EXCELLENCE THROUGH PATIENT AND FAMILY CENTRED CARE

1.1 LITERATURE REVIEW
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June 2012
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INTRODUCTION

The Excellence through Patient and Family Centred Care Project aims to identify best practices and bring about system changes that enable the Bay of Plenty Health Board (BOPDHB) and other organisations to become and remain patient and family centred by bringing the perspectives of patients and families directly into the planning, delivery and evaluation of health care and by building on our existing Health Excellence framework to improve quality and patient safety.

Establishing a culture of patient and family centred care requires long term commitment and is a journey not a destination. The Excellence through Patient and Family Centred Care project will enable the Bay of Plenty District Health Board to establish the resources, needs and priorities of their health consumers and begin the journey of implementation across their services. Overcoming a well-ingrained resistance to open disclosure in all we do is a gradual process.

The development of a self-assessment tool and toolkit for use as a guide for BOPDHB and other organisations across New Zealand presents a unique set of circumstances to overcome. Every organisation has a unique culture and its own set of circumstances, communities served, bed size, governance structure, service lines, available resources, technological capability, reputation, and history and this varies greatly across New Zealand. Accordingly, to claim that every one of the strategies developed for use at BOPDHB would work for every organisation would be the height of folly. Instead, the practices that will be presented are needed to be considered as building blocks. They will be available to share with others throughout the country for others to consider their own ways to adapt them to make them their own, or perhaps to use them as inspiration to
develop a completely new and innovative way to address a similar patient, family or staff need. But most importantly it is hoped they will inspire them to do something to commence their own journey.

WHAT IS PATIENT AND FAMILY CENTRED CARE

The following excerpt from the paper *Partnering with Patients and Families* (2006), explains the concept of patient and family centred care:

“Patient- and family-centred care redefines relationships in health care. It places an emphasis on collaborating with patients and families of all ages, at all levels of care, and in all health care settings. Further, it acknowledges that families, however they are defined, are essential to patients’ health and well-being and are crucial allies for quality and safety within the health care system.”

The Institute for Family Centred Care defines Patient and family centred care as an approach to planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among patients, families and healthcare providers (2004).

There are several definitions of patient and family centred care and although they all vary slightly, there is a high consensus of agreement regarding the key attributes and the definitions offered by the Picker Institute, the Institute for Patient- and Family-Centred Care, and Planetree share common elements (IHI, 2011).

The core elements of patient and family centred care identified most frequently in the documents reviewed are:

- **Dignity and Respect.** Health care practitioners listen to and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

- **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

- **Collaboration.** Patients, families, health care practitioners, and hospital leaders collaborate in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.
Whether drawing on the definition of others or not, organisations should craft an individual definition of patient-and family-centred care that meets their unique needs and mission. The definition should provide the focus to improve the patient and family experience and should be clear, compelling, precise, and concise. It should not be a slogan but a genuine statement of the organisation's beliefs and promises to patients and families, with the intent to engage patients and their families as full partners in care and in all decision making (IHI, 2011).

That's where the lesson lies; it's not about your hospital's goals or anyone else in it, true patient and family centred care is all about the patient. This must be reflected in the simple definition of patient and family centred care.

**PATIENT AND FAMILY CENTRED CARE AS A DIMENSION OF QUALITY HEALTH CARE**

Organising the delivery of health care around the needs of the patient may seem like a simple and obvious approach but in a system as complex as health care, little is simple. In fact, thirty years ago when the idea of patient-centred care first emerged as a return to the holistic roots of health care, it was swiftly dismissed by all but the most philosophically progressive providers as trivial, superficial, and unrealistic. It's defining characteristics of partnering with patients and families, of welcoming, even encouraging, their involvement, and of personalising care to preserve patients' normal routines as much as possible, were widely seen as a threat to the conventions of health care where providers are the experts, family are visitors, and patients are body parts to be fixed. For decades, the provision of consumer, focused health care information, opportunities for loved ones involvement in patient care, a healing physical environment, food, spirituality, and so forth have largely been considered expendable when compared to the critical and far more pressing demands of quality and patient safety, not to mention maintaining a healthy operating margin. (Frampton et al, 2008). How times have now changed.

