

Optimizing patient involvement in quality improvement

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Abstract

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Introduction Patient and public involvement in healthcare planning, service development and health-related research has received significant attention. However, evidence about the role of patient involvement in quality improvement work is more limited. We aimed to characterize patient involvement in three improvement projects and to identify strengths and weaknesses of contrasting approaches.

Methods Three case study quality improvement projects were purposively sampled from a broader programme. We used an ethnographic approach involving 126 in-depth interviews, 12 weeks of non-participant observations and documentary analysis. Data analysis was based on the constant comparative method.

Results The three projects differed in the ways they involved patients in their quality improvement work, including their rationales for including patients. We characterized three very different models of patient involvement, which were each influenced by project context. Patients played distinctive roles across the three projects, acting in some cases as intermediaries between the wider patient community and clinicians, and sometimes undertaking persuasive work to convince clinicians of the need for change. We identified specific strategies that can be used to help ensure that patient involvement works most effectively and that the enthusiasm of patients to make a difference is not dissipated.

Conclusion Patient involvement in quality improvement work needs careful management to realize its full potential.

Introduction

The last decade has seen a markedly increased emphasis on patient and public involvement (PPI) in many areas of health care, including

healthcare planning, service development and research.¹ Potentially distinctive issues are raised by PPI in improvement projects, which aim to enhance quality and delivery of specific services² but often face significant challenges in

achieving the changes in service organization or delivery that they seek.^{3–5} Justifications for involving patients in improvement projects are broadly similar to those for involvement in health care more generally. They include framing patients as the users and funders who have a legitimate stake in health services and are entitled to influence,⁶ and more technocratic rationales emphasizing consumerist logics and the potential for patients' contributions to improve services.^{7,8}

Despite widespread enthusiasm and support for PPI, evidence that it delivers on its aspirations across a range of activities in health care remains disappointingly sparse.^{9–11} How well conceptual frameworks for thinking about involvement in other areas^{12,13} apply to improvement projects is also unclear. Despite some important discussions of its potential,^{14–17} research on PPI in improving the quality of systems and processes in health service delivery is limited. Some have suggested that patients have a unique contribution to make to *identifying* problems of quality and safety in health care,^{14,15} but how and whether they can optimally contribute to improving processes is less clear. In contrast to areas where PPI is better established – including research and resource allocation – improvement projects are often relatively technical affairs, involving, for example, systems redesign.¹⁸

Patient and public involvement faces challenges even where its role is clearly apparent. Among the many unresolved questions is that of *who* should be involved. A sometimes heated debate centres on whether patients should be in some sense representative of the demographic characteristics of the population from which they are drawn,¹⁹ or whether it is preferable that they represent shared experiences and standpoints²⁰ and have particular kinds of skills and capacities.¹⁸ A further challenge concerns how to ensure that patient involvement is not sidelined or subverted. Where patients are brought into existing organizational processes, such as management meetings and decision-making forums, their contributions may be limited by their lack of familiarity with the sys-

tem's language and norms and by power differentials.²¹ An influential critique thus suggests that patient involvement is often more about legitimizing managerial or professional decisions that would have been made anyway than about furthering patient influence.²² Careful attention may thus be needed to the structures and processes by which patients can be included and their views valued, and to reaching agreement on priorities and definitions.¹⁸

The available evidence thus suggests considerable ambiguity about whether and how patients can be involved in improvement projects, in meaningful and distinctive ways which make a tangible difference to projects, rather than duplicating professional roles or offering a token contribution with marginal impact. Yet, much may depend on the *how* of involvement, and little evidence has yet emerged of how it can best be performed. Using three case studies, we seek to characterize and identify the strengths and weaknesses of contrasting approaches to patient involvement in quality improvement.

Methods

The three case studies²³ were drawn from 11 projects participating in *Closing the Gap through Clinical Communities* (CTGTCC), a programme funded by the Health Foundation (THF) (a charitable foundation). Each project was charged with making improvements to bring routine practice closer to established best practice. All projects were based on the clinical communities approach, which provides a structure for improvement that requires the involvement and engagement of those stakeholders likely to be affected by improvement activity²⁴ through peer influence and harnessing the collective power.

