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Subjective Experience or Objective Process: understanding the gap between values and practice for involving patients in designing patient-centred care

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Abstract:

Purpose: Patient-centred care and patient involvement are increasingly central concepts in health policy in the UK and elsewhere. However, there is little consensus regarding their definition or how to achieve 'patient-centred' care in everyday practice or how to involve patients in service redesign initiatives. This paper explores these issues from the perspective of key stakeholders within National Health Service hospitals in the UK.

Methodology: Semi-structured interviews, covering a range of topics related to service redesign, were conducted with 77 key stakeholders across three NHS Trusts in the West Midlands. 20 of these stakeholders were re-interviewed 18 months later. Data were managed and analysed using the Framework Method.

Findings: While patient-centred care and patient involvement were regularly cited as important to the stakeholders, a gap persisted between values and reported practice. This gap is explained through close examination of the ways in which the concepts were used by stakeholders, and identifying the way in which they were adapted to fit other organisational priorities. The value placed on positive subjective experience changed to concerns about objective measurement of the patients as they move through the system.

Implications: Increased awareness and reflection on the conceptual tensions between objective processes and subjective experiences could highlight reasons why patient-centred values fail to translate into improved practice.

Originality: The paper describes and explains a previously unarticulated tension in health organisations between values and practice in patient centred care and patient involvement in service redesign.

Keywords: Patient-centred care, Patient and Public Involvement, National Health Service, Service Redesign

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Introduction

There is increasing emphasis globally on making healthcare services ‘patient-centred’, on measuring patient satisfaction or assessing quality using patient experience data to redress the balance from emphasis on cost containment or clinical outcomes (Institute of Medicine, 2001), and on involving patients in the (re)design of services. Intuitively, it is easier to see the role of patients at a micro-level in the health system – engaging and contributing to decisions about their own care, or that of loved ones – and much of the literature and policy focuses on this level (Coulter *et al.*, 2008). A recent Cochrane review of interventions for providers to promote a patient-centred approach in clinical consultations identified three ‘behaviours’ that constituted patient-centred care: “shared control of the consultation, decisions about interventions or the management of health problems with the patient, and/or a focus in the consultation on the patient as a whole person who has individual preferences situated within social contexts” (Lewin *et al.*, 2009, p.16). However, there is a strong case also for involvement of patients at meso and macro levels, to ensure that organisations and whole health systems are patient-centred.

As part of a larger mixed methods study of service redesign in three Acute Trusts in the National Health Service (NHS), England, UK, we explored the effect of organisational culture on the approaches and success of service redesign, and one part of this involved examining the accounts that leaders and key stakeholders in the Trust gave of the concept of patient-centred care, and the practice of patient involvement. We identify a central tension in the stakeholders’ accounts between understanding patient-centredness in terms of subjective experience or as an objective process. This tension creates a number of challenges in the implementation of patient-centred care, which in turn affects the ways that patients are involved in redesigning services.

Background and Literature

The project

This study is part of a wider National Institute for Health Research (NIHR) initiative, the Collaborations for Leadership in Applied Health Research & Care (CLAHRC), which was initiated to investigate how best to bridge the gap between evidence from research being developed and its implementation in the NHS. The five year project, which set out to investigate and compare drivers, responses and outcomes of service redesign across

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three NHS hospital Trusts, has been divided into two phases: baseline and longitudinal. Baseline involved a comparative 'stock take' of the strategic approach to service redesign at the three Trusts (qualitative), and the outcomes they were achieving (quantitative). The longitudinal phase (currently ongoing) is evaluating redesign processes and outcomes comparatively across the three Trusts within specific clinical areas that were illustrative of key challenges facing the Trusts.

Policy

The World Health Organization (WHO) promotes patient-centredness as one of six attributes of healthcare quality, arguing that healthcare has become overly disease-focused and technology-driven and that medical education gives insufficient consideration to psychosocial, emotional and cultural context of patients (WHO, 2007). Moving towards a 'person-centred' approach to healthcare is suggested to balance the rights and needs of patients and their families with the capacities and responsibilities of health systems and organisations (WHO, 2007). With healthcare organisations seeking ways to make services more responsive to patient need and more efficient, patient engagement, which has been shown to be beneficial in improving experience and satisfaction with services, can often be overlooked and ignored (Coutler *et al.*, 2008). The WHO has provided guidance and policy options for healthcare organisations to improve patient involvement and engagement: initiatives at varying levels within a system (macro, meso and micro level) need to be well co-ordinated, mutually reinforcing and locally determined (Coutler *et al.*, 2008).

