



## Quality improvement in New Zealand healthcare. Part 6: keeping the patient front and centre to improve healthcare quality

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### Abstract

Patient-centred care is arguably the most important of the dimensions of quality as it is likely that a healthcare system which is patient-centred will also perform well against the other dimensions—safety as well as timely, accessible, effective, and efficient care. What does it mean to be patient-centred and how can it be achieved?

This article explores several definitions of patient-centred care and discusses two interpretations—the expert patient and shared decision-making. Being sick is inherently a vulnerable position to be in and our current healthcare system does little to recognise and alleviate this vulnerability. But the patient-centred approach is about more than making the journey for patients less tortuous, it has actually been shown to improve outcomes. The evidence of benefit for a patient-centred approach is reviewed, along with some of the challenges in implementing the concept in practice.

Most providers will see themselves as patient-centred—patients are the reason for coming to work. But many of our structures, particularly in hospital-based care, conspire against effective patient-centred care. For example, restrictive visiting hours create barriers for family to support patients at times of great anxiety and limit opportunities for providers to discuss management options with patients and their families.

A simple rule of “keeping patients and their loved ones together through the care process” would lead to entirely different designs compared with the rule that patients don’t belong in technical areas or that wards should be quiet in the mornings.<sup>1</sup>

In primary care, lack of timely access to care and short rushed visits create dissatisfied patients and frustrated doctors. Alternative reimbursement systems could provide greater flexibility in the delivery of care. For example, team members other than doctors, using web and email patient portals, could perform routine preventive care and manage some patients with chronic conditions.<sup>2</sup> This would free up time for doctors to provide better access for visit-based care (where appropriate), and to improve the quality of the consultation.

Recognition that non patient-centred care is rife has contributed to the call for patient-centred care to become a policy priority in most healthcare systems. This has been reinforced by challenges to traditional medical paternalism and increased access to health information, along with the rise of consumerism and knowledge that patients experiences are potentially powerful levers for quality improvement.<sup>3,4</sup>

In New Zealand, the Code of Health and Disability Services Consumers' Rights Regulation 1996, developed in response to the Cartwright Report of 1988,<sup>5</sup> established patient-centred care as a priority. The Bristol Enquiry led to the British Government placing improving patients' experiences higher up the agenda, thus making it the central theme of its plan for the National Health Service (NHS) in 2000.<sup>6</sup>

In the United States, following publication of the report *To Err is Human*, the Institute of Medicine (IOM) published a second report calling for a complete redesign of the healthcare system to make it more patient-centred.<sup>1</sup> They analysed the needed changes in terms of four levels of healthcare:

- Level A: The experience of patients.
- Level B: The functioning of small units of care delivery (microsystems).
- Level C: The functioning of organisations.
- Level D: The environments of policy, payment, regulation, accreditation, and professional training.<sup>1</sup>

Levels A and B are where patients and the healthcare system interact; organisations support the microsystems that deliver care and these in turn are supported by the healthcare environment. While changes are required at all levels to improve quality, it is the “experience of patients, their loved ones, and the communities in which they live” which are the “true north” of the model.

In other words, actions taken at levels B, C, and D should be measured in terms of their effects on the patient experience “and in no other way”.<sup>1</sup> This message has been reiterated by Ron Paterson, Health and Disability Commissioner for New Zealand. He suggests that the first question whenever a policy issue arises for public debate should be:

“How will this proposal affect the health and wellbeing of the community?”<sup>7</sup>

## Definitions

Patient-centred care—a simple “sound bite” but a complex concept.<sup>8</sup> It is most commonly described in terms of what it is not—disease-, doctor-, technology-, or hospital-centered.<sup>9</sup> Various terms are often used in association with the concept of patient-centred care, such as “shared decision making”, “integrated medicine”, “empowerment”, “informed choice”, “dignity in healthcare”, “concordance”, and the “expert patient”.<sup>8</sup>

In New Zealand, the Ministry of Health's *Improving Quality* document talks about “people-centred” rather than patient-centred care, and defines this as:

...the extent to which a service involves people, including consumers, their families and whanau and is receptive to their needs and values. It includes participation, appropriateness and adherence to the Code of Health and Disability Services Consumer Rights 1996 and adherence to other consumer protections such as the Health Information Privacy Code 1994.<sup>10</sup>

By alluding to the Code of Health and Disability Services Consumer Rights 1996, it acknowledges patients' rights' as integral to patient-centred care, a common omission in other definitions.<sup>11</sup> The words “the extent to which a service involves people” implies an application of patient-centred care beyond the patient practitioner

interaction, thus reflecting to some extent the importance of collaboration between patients, families, healthcare practitioners, and hospital leaders in all aspects of healthcare at all levels of the healthcare system.<sup>12</sup>

The Picker Institute, an international organisation which seeks to improve the quality of healthcare by considering the patient experience, has identified what they believe a patient-centred service should deliver:<sup>13</sup>

- Fast access to reliable health advice.
- Effective treatment delivered by trusted professionals.
- Participation in decisions and respect for preferences.
- Clear, comprehensible information and support for self care.
- Attention to physical and environmental needs.
- Emotional support, empathy, and respect.
- Involvement of and support for family and carers.
- Continuity of care and smooth transitions.

This definition is useful to the extent that it operationalises (to a degree) the definition of patient-centred care for a service.

These definitions of patient-centred care demonstrate similar themes (see Box 1), and are indicative of a fundamental shift in the balance of power in the patient-practitioner relationship—from patients as passive recipients of healthcare to patients as active participants with guaranteed rights.

There is, however, now an emerging discussion in the literature however about patients' responsibilities, particularly with reference to the growing costs of unhealthy lifestyles and the fact that patients can actively influence the outcomes of care both for good and for bad.<sup>14</sup> These are important issues, but such discussions must take account of the fundamental inequality of information, expertise, and power that persists in the patient practitioner relationship.

Being sick is inherently a vulnerable position to be in. Kelley argues that placing more emphasis on professional responsibility is “largely correct” and emphasises the importance of a cautious approach to patient responsibility based on persuasion and encouragement rather than blaming patients for past behaviour.<sup>15</sup>

### **Box 1. Common themes in patient-centred care**

Informing and involving patients. Eliciting and respecting patient preferences. Engaging patients in the care process. Treating patients with dignity. Designing care processes to suit patient needs, not providers. Ready access to health information—both paper and electronic. Continuity of care.
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## Models of patient-centred care

Patient-centred care has mostly been described in the context of chronic disease management (e.g. diabetes) in primary care. The concepts of the *expert patient* and *shared decision-making* are models of patient-centred care.

**The expert patient**—The “Expert Patient Programme” (EPP) is an initiative implemented in the UK by the NHS. Its intent is to enhance patient autonomy and reduce reliance on limited healthcare resources by promoting the need for patients to be more actively engaged in managing their own conditions.<sup>16</sup>

The EPP is based on models of chronic disease self management developed at Stanford University<sup>17</sup> and successfully tested in the 1990s.<sup>18</sup> It involves a structured 6-week training programme designed to give people the confidence, skills, and knowledge to manage their disease and to minimise its impact on their everyday lives. Expert patients are those who “take responsibility for the day-to-day decisions about their health and who work with healthcare providers as collaborators and partners to produce the best possible health given the resources at hand.”<sup>17</sup>

The UK NHS piloted and evaluated the EPP between 2001 and 2004. Self reported data from participant questionnaires before and after the programmes suggested improvements in levels of confidence in managing pain, tiredness, depression, and breathlessness; reductions in GP visits, A&E attendances, and outpatient appointments; and improved compliance with medication and other treatment regimes.<sup>18</sup>

The programme has not, however, been without its critics.<sup>16,19</sup> Questions have been raised about the extent to which a patient can be considered an “expert” and the implications for healthcare practitioners in accepting patients taking a more active role in their care.<sup>19</sup> Some of these concerns can be addressed by understanding the distinction between illness and disease, as expressed in the old adage, “you go in to the doctor with an illness and come out with a disease.”<sup>16</sup>

Illness is what the patient experiences. They bring the knowledge of their condition (gained from a variety of sources) to the patient/practitioner encounter, as well as their unique experience of their illness described in terms of symptoms; how these impact on their quality of life, how they manage these on a day-to-day basis, and what recovery or healing might mean to them. In this respect, they may indeed be considered “expert” in the sense that they understand their illness as they experience it and manage it.