In the programme, each project had a core team that led and coordinated project activities and recruited participating sites to help co-design and implement the improvement work. Teams were supported by THF programme officers and by a technical provider (a management consultancy) that offered a package of leadership support and training in improve-

ment methods. Core team membership varied depending on context but typically included clinicians, a project manager and relevant stakeholders. A key feature of the programme was that it mandated the inclusion of patients in the core team of each project.

Our study was conducted as part of a commissioned external evaluation of the programme and was given a favourable opinion by the Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1.

The projects

Selection of the case-study projects from the 11 in the programme (Table 1), and participating sites within each case, was guided by the desire to include sufficient similarities and differences across the cases (e.g. in terms of project aims,

improvement approaches, and clinical and organizational fields) to allow meaningful contrast and comparison.

Data collection and participants

We conducted ethnographic non-participant observations focused both on project activities (e.g. observations of meetings and events) and participating sites' attempts at implementation (e.g. observations in clinical settings). Our data collection thus covered the 'blunt end' of programme design and management through to the 'sharp end' of implementation where practitioners interacted with patients.²⁵

Interviews were undertaken with members of each project's core team (including clinicians, project managers and patient representatives) and with staff working at a sample of the par-

Table 1 Summary of three case-study projects

Project	Project aim(s)	Clinical setting	Quality improvement methods	Involvement model
Improving Lung Cancer Outcomes Project 'Lung Cancer'	To improve the quality of care and outcomes for patients with a serious condition that has a relatively low survival rate	Multi-disciplinary teams (MDTs) working in secondary care	Reciprocal peer review; development of Quality Improvement Plans; national meetings	Two relevant charities provided input at the project team level; patient experience data were collected at participating sites
Abdominal Aortic Aneurysm Quality Improvement Project 'Aneurysm'	To reduce peri-operative mortality for a condition often treated through elective surgery	Multi-disciplinary teams (MDTs) working in secondary care	Improving data entry and data quality of a national database; development and implementation of a care pathway; regional meetings	One patient representative on the project team throughout; local patient representatives participated in project-organized regional meetings; patient focus groups
Enhancing Care and Saving Lives of People with Chronic Kidney Disease (CKD) 'Kidney'	To achieve better quality of care and better quality of life for patients with a chronic disease	Usually managed by GPs and practice nurses in primary care and patient self-management	Training in disease management for primary care staff; a care bundle; self-management material for patients	Patient and Service User Advisory Group worked closely with the core project team; its leader doubled as a member of the project team

ticipating sites (including clinicians and managers). Interviews focused on participants' views on the project's aims and objectives, the strategies adopted to achieve them and how they would work, and the factors facilitating or hindering progress.

Interviews were audio-recorded and transcribed verbatim. Fieldnotes from observations were de-briefed by the observer to others within the team; these debriefs were audio-recorded and transcribed. Relevant project documents were also collected for analysis, including project plans, reports and training materials. All authors were involved in data collection, although most was undertaken by Herbert and Aveling.

Data analysis

Data analysis was based on the constant comparative method.²⁶ It involved intensive engagement with the data for each of the case studies to ensure that they were understood in terms of their own context and meaning and then compared across projects to generate higher-order themes. Nvivo 8 software was used to assist in coding the data, locating recurrent themes and grouping themes together.

Findings

The three clinical community projects included a serious condition with a high mortality rate (lung cancer) treated in hospital; a condition requiring elective surgery (abdominal aortic aneurysm), also treated in hospital; and a long-term condition (chronic kidney disease) managed in primary care. As abbreviations, we label the three projects studied as Kidney, Aneurysm and Lung Cancer. We conducted approximately 12 weeks of observations (21.5 days with the Aneurysm project, 25.5 days with Lung Cancer and 16.5 days with Kidney) and 126 in-depth interviews with core teams and participating site staff (45 each for Aneurysm and Lung Cancer and 36 for Kidney) over the period October 2010 to April 2012.

The three clinical communities were very different in terms of the clinical setting, the quality

gap being tackled and the strategies they used to try to achieve change. We explored expressed rationales for patient involvement in each of the clinical communities; the different involvement models adopted; the strategies that appeared to help patients contribute in meaningful ways; and how patient involvement contributed to the work of clinical communities. This involved triangulating the perspectives of project core teams, patients involved in the core team, participating site staff and observations by researchers, in particular in comparing rationales and plans to the realization of those plans and the contribution of patients in practice.