Political rhetoric in England, where this study was based, mirrors other parts of the world. The maxim 'nothing about me without me' (Delbanco *et al.*, 2001) has become common parlance in the health sector (Department of Health (DH), 2010). Initiatives have included the creation of Foundation Trusts (FTs), which were intended to enable hospitals to be more responsive to local needs, to give patients and staff greater influence and to increase the diversity of providers from which patients can choose (DH, 2001; 2007). However, commentators have noted that in many cases, there has been poor accountability to patients in FTs (Dixon *et al.*, 2010) and the recent Francis report (2013) on the failures of Mid-Staffordshire FT to protect the safety and dignity of patients has once again brought the issues into the public view. While public involvement is a statutory requirement for the NHS, recommendations made by LINKs (Local Involvement Networks), which include

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patient/user groups, local voluntary and community sector organisations and interested members of the public, are not binding (DH, 2009).

The concept of 'patient-centred' care

Over the past few decades the concept of a 'patient-centred' approach to health care has increased in popularity, yet there still remains little consensus to its meaning or how to achieve it in everyday practice (Florin & Dixon, 2004). Previous attempts at defining and explaining the concept have tended to evoke ideas related to 'seeing the illness through the patient's eyes' (Levenstein *et al.*, 1986), as well as practical suggestions such as involving patients in decision making processes (Winefield *et al.*, 1996). Others have argued the meaning of patient-centred care should be responsive to the needs of individuals and their perspective, in order to ensure patient values guide clinical decisions about treatment (McCormack *et al.*, 2011), which could potentially explain the variation in definitions. The concept has also been used to promote the ideal of an egalitarian doctor-patient relationship (Mead & Bower, 2000). Some studies viewed patient-centred care as an important end in itself while others viewed it as a means to improving particular healthcare outcomes (Lewin *et al.*, 2009). In the US, Berwick had defined it as 'the experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care' (2009: 560).

Most concepts and explanations share some key components: understanding the patient within their own psychosocial context; addressing the patient's perspective; involving patients in their care; reaching a shared understanding and agreement on treatment and care, and making decisions based on best evidence that are consistent with patient values and are feasible (Epstein & Street, 2004). Each of these components has a thriving literature and there are a plethora of related concepts. At the micro-level the literature is particularly well developed, for instance around patient choice and shared decision-making in clinical care (Charles *et al.*, 1997; Elwyn *et al.*, 2000; Elwyn *et al.*, 2003) although it is not at all clear that this has translated into changed practices (Stevenson, 2000). We now go on to explore two related concepts in more detail: patient experience and patient involvement, because of their importance at the service level: in assessing the patient-centredness of services and designing patient-centered services respectively.

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Assessing and measuring patient-centredness

Patient-centredness is difficult to assess. The Institute of Medicine in the US (IOM) includes patient centredness as one part of quality, which is defined as the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge (IOM, 2001). Berwick (2009) has argued, however, that ‘patient-centredness’ needs to be included as a dimension of quality in its own right, and suggests asking either the qualitative question: “Is there anything at all that could have gone better today from your point of view in the care you experienced?” or for quantitative ratings to ask patients on a 1–5 scale disagreement to agreement with the assertion: “They gave me all the care I needed and wanted exactly when and how I needed and wanted it.” (Berwick, 2009: 563). In the UK, the recently published friends and family test recommends that providers ask within 48 hours of using a service: “Would you recommend this service to friends and family?” (NHS Choices, 2013). However, concern remains about the variation in standards of assessing quality of patient care and particularly the quantification of aspects of quality (Campbell *et al.*, 2000) because gaps can occur between the concepts put forward and measures of these concepts in empirical work (Meehl, 1978). As Williams highlights in his review of the popular concept of ‘patient satisfaction’:

“Repeatedly when qualitative methodology is utilized ... little if any support is found for believing that patients think and evaluate in terms of a continuum of satisfaction” (Williams, 1994 :514)

In summary, for the concept of ‘patient-centred’ care, the validity and reliability of measures is limited by lack of clarity of the concept and the challenge of assigning numerical value to something that can be complex in a practical everyday setting (Mead & Bower, 2000). While qualitative investigations into ‘patient experience’ have additional benefits, introducing social context into the picture that emerges and highlighting patient-perceived narrative, which may not be the same as medical timelines (Blaxter, 2009; Hydén, 1997, Pierret, 2006), they can also be much more time consuming to undertake.