In 2001, the **Institute of Medicine (IOM)** issued a highly influential report entitled *Crossing the Quality Chasm: A New Health System for the 21st Century* (2004), which analyses the problems facing the U.S. health care system and sets forth recommendations for it's improvement. Patient and family centred care provides the framework and strategies to enhance the quality and safety of health care and to make the recommendations in this report a reality (Conway et al, 2006).

Today, patient and family centred care is in the consciousness of most every health care leader internationally. Organisational mission statements worldwide, reference it, special committees have been set up to address it, and considerable resources are expended to petition patient feedback on “it”. Nevertheless, many organisations continue to struggle with what “it” actually is (Frampton et al, 2008).

Patient and family centred care is expansive and encompasses a broad array of approaches. The evidence base for patient and family centred care is similarly varied with some aspects being the subject of large bodies of work while others are in their infancy. Overall, however, significant benefits have been associated with patient and family centred care (ACSQHC, 2011).
Research demonstrates that patient and family centred care improves the patient care experience and creates public value for services. When healthcare administrators, providers, patients and families work together in partnership, the quality and patient safety of health care rises, costs decrease, and provider satisfaction increases and patient care experience improves. Patient and family centred care can also positively affect business metrics of health care such as finances, quality, safety, satisfaction and market share (ACSQHC, 2011).

Moving organisational culture to one that is grounded in the values, behaviors, and approaches of patient and family centred care is a process, not a one-time event. It is very appropriately called “a journey.” There is no end-point, but rather a continual evolution toward the goal of creating partnerships among healthcare practitioners, patients, and families that will lead to the best outcomes and enhance the quality and safety of healthcare.

**DRIVERS FOR AND BARRIERS AGAINST PATIENT AND FAMILY CENTRED CARE**

Public value is more than “value for money” returned for the taxes that people pay. Consumers expect to be able to trust those delivering the service, the service itself and the way they are included in the process and decision making (ASCQH, 2011). The New Zealand Code of Health and Disability Services Consumer Rights extends to any person or organisation providing, or holding themselves out as providing, a health service to the public or to a section of the public, whether that service is paid for or not (www.hdc.org) and the need for improved efficiency in service delivery is also driving the engagement of consumers and their families. Recent research indicates that a patient centred approach can make health service delivery more efficient (Charmel & Frampton, 2008).

Beyond seeking out a comfortable, satisfying healthcare experience, foremost on the minds of consumers is their safety and the safety of their loved ones. The public is increasingly concerned about medical errors and other adverse events. Failure to meet consumer expectations for clinical quality has serious implications outside of harm to the reputation of a hospital. There are clear differences between the processes that empower individuals to contribute to improving the quality and safety of health care and the processes that allow the public to hold the health system to account. However with involving the patients in making decisions about their own care and not treating them merely as passive recipients of health care is the basic building block for consumer engagement (ACSQHC, 2011).

Multiple forces, both “push” and “pull,” and are changing the nature of patient and family centred care rapidly and dramatically (Balik et al, 2011).

**Push forces** making the status quo uncomfortable:

- **Consumer movement:** Consumers are aware of their rights and saying to health care professionals, “It isn’t yours alone to decide.”
- **Patient safety:** The voices and faces of those who have been harmed by medical care are more visible to hospital boards and consumers.
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- **Transparency demands**
- **Health care reform**
- **Accrediting and certification organisations**
- **Organisations such as Picker Institute, Planetree, Institute for Patient- and Family- Centred Care, IHI, Lucian Leape Institute, World Health Organisation — all working to advance consumer partnerships**

**Pull Forces:** Making the future attractive:

- Organising the health care system around the patient and family works for everyone. Optimising the patient experience correlates with other outcomes, including clinical, financial and staff satisfaction.
- Patient activation and self-management is enhanced, achieving better chronic disease outcomes and shaping a new standard for performance internationally.
- Health care providers and caregivers

The IOM report *Crossing the Quality Chasm* (2004) defines in its “Six Quality Aims for improving Care,” patient-centred care as “care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.” Partnerships among professionals, patients, and families are essential to such a care giving process.