Each clinical community, as mandated, incorporated some patient involvement. In all three projects, patients were recruited largely opportunistically, for example, through existing personal contacts. In this sense, the extent to which these patients 'represented' the wider patient population might be open to question,¹⁹ but even less clear was the extent to which representativeness mattered. Much more important seemed to be how the clinical communities operationalized patient involvement, and the extent to which patients' views and perspectives influenced the design and/or implementation of the intervention, including the clinical community's success in engaging professionals in improvement work.

The rationale for patient involvement

Members of the three core teams suggested a range of factors that motivated their securing patient involvement including the nature of the clinical condition, perceptions of the value of patient experience, the team's past experience of involving patients and an awareness of the wider context. Members of both the Lung Cancer and Kidney core teams reported clearly articulated rationales for involving patients beyond those of satisfying the formal programme mandate. The Lung Cancer team regarded patients with lung cancer as likely to be particularly vulnerable and not as well represented as other patients on national fora, largely because of the typically poor prognosis, and often rapid progression to severe illness and death. Improving quality of

patient experience was seen by the team as an important outcome of service provision. However, measures of patient experience had not, prior to the project, been included in routinely collected national audit data. These two factors combined to mean that gaining an understanding of patient experience and achieving real improvements were crucial objectives of the clinical community.

Patient experience is not recorded in the audit so we wanted to, when we're going to look at these teams, we wanted them to do a formal patient experience survey before the visit, for a period and then at the end. So we were trying to build patient experiences as well. (Lung Cancer core team member)

The Kidney team was similarly motivated by a focus on patient experiences and had identified the value of patient involvement from previous improvement work.

...where we thought we fell short on [a previous project] was not having enough service user representation...we felt we wanted to do a better job. (Kidney core team member)

In contrast, while the Aneurysm team did recognize the centrality of patient involvement in providing good care, involvement was initially talked about more as a response to external 'pushes' (including from the programme's sponsor and the broader healthcare environment).

It seems to be an important part of the quality programme that's endorsed by The Health Foundation. And the government is saying, patients' choice, and patients' views. (Aneurysm core team member)

However, the Aneurysm team's understanding of the value of patient contributions evolved over time, and the input of patients in shaping some aspects of care was later regarded as one of the most successful elements of the project.

Three models of patient involvement

We saw markedly different approaches to involvement. While the underlying rationale for involvement was one important factor influencing the type of model adopted, other factors

included the nature of the clinical condition and the degree to which each project was located within pre-existing structures.

Lung cancer patients are often terminally ill or severely debilitated, making direct patient representation at the core team level throughout the project unfeasible. Instead, two relevant charities provided representation. The intention was to use these charity representatives to build, through their contacts, a virtual network of patients who could be consulted as required. The core team also introduced a second mechanism – collecting patient experience data using questionnaires distributed at participating sites to identify possible patient-focused improvements. While acknowledging that this model had its limitations, the project team nevertheless regarded it as 'fit for purpose'.

I'm completely aware of some of the downsides and some of the ways where we can't be reflective of every single person who has lung cancer in the UK. But we can certainly work in as many ways as we can to gather those views. (Lung Cancer patient representative)

The Aneurysm project, in contrast, had one patient representative on the project team throughout, as well as more limited involvement of patients in some activities (e.g. regional meetings of participating sites). The core team effectively comprised the membership of a pre-existing committee, of which the patient was a lay member; this patient's committee membership therefore doubled as project membership. Again, a second method of representing patient views was also used. At two-thirds of the project-organized regional meetings, patient representatives from participating sites took part in discussions with clinicians. A third mechanism was local; in participating sites, some patients were asked to express their views in focus groups. The resulting data were presented at the project's regional and national meetings and used in the development of project materials for patients.

The Kidney project adopted a different model. A separate Patient and Service User Advisory Group (henceforth the 'Patients' Group') was established and worked closely

with the core project team. The Patients' Group comprised eight patients and was formed specifically for the project through contacts of the project team. The Group leader doubled as a member of the core team and acted as an important link between them. This individual was well-known for her leadership of campaigning groups, giving her credibility beyond her own personal experience of kidney disease.

Making involvement work well in practice

Improvement teams may genuinely wish to achieve meaningful involvement, but the risk remains that patients may be marginalized or unheard.²⁷ Even the best-intentioned teams may struggle to truly involve patients in a setting where it is not yet the norm and where implicit or explicit barriers may exist.²⁸ Across the three projects, we identified some key features that facilitated effective inclusion of patients' voice and influence.

