient participants positioned themselves as active and legitimate improvement agents, constructing their interpersonal relationships with healthcare professionals as equal and collaborative.

Patient participants also functioned as a 'technology of persuasion' (Armstrong et al. 2013, 7) for improvement by encouraging team members to gather health

outcome data or insisting on making interventions sustainable and 'transferable' to other settings.

Our findings demonstrate that when patients find ways to use elements of organizational culture as symbolic resources to support their involvement, they can influence healthcare in unexpected ways beyond simply providing their views as receivers of care.

Empowering patients to participate in healthcare improvement is not a simple matter of patients acquiring cognitive skills or technical knowledge. Patient engagement in healthcare improvement involves a dynamic interplay between psychological and sociocultural processes. Our study has illustrated how, in this 'mediating moment' (Cornish 2004, 281), patients play an active role in choosing symbolic resources to support their meaning-making about their involvement experience.

Our findings are derived from PPI experiences of a group of people within a particular organizational context in the United Kingdom. We have identified four key elements of organizational culture that facilitate PPI. These elements are likely to be applicable elsewhere, but of course further research should test this. We also need to know more about how programmes can facilitate patients' active selection and use of symbolic resources, and examine further how patients' previous experiences affect the ways they can select and use these cultural resources. Participants in our study were generally educated, white, and middle class and many had been 'public participants' in other settings (e.g. national charity board). Prior experiences may well have helped them adapt to healthcare management structures and processes (e.g. formal meeting procedures) (El Enany, Currie, and Lockett 2013) and may have affected which cultural elements they appropriated as resources for their influence. It is not clear to what extent members of other (i.e. less well-educated, non-middle class, non-white) groups might differ in terms of the range of 'usable' symbolic resources (for them) and the ways in which they would employ them. They might be unable to find any resources at all from organizational cultures 'owned' and created top-down by healthcare professionals themselves. Inviting patients to fit into existing organizational cultures (i.e. to adapt to the organization's way of working) runs the risk of co-opting a particular group of experienced participants to the exclusion of others, a phenomenon described as common for other areas of patient involvement (Rutter et al. 2004).

Improving organizational cultures is essential for effective patient participation: improvements should aim to ensure equitable patient access to positions of influence, to create the best possible collaborative relationships between patients and healthcare professionals, and ultimately to ensure all patients can get involved in a meaningful way to improve healthcare.

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