

**PATIENT-CENTRED CARE:
IMPROVING QUALITY AND SAFETY
BY FOCUSING CARE ON PATIENTS
AND CONSUMERS**

Discussion paper

Draft for public consultation

September 2010

This discussion paper is available on the website of the Australian Commission on Safety and Quality in Health Care (ACSQHC), www.safetyandquality.gov.au

The ACSQHC will be accepting written submissions up to 17 December 2010. Submissions marked 'Patient- and Consumer-Centred Care' should be forwarded to:

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Acronyms and abbreviations

ABS	Australian Bureau of Statistics
ACSQHC	Australian Commission on Safety and Quality in Health Care
AHRQ	Agency for Healthcare Research and Quality
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CMS	Centers for Medicare and Medicaid Services (United States)
CQUIN	Commissioning for Quality and Innovation payment framework
EBD	experience-based design
GP	general practitioner
H-CAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems
IHI	Institute for Healthcare Improvement
IOM	Institute of Medicine (United States)
IPFCC	Institute for Patient- and Family-Centered Care (United States)
MCG	Medical College of Georgia
NHS	National Health Service (United Kingdom)
OECD	Organisation for Economic Co-operation and Development
P4P	pay for performance
WHO	World Health Organization

Executive summary

Patient-centred care is health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. The widely accepted dimensions of patient-centred care are respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers, and access to care. Surveys measuring patients' experience of health care are typically based on these domains.

Research demonstrates that patient-centred care improves patient care experience and creates public value for services. When healthcare administrators, providers, patients and families work in partnership, the quality and safety of health care rise, costs decrease, and provider satisfaction increases and patient care experience improves. Patient-centred care can also positively affect business metrics such as finances, quality, safety, satisfaction and market share.

Patient-centred care is recognised as a dimension of high-quality health care in its own right and is identified in the seminal Institute of Medicine report, *Crossing the Quality Chasm*,¹ as one of the six quality aims for improving care. In recent years, strategies used in the US and UK to improve overall healthcare quality, such as public reporting and financial incentives, have emerged as policy-level drivers for improving patient-centred care.

In Australia, a patient-centred approach is supported by the Australian Charter of Healthcare Rights, the National Safety and Quality Framework, other national service standards, reports of state-based inquiries, and a range of jurisdictional and private sector initiatives.

Recent national health reform arrangements (such as the Performance and Accountability Framework of the 2010 National Health and Hospitals Network Agreement) provide further incentives to improve patient-centred care by linking it to performance and funding. Another driver for improving patient-centred care is the establishment of a National Performance Authority to report transparently on a range of performance indicators, including 'patient satisfaction' for every Local Hospital Network, public hospital, private hospital and primary healthcare organisation.

Against this background, Australian healthcare organisations are becoming increasingly interested in patient-centred care. Most organisations can readily put patient charters and informed consent policies in place, but many find it hard to actively change the way care is delivered, and struggle to involve patients and learn from their experience.² Key strategies from leading patient-centred care organisations include demonstrating committed senior leadership; regular monitoring and reporting of patient feedback data; engaging patients, families and carers as partners; resourcing improvements in care delivery and environment; building staff capacity and a supportive work environment; establishing performance accountability; and supporting a learning organisation culture.

Internationally, healthcare services use a range of strategies to promote patient-centred care, including staff development, leadership, collecting and reporting patient feedback, redesigning and co-designing service delivery, implementing patient rights charters, and engaging patients and carers as partners in improving care. A range of international organisations provide frameworks and tools to help organisations implement these strategies, such as the US-based Institute for Patient- and Family-Centered Care, and Planetree.

Based on these strategies and frameworks (and taking into account Australia’s healthcare system, with its mix of public and private sectors), practical policy and service-level recommendations to foster patient-centred care are outlined in this discussion paper.

Summary of recommendations

Policy level

- | | |
|------------------|---|
| Recommendation 1 | Policy makers and regulators should include patient-centred care as a dimension of quality in its own right in strategic and other policy documentation. |
| Recommendation 2 | Patient survey tools should include a core set of items standardised at a national level to enable the collation and comparison of patient care experience data in key healthcare settings. |
| Recommendation 3 | Patient surveys used to assess patient care experience need to include questions specifically addressing recognised patient-centred care domains and assess more than patient ‘satisfaction’. |
| Recommendation 4 | Implementation of healthcare funding models incorporating performance-based payments should include ‘improving patient care experience’ as an integral indicator of health service quality improvement. |
| Recommendation 5 | To improve transparency, Australian policy makers and regulators should make data regarding patient care experience in health services publicly available via websites. |