Despite nearly fifty years of conversation, research, and application, realisation of patient and family centred environments, systems, and experiences has been elusive and optimising the patient and family experience is still viewed in many organisations as a nice-to-have, but not a fundamental aspect of a health care organisation’s attention (Balik et al, 2011). The *Patient-Centred Care Improvement Guide* (2008), developed jointly by Planetree and the Picker Institute, captures and reports myths that have slowed progress (along with the evidence discrediting them).
The myths include the following:

- There is no evidence to prove that patient and family centred care is effective.
- Providing patient and family centred care is too costly.
- Providing patient and family centred care will add more work for nurses; it will take too much time.
- The first step to patient and family centred care is new construction with individual rooms.
- Patients’ access to the medical record violates confidentiality requirements.
- Patients will have unrealistic demands.
- Families will interfere with care, creating delays, errors, and lapses in infection control.
- Having patients and families at care team meetings will inhibit staff and providers from being open.

Increasing amounts of evidence are showing that improving the patient experience and developing partnerships with patients and families are linked to improved patient outcomes and increased levels of patient safety. The literature reviewed for this project identified five key factors relevant to New Zealand that would contribute to achieving patient and family centred care at the organisational level (Adapted from Balik et al 2011):

- **Leadership**, at the level of the Board, CEO and Executive must demonstrate a commitment to focus the culture of the organisation on patient and family care and be engaged to unify and sustain the organisation in a common strategic vision that is clearly and constantly communicated to every member of the organisation

- **Involvement of patients and families** at multiple levels, not only in the care process but as full participants and / or advisors in key committees throughout the organisation

- **Care for the caregivers through a supportive work environment** that engages employees in all aspects of process design and treats them with the same dignity and respect that they are expected to show patients and families

- **Systematic measurement and feedback** is maintained to continuously monitor the impact of specific interventions and change strategies. Availability of supportive technology that engages patients and families directly in the process of care by facilitating information access and improved communication with their caregivers

- **Quality of the built environment** that provides a supportive and nurturing physical space and design for patients, families and employees alike
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The documents reviewed reveal a number of common barriers that can inhibit the successful implementation of the partnerships required to advance patient and family centred care. These can be attitudinal, educational and organisational and must be overcome to move forward.

Drivers of Patient and Family Centred Care

Dignity & Respect, Information Sharing, Participation, Collaboration

Key Factors
- Leadership
- Involvement
- Support
- Measurement and feedback
- Environment

Push Forces
- Consumer Movement
- Patient Safety
- Transparency
- Certification & Accreditation
- Organisation

Pull Forces
- Organising
- Optimising
- Self Management
- Health Care providers

Patient Factors
- Attitudes & Expectations
- Knowledge & Personality
- Age, gender & Ethnicity
- Personality

APPROACHES AND STRATEGIES TO PROMOTE PATIENT AND FAMILY CENTRED CARE

Establishing patient and family centred care or enhancing current approaches requires a long-term commitment. It entails transforming the organisational culture and this approach to care is a journey, not a destination and requires continual exploration of new ways to collaborate with patients and families.

While extensive literature exists on the patient experience in health care systems internationally, organisations often struggle with where to begin their own journey (Balik, 2011). Health professionals everywhere are well intentioned, competent, dedicated individuals who assume they provide patient and family centred care as a matter of course but that assumption often lies at the heart of the problem. Far too often health professionals only see their interactions with patients and families through their own eyes (www.ipfcc.org/). Self assessment of an organisation, service or individual often reveals that while the care provided, while excellent in many ways, often reflects the needs of providers and does not always adequately respond to the needs and concerns of patients and their families.

Advancing the practice of patient and family centred care is not a programme that can be rolled out and by completing a self assessment, the ever changing
priorities of an organisation can be identified and the self assessment assists in the identifying where each individual journey needs to begin and will assist organisations, services and individuals to recognise which driving force influence is strongest (www.ipfcc.org):

• **System-centred**: the priorities of the system and those who work within it drive the delivery of health care.

• **Patient-focused**: The patient is the focus or unit of care. Interventions are done to and for him/her, instead of with the patient. The patient is not viewed holistically within the context of family or community.

• **Family-focused**: While the family is the focus or unit of care. Interventions are done to and for them, instead of with them.

• **Patient and family-centred**: priorities and choices of the patient and family drive the delivery of care.

Although each of the four principles, Dignity and respect, Information Sharing, Participation and Collaboration, of patient and family centred care stands on its own, they become inseparable in the day-to-day practice of patient and family centred care. In some situations, however, one principle may have a more dominant role than the others.