In contrast, doctors understand and manage diseases. This requires a technical expertise based on knowledge about the pathophysiology of disease as well as diagnostic and treatment procedures. This technical expertise is enhanced by the skill that experienced practitioners, in particular, have in coping with uncertainty and atypical presentations. This key professional attribute, important in medical decision-making, has been called “phronesis”, defined as “the ability to make good decisions and take effective action in unfamiliar situations”.<sup>16</sup>

In the context of the EPP which calls for collaborative partnerships between patients and practitioners, more effective collaboration is possible when there is a clear demarcation of areas of expertise and responsibility.<sup>16</sup>

Ashkam and Chisholm elaborate further on this distinction in their paper *Patient-centred medical professionalism*. They explore the basic concepts underpinning the notion of patient-centred care, namely what it means to be a patient (lay medical role) and what it means to be a doctor (medical professionalism). Furthermore, they identify where the interests and preference of each intersect and where further research is needed to resolve areas of conflict.<sup>20</sup> This type of research should contribute to a better understanding of the issues at stake, and facilitate the implementation of structures and processes that support collaborative partnerships between patients and practitioners in any setting.<sup>20</sup>

**Shared decision-making**—Shared decision-making is another model of patient-centred care which has relevance across a broader spectrum of healthcare provision including prevention, acute, chronic, and palliative care. From an ethical perspective, it promotes patient autonomy and self determination and promotes trust in the patient/practitioner relationship. A more informed patient has more realistic expectations, having weighed their personal preferences and values with information about the benefits and harms of the proposed management.<sup>21</sup>

Shared decision-making is the process of interacting with the patient to assist the patient to make an informed choice.<sup>22</sup> Various models have been described, most of which include the patient’s right to relinquish the decision in varying degrees to the clinician, recognizing that the extent to which patients contribute to the decision-making process will vary according to the patients personal characteristics (age, gender, education, and ethnicity), the practitioners communication style, the health condition, and the clinical setting.<sup>23</sup>

There also needs to be some consideration of the of the differential power in the relationship, given the doctor’s role in legitimising the ability to work, drive, and receive benefits and the fact that they are the gate keepers for healthcare resources.<sup>19</sup>

The World Health Organization’s<sup>24</sup> “5 As” framework (Box 2) offers a systematic approach to shared decision-making which has particular application in preventive and chronic care to ensure consistency of care.<sup>21</sup> Many clinicians will recognise these steps as part of their everyday practice.

**Box 2. A systematic approach to shared decision-making**

<b>ASSESS</b>	Patient’s health needs and their desired role in decision-making.
<b>ADVISE</b>	Inform the patient about recommended preventive service or management options. If needed, provide balanced evidence-based information about the service, the benefits, harms, alternatives, and areas of uncertainty.
<b>AGREE</b>	Elicit the patient’s values and determine preferences, then negotiate a course of action.
<b>ASSIST</b>	Deliver service or prescribe appropriate management.
<b>ARRANGE</b>	Organise follow up and continuity of care.

Adapted from Sheridan et al.<sup>21</sup>

The shared decision-making model is particularly relevant when there are two or more medically reasonable alternatives, such as ‘radical prostatectomy versus radiation treatment for prostate cancer’ or ‘watchful waiting versus surgery for chronic

cholecystitis'.<sup>25</sup> This has been called “preference-sensitive” care.<sup>25</sup> Evidence-based decision tools (designed to provide up-to-date information about the risks and benefits of the available options) assist patients in the decision-making process and help patients clarify their values and preferences. Failure to base the choice of treatment on the patients’ preferences and values in this case has been termed “misuse” which sits alongside underuse and overuse as examples of poor quality care.<sup>25</sup>

The success of achieving an informed and joint decision can be measured in terms of the extent to which the patient:

- Understands the risk or seriousness of the disease or condition.
- Understands the risks, benefits, alternatives, and uncertainties of the preventive service or management options.
- Has weighed his or her values and preferences.
- Has engaged in decision-making at the level he or she desires and feels comfortable with.<sup>21</sup>