Organisational level

Healthcare service executives and managers should:

- | | |
|-------------------|--|
| Recommendation 6 | Ensure that systems are in place for the regular collection and reporting of patient care experience data through quantitative patient surveys and qualitative, narrative-based sources. |
| Recommendation 7 | Ensure that organisational approaches to quality improvement include feedback about patient care experience — alongside clinical and operational data — when determining health service action plans. |
| Recommendation 8 | Contribute to the evidence base for patient-centred care by recording and publishing changes in key organisational and patient outcome metrics over time. |
| Recommendation 9 | Develop a shared patient-centred mission that senior leaders continually articulate to staff to promote the implementation of patient-centred care. |
| Recommendation 10 | Develop and implement policies and procedures for involving patients, families and carers in their own care and, at a service level, in policy and program development, quality improvement, patient safety initiatives and healthcare design. |
| Recommendation 11 | Ensure that the service meets the ACSQHC National Safety and Quality Healthcare Service Standard for ‘Partnering with Consumers’. |
| Recommendation 12 | Resource patient-centred changes to care delivery based on patient feedback and consumer input. |
| Recommendation 13 | Implement training strategies tailored to building the capacity of all staff to support patient-centred care. |
| Recommendation 14 | Focus on work environment, work culture and satisfaction of staff as an integral strategy for improving patient-centred care. Workforce surveys and review of staff recruitment and retention rates should be undertaken at regular intervals to monitor work environment. |
| Recommendation 15 | Integrate accountability for the care experience of patients into staff performance review processes. |
| Recommendation 16 | Foster a culture of learning within the organisation, equally learning from successes and failures, including tragic events, to promote patient-centred care. |

Introduction

The health and health experiences of Australians compare well with those of other countries. Australia's life expectancy at birth remains among the highest in the world. Death rates are falling for many of our major health problems such as cancer, cardiovascular disease, chronic obstructive pulmonary disease, asthma and injuries, and survival from these conditions continues to improve.³

In a recent Commonwealth Fund comparison⁴ of seven international health systems, Australia ranked highly demonstrating health care professionals' commitment to high quality care. However, this achievement should be tempered with the awareness that there is still work to be done. In 2008-09 a large proportion of the complaints made to Australian healthcare commissioners were about health care professionals' attitude and manner.⁵ It has been suggested that these types of complaints may represent a failure to appreciate that in some circumstances the emotional need of the patient may be as important as their physical state.⁶ If health care is to become truly responsive to the needs and desires of the patient then it will be necessary to refine the skills and capacity of health professionals as evidence for, and our understanding of, how to implement patient-centred care becomes clearer.

In 2009, the Australian Commission on Safety and Quality in Health Care (ACSQHC) released a proposed National Safety and Quality Framework⁷ that identified 'patient-focused care' as the first of three dimensions required for a safe and high-quality health system in Australia. Including this dimension in the framework reflected a growing recognition of the importance of placing the patient at the centre of the healthcare system. When the ACSQHC talked to patients, carers, consumers, clinicians, managers and policy makers about the proposed framework, there was strong support for the inclusion of this dimension and an overall framework that will set the strategic direction for safety and quality in Australia over the next decade.

The proposed National Safety and Quality Framework contains a number of strategies for providing care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. The ACSQHC is currently developing a series of guides that will support use of the framework in practice.

In Australia there is wide and strong commitment to a healthcare system that focuses on the needs of patients and consumers. Many health services and health-service providers have taken steps to embed patient-centred care principles into practice, and provide care that addresses for the needs and desires of the patient, as well as their immediate treatment requirements. However, for a range of reasons others can struggle to carry out patient-centred care in practice and more specific and focused guidance in this area may be useful.

Internationally, there has been a focus on patient-centred care for some time, particularly in the US and UK. However, the health systems in these countries are different from the Australian system and questions arise as to whether the lessons and approaches that are used internationally can be applied here.

To address these needs, the ACSQHC has prepared this discussion paper as the first comprehensive review of patient-centred care for Australia. The purpose of the paper is to inform practitioners, managers and policy makers who want to re-orient their systems and practices to be more patient centred, and to work more closely with patients, consumers and carers. The paper recommends strategies for how to do this, and provides background information and helpful resources.

The paper provides an in-depth discussion of the concepts and evidence regarding patient-centred care; a comprehensive review of international approaches and activities; and an examination of some of the national, jurisdictional and other policies and activities in Australia to support patient-centred care. It focuses on strategies that healthcare organisations can use to support patient-centred care.