The following steps identified from the literature reviewed, can help set a hospital or health system on its journey toward patient and family centred care. These steps do not generally occur in a pre-ordered sequence and the order in which they might be accomplished depends on the resources, needs and priorities of each individual organisation:

• Implement a process for all senior leaders to learn about patient and family centred care. Read the literature, visit web sites, and review professional guidelines, standards of practice and accreditation standards. Attend relevant conferences or seminars. Conduct site visits to hospitals with exemplary patient and family centred practices. Include patients and families and staff from all disciplines in this process of continual learning from the beginning.

• Appoint a patient and family centred steering committee comprised of formal and informal leaders of the organisation and patients and families. This committee should provide guidance for the development and establishment of a patient and family advisory council or councils.

• Conduct a self assessment of how the concepts and principles of patient and family centred care are currently implemented within your hospital or health system and identify priorities for change and improvement. Use the findings from the assessment to develop an action plan.

• Using the action plan as a guide, begin to incorporate patient and family centred concepts and strategies into the hospital’s strategic priorities.

• Ensure that your hospital or health system has a written philosophy of care that reflects the core concepts of patient and family centred care.
• Provide education and support to patients, families and staff on patient and family centred care and on effective sharing of information, participation and collaboration.

• Invite patients and families to serve as advisors in a variety of ways. Appoint some of these individuals to key committees and task forces.

• Create the expectation that patient and family centred goals are included in the annual plans of clinical areas and relevant departments and that patients and families participate in developing these goals.

• Offer regular opportunities for all staff to hear patients and family members share stories of their health care experiences during orientation and continuing education programmes. Create similar opportunities for organisational leadership and for other health professionals to learn from patients and families.

• Monitor changes made, measure the impact, continue to advance practice, and celebrate and recognise success.

## INVOLVEMENT OF PATIENTS AND FAMILIES

For care to be patient centred, it must involve the patient and for patients to be truly involved, so must their families who provide vital support and information throughout the care process. Family has many meanings and includes not only bonds created by marriage and common ancestry, but also bonds created by close friendships, commitments, shared households, shared child rearing responsibilities and romantic attachments (Memorial Healthcare System) and the most important “family member” must be determined by the patient.

According to Bev Johnson, president of the Institute for Patient and Family Centred Care, patients and families should be involved in multiple levels of care, consistent with the Institute of Medicine’s recommendations in the *Crossing the Quality Chasm* report.

• The first level is at the point of care delivery, where patients and families can contribute to the process of gathering information about perceptions of care and assist in analysing and responding to treatment strategies.

• The second level is at the clinical micro system, where patients and family advisors should participate as full members of quality improvement and redesign teams, participating from the beginning in planning, implementing and evaluating change.

• The third level is within the organisation leadership, where the perspectives and voices of patients and families are vital to quality improvement, planning and policy and development. Patients and families should participate on key committees such as patient safety, facility design, quality improvement, patient/family education, ethics and research. One example of patient and family involvement at this level would be the patient and family advisory council. Such a council creates an opportunity for patients and families who represent the consumers served by the organisation to become members of a permanent group that meets regularly with senior leaders. While they do not function as boards, patient
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and family advisory councils can play a vital role in problem-solving, since they often identify opportunities or solutions that professional managers may overlook.

- Finally, at the fourth level, the perspectives of patients and families are critical in the development of local and national policies affecting the finance and delivery of care, such as accreditation and certification bodies and education needs (Shaller, 2007).

**MEASUREMENT AND FEEDBACK**

A frequently used phrase in healthcare quality improvement is, “You cannot manage what you cannot measure.” A major factor contributing to patient-centred care is the presence of a robust customer listening capacity that enables an organisation to systematically measure and monitor its performance. Important “listening posts” include patient experience surveys, complaints and walk-throughs (a process by which staff members play the role of patients and experience a service or procedure in the same way that patients and families do). The use of patient and family advisory councils, described above, is another way to gather systematic feedback from patients (Shaller, 2007).

The value of such measurement and feedback lies in using them to design and implement specific interventions or processes to improve the patient experience. Whether the intervention is large or small e.g. adding signs to help patients and families find their way through the building, it is vital to continuously measure the impact of the change to determine if it is working and, if not, how to modify the process for a better result. According to Coughlan, the success of this process depends on having real-time feedback, in order to be able to trace results back to specific actions or processes that can be studied, altered if necessary and spread throughout the organisation if successful (Shaller, 2007).