Involvement in the redesign of services

Involvement can be seen as an ‘end in itself’ as a democratizing and rights-based process, or as a ‘means to an end’ to improve outcomes (Ives *et al.*, 2011) and there is evidence to suggest that there is an important role

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for patients in improving the quality and responsiveness of services (Coutler & Ellins, 2007). Service redesign has been described as a collaborative approach to understanding how things work (Murphy *et al.*, 2011) within (part of) a health system and can have different goals at different times or places, including raising clinical outcomes, reducing costs or improving patient experience. The 'medical home' concept in the US has gained a lot of momentum in recent years for emphasizing patient-centeredness as the primary goal of redesign (Berwick, 2009; Kilo & Wasson, 2010).

Redesign is usually carried out in the context of broader health reforms or drives for more integrated healthcare delivery (Ferlie *et al.*, 2012; Leibert, 2011). Redesigning services and healthcare has been a key concept in improvement efforts internationally, and many countries have seen a rapid growth in redesign initiatives in order to try and achieve quick and effective pathways and care for service users (Locock, 2001). Redesign can involve anyone with a stake in the service - clinicians, allied healthcare staff, clerical and management staff, patients, carers and the public - in order to understand what affects it on a daily basis and on what basis its quality should be judged. It, therefore, relies on a high degree of partnership working and collaboration (Murphy *et al.*, 2011).

However, attempts to involve patients in redesign have had mixed success (Crawford *et al.*, 2002). There are few examples of patient involvement in the literature, especially at a strategic level (Hubbard *et al.*, 2007). Most patient involvement has comprised of 'one off' initiatives to engage patients in looking at specific services (Forbat *et al.*, 2009), which leaves people with very limited opportunities to influence the whole system of care. Forbat *et al.* (2009) have shown that more active models of patient involvement have been identified by healthcare staff after being exposed to an intervention to raise awareness and understanding of 'involvement'. A more recent review found many and varied patient and public involvement activities across the NHS within the UK but little robust evidence of impact was identified, along with a lack in consistency of definitions of involvement (Mockford *et al.*, 2012). Nevertheless, there clearly remains much confusion over how much power or influence patients can have on healthcare services, especially at a strategic or management level (Hubbard *et al.*, 2007).

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In short, while involvement in health services is at the forefront of national policy, and patient and public involvement is also becoming a requisite in health research (Ives *et al.*, 2012), the application of its fundamental principles to practice does not seem to be successful in many cases (Crawford *et al.*, 2002).

Tokenistic involvement, poor organisational support and lack of effective processes have been identified in the literature as potential reasons for this:

1) Early influential literature on involvement of citizens in public decision-making stressed the role of asymmetries of power in mediating involvement efforts, and identified that some strategies, namely informing and consulting, were tokenistic: they allowed citizens to have a voice, but without 'follow through', i.e. real power to change things (Arnstein, 1969). In health, and more recently, Crawford *et al.* (2002) identified that one reason to involve patients may be simply a method of legitimizing decisions of policy makers and administrators. The well-documented imbalance of power between patients and healthcare professionals has been highlighted to act as a barrier to involvement (Forbat *et al.*, 2009), and even the apparent transfer of power to service users can in fact be only tokenistic with no 'real' impact (Florin & Dixon, 2004). In the UK NHS, Anton *et al.* (2007) showed that some stakeholders considered it sufficient to simply inform patients and members of the public about service developments, whereas others expressed that a more active consultation was required, and they argued that it would be worthwhile to explore further current perceptions and practices.

2) Appropriate support, both in terms of organisational infrastructure and culture, has been identified as vital for healthcare organisations to deliver effective patient-centred care (Epstein *et al.*, 2010). Organisational change leading to patient-centred care requires ongoing commitment by 'leaders' within the organisation to support structural and personal transformations (Epstein *et al.*, 2010), and ensure staff have time and resources required to deliver high quality care (King's Fund, 2013).