This is the consultation edition of this discussion paper. The ACSQHC wants to know how the approaches discussed in this paper may apply in Australia, whether the recommendations are useful, and how to move forward in supporting patient-centred care. Details about how to make a submission to this consultation process are provided in Section 6.

Within this paper, the term 'patient-centred care' is used, as this is the most commonly used term in research and literature in this area. The proposed National Safety and Quality Framework used the term 'patient-focused care' when it was released in 2009 and currently uses 'consumer-centred care'. All these terms are conceptually similar, and emphasise the central roles of the patient, family, carer and consumer in individual aspects of care, and also in the broader approach to improving health service planning and delivery.

Much of the evidence and many of the examples provided in the discussion paper come from tertiary healthcare settings, as this has been the main focus and application of patient-centred care at a service level. However, many of the lessons and all the recommendations are equally applicable across the range of healthcare settings.

Section 1 of this discussion paper defines the concepts and origins of patient-centred care. Section 2 examines international approaches and initiatives to patient-centred care, and Section 3 examines its relevance to the Australian healthcare system. Section 4 highlights current patient-centred activity in Australia. In light of the international and current Australian approaches, Section 5 discusses the way forward for patient-centred care in Australia, and provides recommendations. Section 6 sets out the consultation process. The appendices include checklists to help organisations assess their readiness for improving patient care experience, and a list of patient-centred care resources.

1 What is patient-centred care?

This section provides an overview of the concept of patient-centred care as a dimension of high-quality health care, including commonly used terms and their definitions, and a summary of the evidence base for this approach.

Patient-centred care is:

‘is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. Patient- and family-centered care applies to patients of all ages, and it may be practiced in any health care setting.’⁸

1.1 Concepts of patient-centred care

There are numerous proposed definitions of patient-centred care that encompass many of the same core concepts, but there is no globally accepted definition.⁹ Modern concepts of patient-centred care are based largely on research conducted in 1993 by the Picker Institute, in conjunction with the Harvard School of Medicine. This research identified eight dimensions of patient-centred care that were originally documented in the book, *Through the Patient’s Eyes: Understanding and Promoting Patient-Centered Care*.¹⁰ These dimensions are:

- respect for patients’ preferences and values
- emotional support
- physical comfort
- information, communication and education
- continuity and transition
- coordination of care
- the involvement of family and friends
- access to care.

This framework clearly defined the patient’s perspective for the first time and served as the foundation for the NRC Picker surveys measuring patient experience of health care.¹¹

Patient-centred care also has a focus on staff. To succeed, a patient-centred approach should also address the staff experience, because the staff’s ability and inclination to care effectively for patients is compromised if they do not feel cared for themselves.¹²

Organisation-specific concepts of ‘patient-centred care’ have also emerged. Some organisations identify individual elements of patient-centred care as part of an overall patient-centred care framework. An overview of leading organisations promoting strategies for patient-centred care is presented in Section 2.

The World Health Organization (WHO) uses the term ‘responsiveness’ in preference to ‘patient-centred care’. Responsiveness describes how a healthcare system meets people’s expectations regarding respect for people and their wishes, communication between health workers and

patients, and waiting times.¹³ WHO states that recognising responsiveness as an intrinsic goal of health systems reinforces the fact that health systems are there to serve people.

Several studies reviewing patient-centred care in the US¹⁴ (cited in Goodrich and Cornwell 2008¹⁵) have identified the core elements in these frameworks as:

- education and shared knowledge
- involvement of family and friends
- collaboration and team management
- sensitivity to nonmedical and spiritual dimensions of care
- respect for patient needs and preferences
- the free flow and accessibility of information.

In reviewing definitions of patient-centred care more generally, Cronin¹⁶ (cited in International Alliance of Patients' Organizations 2007⁹) identified the same core elements.

Similarly, Robb and Seddon¹⁷ identified the following common concepts in definitions of 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
- continuity of care.

According to the International Alliance of Patients' Organizations, the most common element in definitions of patient-centred care is respect for the needs, wants, preferences and values of patients.⁹ While some definitions acknowledge patients' rights and responsibilities (such as the New Zealand Ministry for Health's definition referred to later in this section), most do not, and safety is rarely included in these definitions or frameworks.⁹

In 2000, a five-day seminar was held in Salzburg, Austria, where 64 people from 29 countries examined what health care could become in a utopian land called PeoplePower. They envisaged informed and shared decision making, mutual commitments to quality and health outcomes, and patient partnership in governance.¹⁸ The phrase 'nothing about me without me' was their guiding principle; this phrase has since been popularised by authors and regulators and is considered synonymous with efforts to advance a vision for patient-centred care.¹⁹

1.2 Some definitions of associated terms

Several terms are used interchangeably or associated with 'patient-centred care'; these are described below.