Heightened recognition of the importance of Patient and Family Advisory Councils is reflected in a growing collection of resources and tools available to assist sites in developing their own councils. Planetree, the Institute for Family-Centered Care, the Dana-Farber Cancer Institute and others have all developed excellent resources that organisations can use. Tools used in the absence of a sincere intent at genuine engagement with patients and families, however, will ultimately prove insufficient (Planetree, 2009).

The New Zealand Quality and Risk Managers, supported by the Health Quality & Safety Commission have compiled a *How to Guide and Toolkit: Capture the Consumer Experience* (2011) and have identified six key steps to assist DHBs identify an optimal way of capturing consumer experiences and to collect, analyse and use the information systematically to recognise opportunities to improve the patient and family experience. This work, already completed by the Quality and Risk Managers will be invaluable to the Excellence through Patient and Family Centred Care project and will be utilised as a guiding reference in developing a systematic approach to collecting and utilising both qualitative and quantitative information.
RELEVANCE TO NEW ZEALAND HEALTH CARE SYSTEM

Patient and family centred care is in the consciousness of most every health care professional. Often it is referred to in organisational mission statements, special committees or liaison groups have been convened to address it, and considerable resources are expended to solicit patient feedback on it. Nevertheless, many organisations continue to struggle with what “it” actually is. In the broadest terms, patient and family centred care is care organised around the patient. It is a model in which providers’ partner with patients and families to identify and satisfy the full range of patient needs and preferences. Not to be overlooked in defining patient and family centred care is its concurrent focus on staff. To succeed, a patient and family centred approach must also address the staff experience, as staff’s ability and inclination to effectively care for patients is unquestionably compromised if they do not feel cared for themselves.

Care must be delivered by systems that are carefully and consciously designed to provide care that is safe, effective, patient and family centred, timely, efficient and equitable. Such systems must be designed to serve the needs of patient and family’s and to ensure that they are fully informed, retain control and participate in care delivery whenever possible and receive care that is respectful of their values and preferences.

Patient and family-centred care is recognised as a dimension of high-quality health care in its own right and is an approach to the planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among patients, families and health care providers. It is founded on the understanding that family play a vital role in the health and well-being of patients of all ages and determine how they will participate in care and decision making.

THE NEW ZEALAND HEALTH STRATEGY (2000)

The New Zealand Health Strategy (2000) is based on seven underlying principles that the Government sees as fundamental. Those principles are to be applied across the sector and be reflected in any new strategies or developments.

1. Acknowledging the special relationship between Maori and the Crown under the Treaty of Waitangi.

   This principle recognises that the Treaty of Waitangi is New Zealand’s founding document and the Government is committed to fulfilling its obligations as a Treaty partner. To date, the relationship between Maori and the Crown in the health and disability sector has been based on three key principles:
   
   o Participation at all levels
   o Partnership in service delivery
   o Protection and improvement of Maori health status.
Not only is it important to improve Maori health status, but other goals based on concepts of equity, partnership, and economic and cultural security must also be achieved.

2. Good health and wellbeing for all New Zealanders throughout their lives.

This principle reflects the sector’s clear focus on good health and wellbeing. This applies at both the individual level (for example, with treatment services) and the community level (for example, with health promotion services), and that continues throughout people’s lives.

3. An improvement in health status of those currently disadvantaged.

This principle identifies the opportunity for health improvement within the population. The benefits of health improvements are not shared equally by all sectors of society. An increase in effort is needed to address the low health status of groups with low socioeconomic status, including Maori and Pacific peoples, and people with serious mental illness.

4. Collaborative health promotion and disease and injury prevention by all sectors.

This principle reflects the Government’s desire to have a health system that promotes good health and ‘wellness’ as well as treating illness.

5. Timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay.

This principle reflects the fact that fairness is a fundamental value for most New Zealanders, and the health sector must ensure that New Zealanders with similar health conditions are able to achieve similar outcomes.

6. A high-performing system in which people have confidence.

This principle reflects the fact that the health sector must continue to perform to the highest standards and reflect the needs of the people of New Zealand within available resources. The quality of health services needs to be continually monitored and improved. Services must be coordinated, and providers must collaborate to ensure institutional boundaries do not compromise quality of care.