Early involvement

Across the three clinical communities, it was clear that involving patients as early as possible brought many benefits. For example, involvement at the protocol-design stage meant patients could help shape the planned work and were not expected to simply come in later and 'run with what's there'. Early involvement also meant patients were more likely to have a clear understanding of the project's aims and objectives, together with the strategies that would be used to achieve them, and so were better able to work alongside other team members.

Initially from going to the meetings, there was a bit of a learning curve for me to understand exactly what it was all about and where I kind of fitted into the project. (Lung Cancer patient representative)

Effective communication channels

Clinical communities benefit from being 'light on their feet' and are able to make quick adaptations and modifications as their work progresses.²⁴ This makes quick and effective

communication essential, and, in this programme, necessitated ways of capturing inputs and integrating them into decision making without unnecessary layers of bureaucracy. A good example was the debriefing that went on soon after each of the Kidney project's training sessions at participating sites. The Patients' Group members provided feedback on how the session had gone and were included in discussions about possible changes to how it be delivered in future. Rather than leaving feedback to a formal meeting, less formal opportunities to feed in thoughts were found, including emails, phone calls and shared travel time. This helped to ensure that patients' contributions had real influence, avoiding a more proceduralized approach that might have made it difficult for patients to contribute.¹¹

I did go back to [project team member] after that day at [participating site] and in fact [project team member] and I talked about it, because I dropped her back at the station, and I think we did jiggle a few things round as well and I think that's one thing that has worked well overall with the whole core team and the patient user group, is that we have changed and adapted things from the experience. (Kidney patient representative)

Non-hierarchical structure

Observations of both the Lung Cancer and Kidney meetings revealed that everyone appeared to be valued as a team member and that there was a strong emphasis on learning from, and listening to, each other. Patients valued this openness, and they, like other project team members, appeared happy not to always get the final say.

Everybody is on a completely equal and even footing. And I don't know whether it's personalities or what we do, or where we come from, or what it is but it seems to work that way. (Kidney patient representative)

I could tell you very little about the patient pack and the development of it because that's been very much driven by the patients actually. So, very much although it is true that I have been able to have some editorial comments I don't, I haven't had any editorial veto. (Kidney core team member)

This openness, and effort to generate a 'level playing field', in the Kidney clinical community also meant that, while patients' views were not regarded as any less important than anyone else's, they were not necessarily regarded as any more important either. If there was a difference of opinion within the group, patients were expected to engage in discussion and debate as much as anyone else. This, of course, relied on patients being willing and able to do so; they had to be prepared to engage as equals, challenge other team members and believe they had something of value to contribute. They also needed the confidence and skills necessary to take forward discrete pieces of work, such as the patient materials in the example above.

A clearly defined role

While effective communication channels and a non-hierarchical structure were important facilitating factors, they needed to sit alongside a clearly defined patient role. Taking the time and effort needed to establish this was important as it served to both help ensure patients were not in a situation where they could not contribute and to channel patients' enthusiasm in the most productive way. Across the three projects, the degree of clarity about the patient role was variable. The Aneurysm project, especially initially, did not appear to have a clearly defined role for patient representation, nor was the role of patients' involvement in discussions at regional meetings always clear. In contrast, there was a clear focus for using the data from patient focus groups: to revise information routinely given to patients. It was used to do so effectively, and revised patient information leaflets were positively received by patients and clinicians.

In the Lung Cancer project, the development and piloting of the patient experience questionnaire relied crucially on effective PPI. However, the most comprehensive attempt to clearly define the patient role was in the Kidney project. Here, the Patients' Group spent considerable time developing and formalizing specifications of their roles and responsibilities, and there was evidence this helped make the role more tangible and to shape their input when they attended project meetings or training sessions.