Consumer-centred care

The term 'consumer-centred care' is sometimes preferred to 'patient-centred care' to acknowledge that care should focus on people who are actual or potential users of healthcare services. For some, the term 'patient' has passive overtones. In contrast, the term 'consumer' is seen as a more active term, encompassing the need to engage people as partners in health service delivery.²⁰ The term 'consumer' also aligns with 'client' and 'user' in business and management models of service delivery.²¹

Person-centred care

The term 'patient-centred care' is often used interchangeably in primary care settings with terms such as 'person-centred care', 'person-centredness', 'relationship-centred care' and 'personalised care'. This term appears more frequently in literature on the care of older people,²² and focuses on developing relationships and plans of care collaboratively between staff and patients.²²⁻²³ This term values the needs of patients, carers and staff, with emphasis on the reciprocal nature of all relationships.²⁴⁻²⁵

Personalised care

'Personalised care' is the integrated practice of medicine and patient care based on one's unique biology, behaviour and environment. Personalised care uses genomics and other molecular-level techniques in clinical care; as well as health information technology, to integrate clinical care with the individualised treatment of patients.²⁶

Family-centred care

This term emerged in the US in the 1980s in response to the needs of families with children who could not leave hospital. These families sought to work more collaboratively with healthcare professionals and successfully advocated for changes to enable them to care for their children in home and community settings.²⁷ More generally, children's hospitals in the US adopted the concept of family-centred care in recognition of input from parents and family members to improve the care of patients who were too young to tell physicians and nurses how they felt.²⁸⁻²⁹ In the UK, family-centred care also relates to children's health care, and encompasses the concepts of parental participation; partnership and collaboration between the healthcare team and parents in decision making; family-friendly environments that normalise family functioning within the healthcare setting as much as possible; and care of other family members.²⁹

1.3 The evidence for patient-centred care

Recent research has shown that there are many benefits to patient-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.^{9 28 30-32}

A study by Stone³³ (cited in Charmel and Frampton 2008³⁴) examined data for inpatient units at two similar hospitals in the US over five years. One hospital introduced an extensive program of patient-centred practices, and the other continued their usual practices. The study found that the patient-centred inpatient unit consistently demonstrated a shorter average length of stay; a statistically significantly lower cost per case; a shift in emphasis from the use of higher cost staff to lower cost staff; and higher than average overall patient satisfaction scores. Similarly, Iacono³⁵ found that patient satisfaction rates in 12 hospitals using the Planetree method (see Section 2.5) increased after implementing the patient-centred approach.

Other benefits associated with patient-centred care include decreased mortality,³⁶ decreased emergency department return visits, fewer medication errors, lower infection rates,³⁷ higher functional status,³⁸ improved clinical care,³⁹ and improved liability claims experience.³⁴

In the care of patients with chronic conditions, studies indicate that patient-centred approaches can improve disease management; increase both patient and doctor satisfaction; increase patient engagement and task orientation; reduce anxiety; and improve quality of life.^{32 40-41} Patient-centred care can also increase efficiency through fewer diagnostic tests and unnecessary referrals, and reduce hospital attendance rates.^{32 40} A patient-centred care approach has been linked to improvements in long-term outcomes in cardiac patients.⁴² Patient-centred care is therefore regarded as an integral component of preventative care.^{40 43}

Increasing patient satisfaction through patient-centred approaches also increases employee satisfaction, and this, in turn, improves employee retention rates and the ability to continue practising patient-centred care.³⁴ According to Charmel and Frampton³⁴ the link between patient satisfaction and employee satisfaction is reflected in the fundamental philosophy of patient-centred care: the importance of staff feeling cared for themselves, so they can best care for their patients.

The Institute for Patient- and Family-Centered Care (IPFCC)³⁰ states that patient-centred care has become the business model for the Medical College of Georgia (MCG) Health System in Augusta, Georgia, because it positively affects each of the MCG's business metrics (finances, quality, safety, satisfaction and market share). The following represents three years of quality improvement data:

- patient satisfaction increased from the 10th to 95th percentile
- volume of discharges increased by 15.5 per cent
- length of stay in neurosurgery decreased by 50 per cent
- medical error decreased by 62 per cent
- staff vacancy rate decreased from 7.5 per cent to 0 per cent
- perception of the unit by doctors and staff underwent a positive change.