7. Active involvement of consumers and communities at all levels.

This principle identifies the need to have consumers and communities involved in decisions that affect them. This process should also ensure services at all levels of the health sector fully reflect the needs of individuals and communities.
MAORI HEALTH STRATEGY (2002)

He Korowai Oranga: Māori Health Strategy sets the direction for Māori health development in the health and disability sector. The strategy provides a framework for the public sector to take responsibility for the part it plays in supporting the health status of whānau.

The overall aim of He Korowai Oranga is whānau ora - Māori families supported to achieve their maximum health and wellbeing.

Whānau (kuia, koroua, pakeke, rangatahi and tamariki) is recognised as the foundation of Māori society. As a principal source of strength, support, security and identity, whānau plays a central role in the wellbeing of Māori individually and collectively.

He Korowai Oranga asks the health and disability sectors to recognise the interdependence of people, that health and wellbeing are influenced and affected by the ‘collective’ as well as the individual, and the importance of working with people in their social contexts, not just with their physical symptoms.

Whānau ora is a strategic tool for the health and disability sector, as well as for other government sectors, to assist them to work together with iwi, Māori providers and Māori communities and whānau to increase the life span of Māori, improve their health and quality of life, and reduce disparities with other New Zealanders (accessed from http://www.moh.govt.nz).

WHANAU-ORA: TRANSFORMING OUR FUTURES

Whānau Ora is an inclusive, culturally-anchored way of working with whānau and families across New Zealand. It identifies their needs and their strengths so that they can meet their own social requirements and move towards self-reliance. It promotes collaboration in determining the best mix of services for each community, family and individual (Peter Hughes, Chief Executive of Ministry of Social Development).

THE HEALTH AND DISABILITY COMMISSIONER CODE OF RIGHTS

The Health and Disability Commissioner Code of Rights establishes the rights of consumers, and the obligations and duties of providers to comply with the Code. It is a regulation under the Health and Disability Commissioner Act.

- **Right 1:** The right to be treated with respect
- **Right 2:** The right to freedom from discrimination, coercion, harassment, and exploitation
- **Right 3:** The right to dignity and independence
- **Right 4:** The right to services of an appropriate standard
- **Right 5:** The right to effective communication
- **Right 6:** The right to be fully informed
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Right 7: The right to make an informed choice and give informed consent
Right 8: The right to support
Right 9: Rights in respect of teaching or research
Right 10: The right to complain

Every consumer has the rights in this Code and every provider is subject to the duties in this Code. Every provider must take action to inform consumers of their rights and enable consumers to exercise their rights.

HEALTH QUALITY & SAFETY COMMISSION NEW ZEALAND FRAMEWORK

IMPROVING PATIENT SAFETY:

Patient and family centred care has been linked to effective team performance, which can, in turn, have a positive impact on quality and patient safety. The safety literature emphasizes the value of highly collaborative teams and links them to error reduction and effective performance in multiple settings.

Although patients may not always be able to accurately assess the clinical quality of their care, or whether safety processes are in place, patient safety and high clinical quality are fundamental to a patient and family centred approach. Patient and family centred care does not replace excellent medicine it both complements clinical excellence and contributes to it through effective partnerships and communication. A wealth of resources exists to guide organisations in addressing clinical quality and patient safety, so for purposes of this project, we will narrow our focus to discussing the patient and staff experience of care. We recognise, however, that it is essential for efforts to improve the patient experience to be grounded in and closely connected with quality and safety efforts.

FOSTERING QUALITY IMPROVEMENT:

Recent research has shown that there are many benefits to patient and family centred care, broadly categorised as care experience, clinical and operational benefits. Studies show that when healthcare administrators, providers, patients and families work in partnership, the quality and safety of health care rises, costs decrease, and provider and patient satisfaction increase.

If the first step to adopting a patient-centred approach is to acknowledge that we are failing to adequately meet our patients' needs, we must next understand what those needs are and where the disconnects exist that impede our ability to satisfy them. This might be accomplished through focus groups where patients and their family members are asked to share what went well during a recent hospital experience and what could have been improved. Focus groups can be a very
effective way to supplement patient satisfaction surveys as they provide the opportunity to more comprehensively explore individual patients’ stories to get at the heart of why a particular experience was disappointing or what made another interaction memorable and meaningful in a positive way.

Any strategies for better meeting the needs of patients and their families can not be made without first consulting patients and families themselves about just what those needs are? Throughout this project, their experiences, in their own words, will underscore what patients and families seek from their providers and define opportunities for improvement.