3) This leads onto the third problem, which is identifying effective practical processes to redesign services that are patient-centred. While researchers in the field have suggested that "attitudes" need to change in order to reduce paternalism and encourage more collaborative working with patients, including a commitment to

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sharing power and control (Hubbard *et al.*, 2007), they do not always identify how it is possible to change attitudes. There are some places in the literature where this has been more developed, such as through the development and growth of experience-based co-design. Co-design is intended to promote meaningful involvement and ensure a sense of ownership among participants in decision making (Idema *et al.*, 2010), and there are parallel discussions in relation to co-production in research (Hewison *et al.* 2012). Experience based co-design (EBCD) goes one step further by introducing experience as a central goal of the redesign process. Healthcare has traditionally been associated with aspects of *performance* and *safety* in relation to providing 'good' quality care. Bate and Robert (2006) propose that in addition to these two core elements of 'good design' a third element, *experience*, should be considered. They argue that designing 'human experiences' is distinct from designing processes, and the process of EBCD (collecting patient accounts of their experience, identifying 'touchpoints' where poor experiences occurred commonly, and involving clinicians, managers and patients in leading working groups to address those problems) lends itself to the service user being integral to this. Further support for EBCD being utilised in the healthcare sector has shown that the process can lead to increased understanding of different perspectives, resulting in broader potential changes to mindsets and ultimately behaviour, as well as healthcare staff reporting a greater sense of empowerment to make service changes (Tsianakas *et al.*, 2012). However it has also been noted that quality improvement based on these experiences, is not always made a priority and most organisations have inadequate systems for the collection and co-ordination of such information (Tsianakas *et al.*, 2012).

During our research, our analysis brought us full circle to the challenges of definition and meaning. Clearly there is a lot of disagreement in the literature about the definitions, boundaries and scope of patient-centred care and patient involvement and, for the purposes of our research, we felt it was important that we did not close down our definitions too early. What is clear is that in policy, at least, 'more' is 'better' around these two concepts. Our interest was sparked not by an attempt to resolve or clarify technical definitions of either concept, but to ask ourselves critical questions about the context and deployment of these concepts when people talked about them. To help understand how patient-centred care is conceptualised, perceived and implemented at a strategic level within NHS organisations, we asked the question of our data: 'What are the attitudes towards and accounts of patient-centred care and patient involvement among key organisational

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stakeholders in acute Trusts?' Our aim was to try and discern at a theoretical level where the 'problems' lie with how these concepts are interpreted and operationalized for those in leadership and senior positions within the health services. We present in this article, our findings in relation to the conceptual slippage in the way those in strategic positions talked about involving patients in the design of patient-centred care – between patient-centred care as subjective experience or objective process.

Methodology

This project was part of a broader mixed methods study of service redesign at three Acute Trusts in England. A major theme of this work was to understand the way that organisational culture shapes redesign efforts within the Trusts and we focused our efforts around, what we termed within the project, three 'domains of culture' – patients, people and place. This paper draws on analysis undertaken in the 'patients' domain. We employed a qualitative methodology, collecting individuals' accounts of the approach to service redesign at their Trust. This was intended to access subjective accounts of actions and behaviours, as well as the values and habits that underpin them (that can be reflective or pre-reflective). Through the analysis, we wanted to describe these values and habits, and unpick interpretively the basic cultural assumptions in which these more visible layers of culture are embedded (Schein, 2010). In explaining how these accounts have been formed, we aim to identify at a more theoretical level what it is about the organisational culture that produces the behaviours that we can observe. The truism, 'Every system is perfectly designed to achieve exactly the results that it achieves' is clearly relevant for cultural systems.

The project was deemed service evaluation by the National Ethics Research Service (NRES) therefore did not require NHS ethical approval. Ethical approval was sought and obtained from each of the Trust Research and Development departments as well as university ethics (ERN_10-0034). Semi-structured interviews were conducted with 77 key informants (Table 1) in three acute Trusts and across the local health system. Purposive sampling was employed with the aim of obtaining a strategic view of the organisations by interviewing senior executives, managers and clinicians (medical, nursing and allied health professions) and staff side representatives. Interviewees were identified from a list, populated by the three Trusts, which gave details of

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post-holders with strategic responsibilities. Eighteen months later (approximately six months after our baseline report was delivered to the Trusts), 20 of the original sample were re-interviewed, focusing on the most senior posts. Naturally, there were a few cases where people had moved jobs so we interviewed the new post-holder. The interviews covered the individual's role in the organisation and in relation to service redesign, their view on the changes taking place, their objectives in their role, the methods being used to deliver those objectives, current working priorities, the impact that changes were likely to have across the wider healthcare system, and their views on the research project. At the follow up interviews, the same questions were asked, and the research team were keen to explore whether any of their formative feedback had influenced the development of strategy in the Trust.