Patients as a 'technology of persuasion'

We identified two key ways in which, when involvement was effective, patients could make a distinctive contribution. The first mobilized patients as persuaders. A key task in improving healthcare quality, as undertaken by these clinical communities, was persuading clinicians both that there was an important problem to be addressed and about how it should be addressed.²⁴ This sometimes required challenging clinicians who could be reluctant to change, not agree that a problem exists, and be sceptical about the proposed solution.²⁹ In both the Aneurysm and Kidney projects, patients acted as a *technology of persuasion*: a means of influencing opinion and debate. Most commonly this was through their participation in meetings and training events with clinicians from participating sites. Patients could act as powerful advocates on these occasions. Involving them at the centre of improvement activities could add weight to discussions of patients' views and enhance project credibility. Putting the 'patient in the room'³⁰ seemed to help particularly in challenging assumptions that everything was fine as it was, and in resolving contestation about whether the proposed changes were appropriate.

A potent example was provided by the Kidney project's Patients' Group members, who were trained in self-management education along with the core team and helped facilitate training of general practice staff. The core team recognized that patients had a different perspective and could offer persuasive properties that would otherwise be lacking.

They're very powerful advocates ... They have a moral stature that you can't really question. If a patient tells you that the service feels a certain way, you can't really argue that it doesn't, because that's their experience. (Kidney core team member)

This idea appeared to translate well in practice. It was used, for instance, to address the issue that doctors sometimes did not advise patients they had been diagnosed with early stage chronic kidney disease, mainly because they were unsure whether they should tell patients and did not always feel confident in so doing. When the

question of withholding the diagnosis was raised at one training session, the patient members immediately challenged professionals' perceptions that patients might not want to be told, emphasizing that, as patients, they certainly would. They were also able to offer practical suggestions on how to broach the subject. Clinicians seemed to appreciate this direct contact with patients, suggesting that it provided an important additional dimension of their understanding:

It brings it home a bit more, the emotional side of it, rather than just dealing with numbers like EGFRs and blood pressures and urine results, it brings home the effect it actually has on someone's life. (Kidney participating site GP)

Patient involvement in clinician-facing activity, then, seemed to help to legitimize both the need for change and the approach proposed. It appeared to reduce the likelihood of clinician reticence or resistance by showing that the changes proposed were likely to be well received by patients. However, the use of patients as a technology of persuasion was not a simple matter of co-option: the patients themselves were active agents, keen to contribute to what they saw as a worthwhile project and were able to develop their own role in a forum independent of the project's management.³¹

A similar activity was attempted in the Aneurysm project, with somewhat more mixed results. At regional project meetings, patients (recruited on a fairly ad hoc basis by surgeons from their own clinics) took part in small round-table discussions. These groups of clinicians, administrators and others were asked to discuss various elements of a proposed elective care pathway from preoperative assessment to postoperative care. Where patient experiences could clearly add something to discussion of a particular pathway stage (e.g. communication with the patient), their opinions were highly valued and actively sought. However, when discussion focused on technical issues (e.g. specifications for equipment standards), it was less clear how patients could contribute. Clinicians appeared dubious about patients' ability to contribute meaningfully to debates about safety

issues, seeing them as lacking either the required professional knowledge or breadth of experience. We observed dynamics such as awkward silences when patients finished speaking, suggesting discomfort on the part of both patients and professionals.

When the discussion was on something the patients couldn't really have a constructive input to on the specific issue, it was that sort of polite listening to the patient because they're a patient and then the conversation resumes ... Whereas on the communication table it was very much the surgeon saying [to the patient] 'Well, what did you think? What would have been good for you?' (Aneurysm observation debrief)

The degree to which the rationale for involving patients in these activities, or the role they were intended to fulfil, aligned with the novel contribution they could make as patients was clearly important to effective PPI. While the Kidney project could clearly identify a unique contribution that they hoped patients would make, and that fitted with their identity as patients, there was perhaps not such a good fit in the Aneurysm project. Discussions about some parts of the pathway obviously benefitted from patient input, and professionals actively sought this out, but the contribution that patients could meaningfully make to other aspects was not so clear.

Patients as 'knowledge brokers'

A second key role was patients as 'knowledge brokers': individuals who facilitate knowledge exchange and adoption and help to build links between different groups.³² Patients were able to act as mediators between the world of the patient and the world of service provision. All projects produced patient-related material, either for patients' own use (e.g. information sheets or questionnaires to give feedback on the care they had received) or to guide clinicians on how they could best engage patients in discussions. All made patient influence central to the design of this material, and rationales for this were clearly articulated. An important example was seen in the Aneurysm project. Here, the quality of decisions about appropriate surgical candidates was thought to contribute in part to poor outcomes – for

instance when patients whose physical condition was probably too frail to survive surgery were unaware they might be better off not having it. The project team was committed to solving this problem but recognized considerable uncertainty about how best the treatment options should be explained to patients. Project-run patient focus groups thus sought, among other things, to identify ways of improving communication and sensitivity to patients' views. These views were used to inform development of new patient information leaflets.