Such findings led Charmel and Frampton³⁴ to conclude that patient-centred care is not merely philosophical, it is sound business practice.

1.4 Patient-centred care as a dimension of high-quality health care

Over the past two decades, patient-centred care has become internationally recognised as a dimension of the broader concept of high-quality health care. In 2001, the US Institute of Medicine's (IOM) *Crossing the Quality Chasm: A New Health System for the 21st Century* defined good-quality care as:¹

- safe
- effective
- patient-centred
- timely
- efficient
- equitable.

It defined patient-centred care as 'care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient's values guide all clinical decisions'. The report set out several rules to redesign and improve patient-centred care, including ensuring that care is based in continuous, healing relationships; customising care based on patients' needs and values; ensuring the patient is the source of control; sharing knowledge and information freely; and maintaining transparency.

The IOM report outlined four levels that further define quality care and the role of patient-centred care in each level:

1. The **experience level** refers to an individual patient's experience of their care. At this level, care should be provided in a manner that is respectful, that assures the candid sharing of useful information in an ongoing manner, and that supports and encourages the participation of patients and families.
2. The **clinical micro-system level** refers to the service, department or program level of care. At this level, patients and family advisers should participate in the overall design of the service, department or program; for example, as full members of quality improvement and redesign teams and participating in planning, implementing, and evaluating change.
3. The **organisational level** refers to the organisation as a whole. The organisational level overlaps with the clinical micro-system level, in that the organisation is made up of various services, departments and programs. At this level, patients and families should participate as full members of key organisational committees for subjects such as patient safety, facility design, quality improvement, patient or family education, ethics and research.
4. The **environment level** refers to the regulatory level of the health system. Here, the perspectives of patients and families can inform local, state, federal and international agency policy and program development. These agencies, along with accrediting and licensing bodies, are in a position to set expectations and develop reimbursement incentives to encourage and support the engagement of patients and families in healthcare decision making at all levels.

According to Charmel and Frampton,³⁴ the IOM report reinforces patient-centred care not only as a way of creating a more appealing patient experience, but also as a fundamental practice for providing high-quality care in the US.

Like its evolution in the US, the concept of patient-centred care in the UK became a dimension of high-quality health care over time. From 1997, when the UK government began a 10-year program to reform the National Health Service (NHS), strategy documents and policies increasingly referred to the ambition to create a 'patient-centred NHS'.²³

By 2004, the NHS had set out its priorities for the next four years in its *NHS Improvement Plan: Putting People at the Heart of Public Services*.²³ The aim was 'to ensure that a drive for responsive, convenient and personalised services takes root across the whole of the NHS and for all patients' (cited in Goodrich 2009²³). *Creating a Patient-led NHS: Delivering the NHS Improvement Plan*⁴⁴ outlined how the quality agenda could be delivered: patient-led services would ensure that patients were treated with respect, dignity and compassion.²³

The 2008 *NHS Next Stage Review*⁴⁵ aimed to improve patients' overall experience by putting 'quality at the heart of what we do'. The review committed to providing 'safe, personalised, clinically effective care' and 'locally-led, patient-centred and clinically-driven change' (cited in Goodrich 2009²³). In his introduction to the Next Stage Review, Lord Darzi stated: 'High quality care should be as safe and effective as possible, with patients treated with compassion, dignity and respect. As well as clinical quality and safety, quality means care that is personal to each individual'.⁴⁵

Recently, The King's Fund⁴⁶ assessed the effect of NHS reforms on various factors within the service (accessibility, safety, promoting health and managing long-term conditions, clinical effectiveness, equity, efficiency, accountability and patient experience). The study was based on the best available evidence and measured improvements from patients' perspectives. The authors found that, overall, the NHS had improved the standards for high-quality, safe health care. Waiting times for hospital care had been reduced, and access to primary care had improved. There had also been progress in making the NHS more accountable and transparent to government and taxpayers. However, there was still some way to go to firmly embed a strong safety culture in some parts of the service.