### **What is the evidence for a patient-centred care approach?**

In terms of health outcomes, the evidence base for patient-centred care is growing (see Box 3). Studies have shown that there are benefits in terms of patient satisfaction,<sup>26</sup> adherence to best-practice protocols, reduction of anxiety, and improved quality of life.<sup>27</sup>

#### **Box 3. Benefits of patient-centred care**

Improved patient satisfaction.  
Improved patient compliance and engagement in health process.  
Reduced anxiety.  
Improved quality of life.  
Improved efficiency of care (decrease in inappropriate tests, treatment, and GP visits).

Interventions that have provided patients with training in information-seeking and negotiating skills have resulted in improvements in symptoms and outcomes.<sup>28</sup> Expert patient models of care in diabetes has resulted in better blood sugar control and quality of life.<sup>29,30</sup> There have also been benefits in terms efficiency through fewer diagnostic tests, unnecessary referrals, and treatment.<sup>25,27,31</sup>

A Cochrane review of interventions to promote a patient-centred approach in clinical consultations found some evidence for improved patient-centredness of care, but also found mixed evidence about the effects of such interventions on patient healthcare behaviours or health status.<sup>32</sup> The review noted that the included studies varied considerably in terms of types of interventions, the clinical conditions, the comparisons made, and outcomes assessed; and methodological quality was generally poor.

A comprehensive review of studies relating to chronic care management (560 systematic reviews, randomised trials, and other studies) found evidence for involving people with long-term conditions in decision-making, providing accessible information, self management education, and self monitoring and referral systems.<sup>31</sup>

## **Barriers**

Numerous barriers to achieving patient-centred care have been described: the design of healthcare systems, poor communication skills, attitudes of doctors, inadequate training of health professional, limited resources (people, time, and money), lack of information in an accessible format to patients, failure to involve family and friends, lack of integrated care, lack of patients rights, and so the list goes on.<sup>11</sup>

In addition to physician and structural barriers to patient-centred care, there are also barriers for patients in actively engaging in making decisions about their healthcare. Lack of understanding about the nature of medicine as an “inexact science” and limited understanding of medical concepts such as “risk”—and what words such as “some” and “likely” mean—are confusing even for the more numerically literate patients.<sup>21</sup> Lack of awareness of treatment alternatives, coupled with inexperience and discomfort in engaging with clinicians in this way represent common reasons why patients may fail to engage fully in healthcare decisions.<sup>21</sup>

Social, linguistic, and cultural attributes have also been cited as barriers.<sup>3</sup> It is worth remembering that the concept of patient-centred care originated in North America and Europe and may have limited relevance for some patients.<sup>11</sup> For example, ethnic groups who do not value autonomy may also be reluctant to engage in shared decision-making.<sup>21</sup>

## **Conclusions**

Patient-centred care is one of the most important dimensions of quality; in fact adhering to its principles can help drive those dimensions—making healthcare safer, more accessible, and timely; more equitable and effective (including the concept of appropriate care); and even more efficient. However, it is clear that the concept of patient-centred care is complex and contested. Its effective implementation is impeded by the variety of understandings, lack of leadership from policy makers, and the divergence of views between clinicians and managers.<sup>3</sup>

The expert-patient approach has been adopted in the UK and is best suited to patients with chronic care conditions. Shared decision-making is another approach and is useful when there are competing alternatives. These approaches do not decrease the importance of practitioners skilled in biomedical science with up-to-date knowledge of evidence-based diagnosis and management. But they do require additional skills—especially in effective communication—that allow practitioners to be guides to their patients.

For the clinician this is not about ‘behaving correctly’ but about practicing sound medicine by engaging the patient in a way that provides additional information to achieve the desired outcome for the patient.<sup>33</sup>

Some of the structures and the way that we organise care are in conflict with patient-centred care. For this to change, the meso and macro levels of healthcare need to pay more than lip-service to patient-centred care. In the broadest sense, the phrase

“nothing about me without me” expresses the ideal of patient-centred care in which patients work together with health professionals as “full partners to design and implement change”.<sup>34</sup>

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