They did sort of change all the patient information leaflets as a result of these focus groups, like one of the changes was the patient said 'it was way too scary. You do have to be a lot more subtle about, you know, some of the bad bits... the fact that you might die'. And so they have changed the patient information leaflets quite a lot. (Aneurysm observation debrief)

Discussion

Our analysis of patient involvement in three improvement projects within a single programme based on a clinical communities model²⁴ surfaces some interesting contrasts in approach, along with both alignments with and divergences from the wider literature on involvement in healthcare provision more broadly. It suggests that improvement work can draw productively on patients' contributions – but not necessarily in a uniform and standardized way. Involvement as realized in these projects seemed contingent on both the clinical condition and project objectives, and involved a complex and variegated role drawing not simply on the positionality of patients *as patients*, but on their broader knowledge, skills and experiences. We do not wish to suggest there is only one model for PPI in healthcare improvement projects. However, our analysis suggests a number of key lessons (Box 1) and adds to a currently limited domain of research concerning *how* patients can be involved in improvement work. Crucially, it suggests that patients may have a distinctive role to play in improvement interventions. Despite the specialized, esoteric nature of much improvement work, it is clear that PPI can add an extra dimension to a clinical community that does not just mimic the work of professionals and is not limited to tokenism.

Box 1 Tips for successful patient involvement in improvement projects

Clarity on the rationale for patient involvement

- Take time to think through the rationale for involving patients.
- An unclear rationale can easily slip into tokenism.

Identifying the right model to achieve the desired outcomes

- There is no 'one-size-fits-all' model; instead a range of options is available to suit different situations.
- Consider issues such as: the nature of the quality gap; the clinical area; the improvement tools being used; and the characteristics of the patients served.
- Be flexible about the role patients can play and tailor to the project's context.

Clear roles and responsibilities for patients

- Identify clear roles and responsibilities, allowing patients to develop these themselves where appropriate.
- Patients can undertake a range of roles, including patient-facing (e.g. developing information material) and clinician-facing (e.g. training and meetings) activities – think about the full range of ways in which patients may contribute.
- Clearly define what patients will contribute, and how they will work with other team members to achieve the project's aims.
- Ensure patients have the qualities and skills congruent with the chosen activities.

Involvement that is meaningful

- Ensure early involvement wherever possible – ideally at the protocol-design stage.
- Establish effective communication channels between patients and other team members – opportunities for less formal discussion outside of meetings is important (e.g. emails, phone calls and shared travel time).
- Create a non-hierarchical structure by valuing and giving weight to each team member's views.

While this study is limited to data gathered from only three improvement projects, they were purposively selected to include areas of similarity and difference, and therefore allow

meaningful contrast and comparison in how involvement was operationalized in each case.

We identified some critical factors determining the kind of involvement that is achievable including the nature of the quality gap, the clinical condition being targeted (and how it affects patients), the strategies being used to drive change and the characteristics of the patients served. No 'one-size-fits-all' solution exists. In the Kidney project, the long-term nature of the condition and the focus on self-management meant that an active, ongoing role for patients was feasible, and the use of a group model allowed flexibility and substitution between individuals where required. The same was not true of lung cancer patients, who were not physically able to sustain an ongoing engagement, but whose views the clinical community were keen to access. In such circumstances, other means of ensuring the patient voice is heard may be appropriate; the Lung Cancer project's model of patient representation through charities and emphasizing collection of data on patient experience appeared successful in delivering on their goals. The Aneurysm project's approach of having one lone individual as a 'representative' on the project team was complemented by other means of involving patients and accessing their views, but might have benefited from a different structure and more clarity about what patients might best be able to contribute.