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Job role	Baseline Phase			Follow up		
	Town	University	Urban	Town	University	Urban
Executive team	11	8	6	5	4	4
External Executive	1	0	11	0	0	2
Managerial	5	17	2	3	0	2
Clinician (including GPs)	1	0	8	0	0	0
Patient representative	1	1	1	0	0	0
Other	1	1	0	0	0	0

Table 1: Participants included in the study

There were no specific questions on patient-centred care or patient involvement in the interview schedule, but the topics emerged spontaneously in the discussion. Interviews were conducted in a manner that gave respondents the opportunity to expand on areas of concern. They were encouraged to discuss experiences and perceptions freely as all data are reported anonymously. Analysis of these data was useful to draw out views and values about these issues, without priming interviewees. If you ask people directly about concepts such as patient-centred care, then you risk getting only the ‘right’ answers, as the interviewee tries to present themselves as compliant with the dominant value system, and will give an account that fits the image s/he is trying to present. Analysing data that is collected in the wider context of a study on service redesign, at worst, provides an alternative account which can counterbalance overly optimistic accounts and, at best, actually increases the validity of the data.

The research team that carried out the interviews and analysis was multi-disciplinary (clinical – surgical and medical, medical sociology, health economics, health services research, health psychology). To promote consistency of approach in interviewing, each interviewer observed at least two other interviewers at the early stages of the process. Data were managed and analysed using the Framework Method (Ritchie & Lewis, 2003), a qualitative analysis method where data are analysed to develop content-based themes, transcripts are coded

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using this analytical framework, then data are summarised into a matrix, with themes on one axis and individual participants (cases) on the other. This enables within case and between case analysis. The themes that we interrogated for this article were:

NATIONAL CONTEXT – User involvement and patient choice

LOCAL CONTEXT – Community attitudes [to the Trust and its services]

LOCAL CONTEXT – Workforce

TRUST OBJECTIVES – Trust values and vision

TRUST OBJECTIVES – Patient-centred care

PROCESSES – User Engagement

The constant comparative method was used to analyse these data. After the baseline phase, formative findings were fed back to the collaborating Trusts. This feedback aimed to highlight key strengths and weaknesses of the Trusts' approaches to patient-centred care, and offer a comparative picture of how the other Trusts were addressing the same issues. The feedback was delivered via facilitated workshops with each Trust that were designed to encourage collaboration with clinicians and NHS managers in order to identify appropriate clinical services to focus on over the longitudinal phase of the project. This feedback is being repeated for the second round of interviews.

Findings

The perceived importance and practical role of patients in service redesign was an important theme in the accounts given by those in strategic positions in the Trusts, however, the picture was not straightforward. Concepts of patient-centred care and patient involvement were frequently evoked by participants as representing a core *value*, but accounts of successful *translation* of these values into *practice* were much less forthcoming. Interviewees often provided accounts of contextual or attitudinal factors that were either explicitly or implicitly *obstacles* to the implementation of these values.

There were some noticeable differences between the three participating Trusts that can be understood within the wider context of their size, financial position and the population they serve. University Trust is a large

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hospital that was recently formed from the merger of two medium sized hospitals; during this project, a new privately-financed hospital has been opened and all services have moved to the single new site. Urban Trust is also the result of a merger between two medium sized Trusts. It remains on two main sites, plus a small community hospital. Town Trust is a single site, with a new hospital building, completed during this study, serving the inhabitants of a town. We will draw out distinctions where necessary but, for the purposes of this discussion, we will focus on the issues that cut across the three Trusts.

Objective and subjective definitions of patient-centred care

In all three Trusts, the concept of 'patient-centred care' was regularly alluded to as an aim or principle underlying service redesign, and implicated in the Trust visions more broadly in terms of 'improving patient experience'. For instance, an Executive team member of University Trust said, 'everything we do... it has got to improve the quality of care for patients, otherwise we're not doing it'. A clinician at Urban Trust said, 'we focus on the fact that there is a patient as the end of every sample [we process]', and an Executive team member at Town Trust explained, 'we came up for a brand for the hospital which is, we just call it "Better", because it fits with so many things, like getting better for patients, getting better for staff'.

Embedded in the rhetoric about patient-centred care, as it was described by the interviewees, was the belief that it would inevitably also result in improved organisational efficiency, thereby meeting the requirement for financial discipline within the organisation. In order to achieve this, perhaps counterintuitive, melding of financial and quality aims, the accounts engineered a shift from patient-centredness as a subjective experience to one of objective processes:

The patients are the widgets that we move around the system, but we've missed the fundamental point, the inefficiency of the service comes because we move the patients. If you keep the patient in one place and move the service to the patient the service actually becomes far more efficient because you're not fragmenting the service. (Executive #1, University Trust).