IMPROVING CONSUMER ENGAGEMENT:

Patient and Family Centred Care: Priorities and choices of the family drive the delivery of care.

As we seek improved health outcomes and healthier lifestyles to reduce the risk and cost of chronic illness, the consumer is a critical stakeholder and must become an engaged partner. Even the most capable and caring of clinicians cannot unilaterally improve a patients’ health. It is a team effort among providers, caregivers, patients and health plans.

Patient and family centred hospitals internationally, are increasingly turning to the voice of patients and families themselves to guide their efforts to better satisfy consumer demands and expectations. What better way is there to understand what patients want from their health care providers than to ask, and then listen to what they have to say? These hospitals further recognise that needs may evolve over time, so efforts to engage patients and families in defining quality care must be on-going versus a one-time meeting.

Patient focus groups can be a source of in-depth qualitative information for an organisation. In addition to ongoing satisfaction surveys that may be done with patients and employees, focus group data can aid in identifying trends, common feelings and concerns. An important goal in conducting focus groups is to identify where opportunities exist for organisational improvement.

The New Zealand Health Quality and Safety Commission has supported the national Quality and Risk Managers in their work to compile the How to Guide and Toolkit: Capture the Consumer Experience (2011).

LEADING INTERNATIONAL ORGANISATIONS

WORLD HEALTH ORGANISATION

The World Health Organisation (WHO) supports including patients and families, consumers and citizens in patient safety work: Patients for Patient Safety is one of the main action areas of WHO Patient Safety and is designed to ensure that the perspective of patients and families, consumers and citizens, whichever term resonates best, in both developed and developing countries is a central reference
point in shaping the important work of the programme. Patients and their lay caregivers see things that busy health-care workers often do not and it follows that safety will be improved if patients are included as full partners in reform initiatives, and learning can be used to inform systemic quality and safety improvements (www.who.int/).

INSTITUTE FOR HEALTHCARE IMPROVEMENT
The Institute of Medicine’s 2001 report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, called for health care systems that:

- Respect patients' values, preferences and expressed needs
- Coordinate and integrate care across boundaries of the system
- Provide the information, communication, and education that people need and want
- Guarantee physical comfort, emotional support, and the involvement of family and friends

IHI recognises that while these characteristics of care are widely accepted, they are not always well implemented. Today’s complex, fragmented healthcare systems put great pressure on providers and centre care on the needs of the system itself, not the needs of patients.

Working together, we can do better, and in doing so, improve patient well-being while reducing unwanted care (www.ihi.org/).

THE INSTITUTE FOR PATIENT AND FAMILY CENTRED CARE
The Institute for Patient- and Family-Centred Care is a non-profit organisation founded in 1992, which takes pride in providing essential leadership to advance the understanding and practice of patient and family centred care. By promoting collaborative, empowering relationships among patients, families, and health care professionals, the Institute facilitates patient and family centred change in all settings where individuals and families receive care and support (www.ipfcc.org/)

PICKER INSTITUTE
The Picker Institute is an independent non-profit organisation dedicated to advancing the principles of patient centred care. In cooperation with educational institutions and other committed entities and individuals, Picker Institute sponsors awards, research and education to promote patient-centred care and the patient-centred care movement (http://pickerinstitute.org/).

PLANETREE
Since its founding as a non-profit organisation, Planetree has pioneered methods for personalising, humanising and demystifying the healthcare experience for patients and their families.
The Planetree model of care is a patient-centred, holistic approach to healthcare, promoting mental, emotional, spiritual, social, and physical healing. It empowers patients and families through the exchange of information and encourages healing partnerships with caregivers. It seeks to maximise positive healthcare outcomes by integrating optimal medical therapies and incorporating art and nature into the healing environment. Planetree continues to innovate, broadening our collective understanding of the concept of healing, and continuing our network’s expansion so that a growing number of patients and caregivers can experience the dignity, compassion, and humanity that are hallmarks of the Planetree philosophy (www.planetree.org).

KENNETH B SCHWARTZ CENTER

Rooted in the experience of one patient, the center has grown into an organisation addressing the universal concerns of many (www.theschwartzcenter.org).

THE KING’S FUND

The King's Fund seeks to understand how the health system in England can be improved. Using that insight, they work with individuals and organisations to shape policy, transform services and bring about behaviour change.