Underscoring the need to deepen understanding of how patients can be effectively included in improvement interventions, our study also identified some of the ways in which patients can play a distinct role in improvement projects. Patients had an important role as knowledge brokers, acting as envoys from the social world of patients to the social world of clinicians. For example, in contributing to information materials produced for both patients and clinicians, they acted as interpreters who could bring patient experience to bear on clinical knowledge and translate clinical language into something more comprehensible.³³

Perhaps more intriguingly, patients seemed to be able to accomplish some of the persuasive

work involved in improvement. Our findings suggest that a carefully harnessed form of patient involvement can, if performed well, be a powerful tool in achieving this. Most notably in the Kidney project, the active involvement of patients in events and training seemed crucial in conferring legitimacy and securing emotional commitment, evidencing the need for change in a way that peer-to-peer influence alone may not. Here, in particular, the distinctiveness of the PPI contribution to improvement was evident, with the involved patients playing a complementary role to that of professionals. In some ways, this role echoed the part that patient stories have been noted to play in persuading clinicians of the need for change,⁵ but the interplay between professionals and patients in the Kidney project seemed to substantially increase the persuasive power of those advocating improvement.

While patients may have a distinctive role to play in improvement projects, the challenges common to PPI in other areas of health care were no less evident in this context. It is not always easy to find a way for patients to feel able to assert their views and have them recognized and valued. The danger is that patient involvement can feel awkward and tokenistic if it is not performed well. Our study findings suggest a number of strategies for ensuring positive involvement.

First, clarity on the rationale for bringing patients and clinicians together, and thinking through how the intended outcomes can best be achieved, is likely to help ensure patients are not put in situations where they cannot make a meaningful contribution. However, tensions arise in implementing this principle in practice. There is a need to balance definitions of role with openness to the views of patients, and to novel, unanticipated benefits that may accrue from their involvement. Giving direction and purpose to involvement must not equate to inflexible predetermination of the patient role by professionals.

Second, strong communication links between patients and other team members must be established if patients' voices are to be meaningfully

heard. Importantly, too, certain qualities may be required of patients themselves: they may need to be strong characters with the necessary confidence and skills to get their voices heard, either among the project team or when interacting with clinicians at participating sites. Again, this may challenge the calls of those who see patient involvement principally in terms of 'representativeness': patients with the qualities necessary to get involvement to work may well be atypical of their peers. The contributions of such individuals may make them particularly valuable, but makes the question of how far their interests and concerns reflect those of the wider patient population all the more pressing.

Our findings provide some support for the idea that careful selection of patients, according to the particular role envisaged for them, may be important. While Peat *et al.*¹⁸ argue that effective patient involvement in QI will need to draw on 'well-informed' patients, others are less convinced about such selectivity.⁹ However, recent studies have articulated and advocated a role for patients beyond simple 'demographic representativeness',³¹ noting how the wider knowledge and interests that constitute 'laity' can contribute productively to patient involvement.

Our data suggest that patient involvement in improvement work can be beneficial and play an important role in achieving the desired changes, but requires careful management if its full potential is to be realized. Thinking carefully about the rationale for patient involvement, identifying the most appropriate model to use, having clarity on the role(s) patients will play and ensuring that effective involvement strategies are in place, are important steps towards facilitating the involvement of patients in ways that harness its full potential, and the distinctive roles that patients can play in improvement work.

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References

- 1 Davies C, Wetherell M, Barnett E. *Citizens at the Centre: Deliberative Participation in Healthcare Decisions*. Bristol: Policy Press, 2006.
- 2 Øvretveit J. *Does Improving Quality Save Money? A Review of the Evidence of Which Improvements to Quality Reduce Costs to Health Service Providers*. London: Health Foundation, 2009.
- 3 Dixon-Woods M. Why is patient safety so hard? A selective review of ethnographic studies conducted as part of the Patient Safety Research Programme. *Journal of Health Services Research and Policy*, 2010; **15**: 11–16.
- 4 Shekelle PG, Pronovost PJ, Wachter RM *et al.* Advancing the science of patient safety. *Annals of Internal Medicine*, 2011; **154**: 693–696.
- 5 Dixon-Woods M, McNicol S, Martin G. Ten challenges in improving quality in healthcare: lessons from the Health Foundation's evaluations and relevant literature. *BMJ Quality and Safety*, 2012; **21**: 876–884.
- 6 Abelson J, Forest PG, Eyles J, Smith P, Martin E, Gauvin FP. Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. *Social Science and Medicine*, 2003; **57**: 239–251.
- 7 Martin GP. Public and user participation in public service delivery: tensions in policy and practice. *Sociology Compass*, 2009; **3**: 310–326.
- 8 Frankish CJ, Kwan B, Ratner PA, Wharf Higgins J, Larsen C. Challenges of citizen participation in regional health authorities. *Social Science and Medicine*, 2002; **54**: 1471–1480.
- 9 Craig GM. Involving users in developing health services. *British Medical Journal*, 2008; **336**: 286–287.
- 10 Fudge N, Wolfe CDA, McKeivitt C. Assessing the promise of user involvement in health service development: ethnographic study. *British Medical Journal*, 2008; **336**: 313.
- 11 Staniszewska S, Herron-Marx S, Mockford C. Measuring the impact of patient and public involvement: the need for an evidence base. *International Journal for Quality in Health Care*, 2008; **20**: 373–374.