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With this rhetorical shift in place, 'patient-centred' care could then be aligned with other organisational objectives, such as reducing the length of stay:

[For] services that are better aligned to patients ... throughput of patients will be better, or higher, because of less time spent in hospital. (Patient Representative, Town Trust).

Good quality care is not keeping this patient in hospital, good quality care is getting them out and back to a healthy living standard outside of the hospital. (Executive #2, University Trust).

The patient in these accounts is not a subject with independent views and experiences who can take control of their journey, but an object of care around which an efficient organisation can be planned. Notably, some interviewees did recognise the limitations of this approach:

I think ... because we've become very target driven, there's a sort of conveyor belt mentality ... We've got to get the patients through, rather than looking at them as people, they've become a product on a journey that's got to quickly get out of the hospital. (Nurse, Urban Trust).

However, the focus on objective processes was bolstered by other organisational drivers, such as the improvement of information management and technology. It is not an overstatement to say that there was a preoccupation with trying to *measure* patient experience. A few interviewees did describe the limitations of quantitative measures to assess patient experience:

When people write and complain ... "I felt undignified, I felt frightened", it's feel, it's that powerful word, which is not an objective word ... when they're writing to give compliments, they say "I felt safe, I felt cared for", that's what we've got to capture. They don't say my wound was clean. I got my drugs on time. Do they? ... They're not measuring us by metrics. (Executive #3, University Trust).

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Nevertheless, in practice, effort was focused at all Trusts on refining measurement and collecting more information and more promptly, rather than questioning its basic value. As a result, the information collected through various information systems was largely *about* patients, or even more abstractly about performance, rather than *for* patients:

Informatics [is] driving quality without a shadow of a doubt ... it's about measuring it better.

(Executive #4, University Trust).

So there's a drive within the division to get patients there rather than sitting on the ward once they're waiting for their tablets, waiting for someone to come and pick them up, sitting on the bed when someone else could be in it. And that's all monitored and measured and sent out monthly in terms of which wards are performing and which aren't. (Nurse, Urban Trust).

An exception to this was a potential new initiative at University Trust to create information for patients:

I'm toying with trying to work out a way to ... develop an electronic schedule for patients that tells them ... when they can expect things to happen ... because I think that some patients do get confused by what they're told and I think that people use different terminology and mean the same thing ... if we've got it all in one place and the patients that were able to could actually look at what was going on they could see I'm due for an x-ray today at 11.00 and I'm going to get my drugs at around 1.00pm and I thought that would be quite useful. (Executive #5, University Trust).

In some cases, measuring objective processes gave unexpected insights into subjective experience, which could then be acted upon:

So one of the things our audit showed us was that huge numbers of our patients were getting – were coming in, were being put on a production line that was completely inappropriate ...what they really

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*wanted was to be put on an end of life care pathway and managed in a much more humane way
(Executive #1, Urban Trust).*

Ironically, attempts to measure patient experience were contributing to suspicion about the value of the concept, because they were seen (correctly) as problematic, for instance:

So the quality of care is good and we're marginally improving that, the patient experience, well the new hospital is improving although paradoxically people are more unhappy with the new hospital because of expectation. Our complaints have gone up since we moved (Executive #1, University Trust).

Engagement/involvement of patients in service redesign

It is a logical step from arguing that patient experience is vital to the whole picture of quality, to arguing that patients should have a voice in redesign processes. Certainly, some of the interviewees expressed views and values that would support this in terms of the patient being able to provide a unique perspective on the service:

What we have also found though is that staff don't always know best about what produces the best service, they know a lot about how to organise their services, but they don't necessarily see things from a patient's perspective (Executive #2, Urban Trust).

Some of the interviewees' accounts do show a willingness to listen to patient's concerns and act on them, however, in practice, what was happening was more often *consultation* about proposed changes or *communication* about actual changes that had taken place and asking people's views on these. Underpinning this mixed picture of involvement was a marked ambivalence about what contribution patients and the public could make to debates on redesign (i.e. the value of subjective experience). Many clinical and managerial interviewees from all three Trusts expressed the view that the local population did not really understand how the health system worked, giving examples such as the inappropriate use of emergency services. The

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conclusion they then came to was that patients did not have sufficient expertise to contribute usefully to service redesign:

At the end of the day I've been in other places where I've worked is that we've had patients who have been involved in trying to sort out patient pathways and because they haven't got the experience and the knowledge and expertise, they just get completely lost in the system ... in the end, patients do get disillusioned and what they would prefer really is to see an output, really, to say, actually, and then share that with them, would that work, rather than being involved up front. (Executive #1, Town Trust).