Patient-centred care has many definitions but a well-accepted one is offered by the Institute of Medicine: ‘providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions’. In today’s NHS it has come to mean putting the patient and their experience at the heart of quality improvement (www.kingsfund.org.uk).

THE WAY FORWARD IN NEW ZEALAND

According to the International Alliance of Patients’ Organisations, the traditional approach to defining quality has lacked the necessary concepts of patient and family centred care, because there are no indicators or criteria to determine the level of patient centredness in health care. Where indicators do exist, they are not standardised across service providers or jurisdictions, making the necessary comparisons and benchmarking needed to improve service delivery difficult.

Beyond seeking out a comfortable, satisfying healthcare experience, foremost on the minds of consumers is patient safety. The public is increasingly concerned about medical errors and other adverse events, and today's consumers can obtain information about hospital performance from a variety of sources.

This project will ensure that systems are in place for the regular collection and reporting of patient and family care experience data through quantitative patient and family surveys and qualitative, narrative-based sources.

The BOPDHB currently collects a variety of patient feedback, including local
surveys, complaints data and other types of feedback. The project will identify standard measures of patient care experience and indicators that can be used at the service level across and healthcare sectors using reference works and toolkits already developed in New Zealand including the *Capture the Consumer Experience* (2011) How to Guide and Toolkit and Waitemata DHB’s *Health Service Co-design* (2010) guide and toolkit.

Patient surveys might be used to assess patient care experience and would need to include questions specifically addressing recognised patient and family centred care domains and assess more than patient satisfaction. Patient feedback consists of the views and opinions of patients and service users on the care they have experienced. Healthcare organisations can gather patient feedback in a variety of ways including surveys, audits, comments and complaints. Staff who work directly with patients can also offer a useful perspective. In addition, reliable evidence can be gathered systematically using a range of techniques including focus groups, one-to-one interviews and patient stories. It will be important to select the most appropriate method for any particular task for example:

- Quantitative research techniques such as surveys enable the gathering and analysis of a large number of views about certain issues. They generate numerical data about the number of people who think about a topic in a particular way.
- Approaches such as focus groups and interviews are examples of *qualitative* research. They provide an in-depth examination of views and opinions and provide stories and narratives from the people taking part.

The real test of performance by the BOPDHB, or any healthcare provider, must be the views and experiences of its users. By asking patients in a rigorous, systematic fashion about their experiences of care and treatment healthcare services can be accurately measured and improvements made.

The importance of communication and attention to the patient’s perspective is reinforced in Press Ganey’s April 2007 *Hospital Pulse Report*, which found that, based on survey results from more than 1,700 hospitals in the USA, the top five issues identified by inpatients as priorities for hospitals all relate to communication and empathy, and include staff responsiveness and sensitivity, being included in treatment decisions, being kept informed, and having one’s emotional needs addressed while hospitalised. Each of these priorities is directly related to staff interactions with patients, underscoring the impact frontline healthcare workers have on a patient’s overall experience.

Hospitals that provide patient-centred care can reap a number of financial benefits, including:

- Reduced length of stay
Excellence through Patient and Family Centred Care

- Lower cost per case
- Decreased adverse events
- Higher employee retention rates
- Reduced operating costs
- Decreased complaints

The risk of not moving to patient and family centred care is greater than any potential risks of this project.

All resources, tools and information developed will be available to guide and assist the implementation of patient and family centred care in other organisations in New Zealand.

CONCLUSION

Patient and family centred care can not be mandated; people working in healthcare must feel supported in order to be empathetic and compassionate care providers (Balik, 2011). The patient and family centred care movement powerfully demonstrates that fully involving the individual patient at all stages of their health care experience will lead to more successful and satisfying outcomes for all involved (ACSQHC, 2011).

A patient and family centred care approach leads to safer, high quality care where:

- People are treated with dignity and respect
- Health care providers communicate and share complete and unbiased information with patients and families that are affirming and useful
- Individuals and families build on their strengths by participating in experiences that enhance control and independence.
- Collaboration among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care (The Institute for Patient and Family Centred Care).

Socrates wrote “the beginning of wisdom is the definition of terms”. The BOPDHB has recently selected the acronym CARE (compassion, attitude, responsiveness and excellence) as its core values.

Let the journey begin!
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