- 12 Oliver S, Rees R, Clarke-Jones L *et al.* A multi-dimensional conceptual framework for analysing public involvement in health services research. *Health Expectations*, 2008; **11**: 72–84.
- 13 Nilsen E, Myrhaug H, Johansen M, Oliver S, Oxman A. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews*, 2006; CD004563.
- 14 Vincent CA, Coulter A. Patient safety: what about the patient? *Quality and Safety in Health Care*, 2002; **11**: 76–78.
- 15 Koutantji M, Davis R, Vincent C, Coulter A. The patient's role in patient safety: engaging patients, their representatives, and health professionals. *Clinical Risk*, 2005; **11**: 99–104.
- 16 Jaques H. Putting patients at the heart of quality. *British Medical Journal*, 2012; **344**: e3164.
- 17 Ling T, Soper B, Watt A *et al.* *Evidence: Involving Primary Care Clinicians in Quality Improvement*. London: Health Foundation, 2012.
- 18 Peat M, Entwistle V, Hall J, Birks Y, Golder S, on behalf of the PIPS Group. Scoping review and approach to appraisal of interventions intended to involve patients in patient safety. *Journal of Health Services Research and Policy*, 2010; **15**: 17–25.
- 19 Church J, Saunders D, Wanke M, Pong R, Spooner C, Dorgan M. Citizen participation in health decision-making: past experience and future prospects. *Journal of Public Health Policy*, 2002; **23**: 12–32.
- 20 Martin GP. Representativeness, legitimacy and power in public involvement in health-service management. *Social Science and Medicine*, 2008; **67**: 1757–1765.
- 21 Harrison S, Mort M. Which champions, which people? Public and user involvement in health care as a technology of legitimation. *Social Policy and Administration*, 1998; **32**: 60–70.
- 22 Entwistle VA, McCaughan D, Watt IS, *et al.* Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. *Quality and Safety in Health Care*, 2010; **19**: e33.
- 23 Eisenhardt KM. Building theories from case study research. *Academy of Management Review*, 1989; **14**: 532–550.
- 24 Aveling E-L, Martin GP, Armstrong N, Banerjee J, Dixon-Woods M. Quality improvement through clinical communities: eight lessons for practice. *Journal of Health Organization and Management*, 2012; **26**: 158–174.
- 25 Woods DD, Dekker S, Cook R, Johannesen L, Sarter N. *Behind Human Error*. Farnham: Ashgate, 2010.
- 26 Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine, 1967.
- 27 Rutter D, Manley C, Weaver T, Crawford MJ, Fulop N. Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science and Medicine*, 2004; **58**: 1973–1984.
- 28 Martin GP, Finn R. Patients as team members: opportunities, challenges and paradoxes of including patients in multi-professional healthcare teams. *Sociology of Health and Illness*, 2011; **33**: 1050–1065.
- 29 Dixon-Woods M, Bosk CL, Aveling E-L, Goeschel CA, Pronovost PJ. Explaining Michigan: developing an ex post theory of a quality improvement program. *Milbank Quarterly*, 2011; **89**: 167–205.
- 30 Donaldson LJ. Put the patient in the room, always. *Quality and Safety in Healthcare*, 2008; **17**: 82–83.
- 31 Barnes M, Newman J, Sullivan H. *Power, Participation and Political Renewal: Case Studies in Public Participation*. Bristol: Policy Press, 2007.
- 32 Lomas J. The in-between world of knowledge brokering. *British Medical Journal*, 2007; **334**: 129–132.
- 33 Martin GP. 'Ordinary people only': knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of Health and Illness*, 2008; **30**: 35–54.