In the second round of interviews (after the executive teams had received feedback from the research team) some changes were evident, even if the involvement described remains primarily at a service, rather than strategic, level:

Where we pick up an issue that's recurrent, we're going to set up a system, a system of triggers to it triggers an intervention whereby we then meet face to face a group of those patients and we hear straight off, as with the bariatric, what the issues are from their mouths, let them get it off their chests, work with them to put it right, so the patients have got a degree of ownership, empowerment at an early stage and are brought in as part of the process. (Executive #2, Town Trust).

In many of the accounts, there was confusion between patient involvement and patient choice. This then led to language around 'marketing' or 'selling' the service to patients, and methods being used such as consultation on changes or even simply communication about changes after the event:

With a good debate with them, we do it all the time, our patients have been involved, hugely involved in our service redesign efforts, we're saying to them 'Actually we're shutting this bit of the service but we're opening this, what do you think?' And actually we're selling it to our

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patients and they're designing it with us. We've have no problem with our patients, it's how you do it. (General Practitioner, in Urban Trust region).

It's about patient choice, so it's about putting the market out there so people know they can come here and look at things like our waiting times to make sure that they're nice and short, so people choose then to come here. (Nurse, Town Trust).

Nevertheless, even within this language of consumer choice, a paternalistic attitude persisted in some accounts, especially in the context of a deprived local population:

I don't know what choice do you really have if you live in some of the housing estates in [Town] ... Your bus comes into the centre and then the bus takes you to the Hospital ... [choice is] absolute rubbish and there are some people, educated middle class people who will take advantage of it, but the core people ... They're not comfortable with choice, they're comfortable with what they want, so our job is to deliver the best service to them here. (Non-Executive Director, Town Trust).

At Urban Trust, however, there was some evidence of more positive accounts of engaging the public on not only service-level but also strategic changes:

So we kind of did a whole load more ground work, pre, pre consultation, you know, what are the things that are bugging you, what are the weaknesses of services? What might be some of the options and I just think we kind of got off on the right foot and didn't try and come to them saying we know what we're doing here please will you agree with it? And I think they've carried on doing that. (Executive #3, Urban Trust).

Discussion and Limitations

There is an underlying tension in these data between the recognition of the centrality of the patient to the aims of redesigning services to be more patient-centred, with ambivalence about the role that patients could

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usefully play in the redesign process. Our findings certainly support the argument elsewhere in the literature that there is great variation in the meaning of patient-centred care (i.e. Florin & Dixon, 2004). We add to that literature by exploring empirically the way the concept is perceived and used by those in strategic roles in acute Trusts, and argue that this can help explain some of the problems in implementing change that involves patients in a meaningful way. We have observed that those with strategic responsibilities to the organisation, tend to emphasise the objective processes over the subjective experience of patients, and those embedded in specific professional value systems tend to emphasise the value of their professional knowledge (clinical outcomes) over patient-identified outcomes. These specific findings can be generalized by the observation that the variation in definitions can be accounted for by critically examining positionality (Walt *et al.*, 2008), i.e. the social location and goals of the individual or organisation doing the defining.

As we noted in the background, 'quality' is often uncritically defined in terms of quantitative outcome measures rather than qualitative assessments (Popay & Williams, 1998) but there are a number of problems with measuring patient experience because it is a complex concept not easily reducible to metrics (Campbell *et al.*, 2000). Our research has shown that when the emphasis is on objective processes, with the aim of increasing efficiency and improving clinical outcomes, the tendency is to continue to collect quantitative data to assess progress on 'patient experience', even when the complexity and qualitative nature of patient experience is openly acknowledged. Indeed, energy is put into refining and speeding up the process of data collection and analysis, rather than questioning its value or comprehensiveness. Ironically, the challenge of assessing patient experience is then sometimes used rhetorically to undermine the value of assessing patient experience because the measures used are not seen as valid or reproducible in other situations. This disconnect between subjective experience and objective process is also mirrored in the disciplinary boundaries and power relationships between different types of health service scholarship – particularly between those disciplines that place value on subjectivity, such as qualitative medical sociology, nursing and medicine, and those that tend to value objectivity, such as health economics and management. Similarly, there are echoes of this duality in different health and care settings (nursing and social care, as opposed to medicine and surgery) and in different reform ideologies (such as those focused on principles of democracy and involvement and

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those, such as the New Public Management, focused on markets, managers and measurement (Ferlie *et al.*, 1996)).

From the data it appears that the Trusts have a willingness to strive towards involving patients in service redesign to ensure services become patient-centred, not least to align themselves with national and international policies and values; however some of the interviews highlight the finding that patients and the public are perceived, by some stakeholders, to be 'lacking' in the knowledge/expertise and experience required for direct input into redesign efforts. This is not to say that the experiences of patients are not valued, but that patients are not perceived as well placed, at a strategic level, to assist in major redesign initiatives.

Overall, organisations hold patient-centred care as an important value but there are a number of reasons why this does not translate into successful implementation. Adapting Schein's (2010) levels of culture model, we observed that, first, other values intersect with these, such as professional values, corporate values or personal values (including those that are a result of previous experience). Second, even when values support a concept, habits within the organisation may mean that it is difficult to change practice. Habits are the 'way things are done' in the organisation that largely go unchallenged. Third, values and habits must intersect with organisational and professional structures, such as complying with national and local targets or lines of accountability within the organisation. Sometimes, these structures are not set up to support patient involvement, or would require significant bureaucratic changes. Finally, the values and habits of individuals and the structure of organisations are underpinned by the basic assumptions within the health and political system, such as the medical model (that emphasises clinical outcomes over patient experience) and the value of different types of knowledge (medical and quantitative knowledge, over lay or qualitative knowledge).

Implications

There are implications of this study both for practice and policy. The concepts of subjective experience and objective process have a clarity and pleasing simplicity to them which is easy to convey to policy makers, managers, clinicians and the public. This clarity makes them a useful way to start critical and open

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conversations in a variety of health and care arenas where problems are identified by any stakeholders in terms of creating patient-centred services. Discussions could be facilitated using the following model of simple starting questions:

- What does patient-centred care mean to me?
- How would I know that it was taking place?
- How does our organisation measure or qualitatively assess patient-centred care?

‘Subjective experience’ and ‘objective process’ could then be used as sensitizing concepts to categorize the ideas that had emerged and prompt discussion about what could be done differently, for instance, using the triad of questions often used in engagement work in many fields: What should we stop doing? What should we keep doing? What should we start doing? (Daniels, cited in DeLong & DeLong, 2011; Hewison *et al.*, 2012). The involvement of people at all levels, including organisational leaders, is required to ensure buy-in to the recommendations from this kind of discussion. This might also complement, or lead to, work to undertake experience-based co-design.

Policies, at national and organisational level, should go beyond the rhetoric – a commitment to patient-centred care – to outline the mechanisms that might help and the ways in which success could be assessed. The problem is well illustrated by our study participants who valued patient-centred care, knew they should be doing it, but struggled to articulate what it involved. In the UK, the NHS Constitution, for instance, stated that ‘The NHS aspires to put patients at the heart of everything it does’ (DH, 2013) but does very little to articulate how this might be achieved. Caution should then be exercised by those writing policy statements or commissioners of services not to fall into the conceptual slippage between objective process and subjective experience themselves: for instance, by asking for patient-centred care to be evidenced solely through objective measures (e.g. length of stay, clinical outcomes). Real attention to patient experience (not simply satisfaction) as an indicator of patient-centred care and use of well developed methods such as experience-based co-design where problems are found, could provide a useful counterbalance to clinical and financial outcomes as central measures of quality.

Conclusions

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While those involved in strategic decisions in these three hospital Trusts articulated values that emphasised the importance of redesigning services to be patient-centred and supporting patient involvement in those processes, the emphasis in their accounts was much more on the patient as an object within an organisational process, rather than as an active independent subject with control and ownership over their experience. We have argued that a mismatch between the needs of the organisation and the needs of the patient creates a dissonance between objective processes and subjective experience, which needs addressing. This dissonance can also be explained by the persistence of habitual action (for non-involvement) by those in the health system and basic assumptions about power and responsibility (clinician- and management-centred) built into the structure of the health system. Future redesign initiatives to make services more patient-centred need to consider how to redress this balance, in order to give more weight and value to the subjective experience of patients. Part of redressing the balance involves rethinking the methods of assessing patient experience because encouraging narrative accounts of experience could be more valid and meaningful to those with the power to make changes.

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