The effectiveness of efforts to improve patients' experiences of the NHS presented a mixed picture in this study. Overall, patient experience scores were high and public satisfaction, as a whole, had been improving steadily since 2002. Patient experience had been built into regulation and many providers were monitoring survey results routinely. However, the surveys revealed several weaknesses, including limited progress in delivering greater choice of treatments, information about care, involvement with decisions, and problems with aspects of privacy for inpatients, especially mental health inpatients. To address this issue, The King's Fund recommended that organisations find more effective ways of encouraging and acting on feedback from patients, carers and staff, ensuring that patients' experiences have a real impact on the quality of care.⁴⁶

In New Zealand, the Code of Health and Disability Services Consumers' Rights Regulation 1996⁴⁷ (the Health and Disability Code) and the New Zealand Ministry of Health's *Improving Quality* document⁴⁸ established patient-centred care as a priority.¹⁷ *Improving Quality* talks about 'people-centred' rather than 'patient-centred' care and defines this concept as: '...the extent to which a service involves people, including consumers, their families and is receptive to their needs and values'. It includes participation, appropriateness and adherence to the Health and Disability Code, and adherence to other consumer protections, such as the Health Information Privacy Code 1994.^{17 48} According to Robb and Seddon,¹⁷ by referencing the Health and Disability Code, this document acknowledges patients' rights as integral to patient-centred care, a common omission in other definitions. In addition, the New Zealand Ministry of Health definition, like its IOM counterpart, implies extending patient-centred care beyond the patient–practitioner interaction. This reflects the importance of collaboration between patients, families,

healthcare practitioners and hospital leaders in all aspects of health care and at all levels of the healthcare system.¹⁷

At the federal level in Canada, the term ‘collaborative patient-centred care’ is used to describe Health Canada’s current initiatives in the primary healthcare sector to increase patients’ self-care⁴⁹ and educate professionals about working together to achieve patient-centred care.⁵⁰ At the state and provincial level, many jurisdictions are adopting a patient-centred approach as part of their aim to increase healthcare quality.⁵¹⁻⁵²

Overall, many regulators and organisations recognise patient-centred care as a key dimension of quality. Of the Organisation for Economic Co-operation and Development (OECD) member states, the US, UK, Canada and Australia include patient-centred care, patient focus or responsiveness as a dimension of healthcare quality in national documents and frameworks. The OECD and WHO included these concepts as a dimension of healthcare performance.⁵³ One study found that, in addition to the US, UK, Canada and Australia, several European countries — Germany, France, Denmark, the Netherlands and Switzerland — had all implemented various performance measures that include patient-centred health care.⁵⁴

2 International approaches and initiatives

There is wide agreement about the need to place patients at the centre of their own care, and at the centre of the health system more generally. However, there is a need to highlight appropriate strategies for building and maintaining patient-centred care, as healthcare organisations often have difficulty implementing the type of change necessary to sustain patient-centred care.

This section presents an overview of the policies that drive patient-centred care, and the approaches and initiatives used successfully by international healthcare regulators and organisations to put patient-centred care into operation at different levels and in different sectors of the healthcare system. It includes a summary of the leading organisations that provide tools and resources, and a case study of the patient-centred approach adopted by the Medical College of Georgia (MCG).

A list of the leading organisational websites, together with other websites and resources mentioned in this section, are included in Appendix B.

2.1 Policy-level drivers for patient-centred care

Internationally, there has been a focus on patient-centred care for some time, particularly in the US and UK. These countries have three main policy-level drivers for patient-centred care:

- mandatory government requirements for service providers to collect and publish patient experience data (other jurisdictions, such as Canada and New Zealand, also collect patient experience data, although there is no mandatory requirement to do so)
- publicly available information that enables consumers to choose between service providers
- financial incentives for providers who achieve high measures of patient-centredness.

The different approaches to these policies are discussed below.

Collecting and publishing patient experience data

The UK, the US and some European countries have implemented patient survey programs to systematically collect patient and carer experience feedback at a national level.

United Kingdom

In the UK, the government's vision is for patients and the public to drive the design and delivery of high-quality services. In relation to health care, this will be achieved through 'putting patient experience centre stage'^{45 55} and a number of regulatory requirements are currently in place to meet this aim. Measuring patient experience is a requirement under the Public Service Agreement Target on patient experience and the Care Quality Commission assessment process.⁵⁵⁻⁵⁷ It has also been made an equal partner in the *National Health Service (NHS) Quality Framework*, alongside effectiveness; and is a 'vital sign' in the *NHS Operating Framework* for 2010–11. Patient experience is a standard measurement in the NHS Indicators for Quality Improvement, Measuring for Quality Improvement, Quality Accounts and local Commissioning for Quality and Innovation (CQUIN) schemes.

In the UK and Europe, patient experience surveys are conducted using standardised questionnaires and methods based on Picker Institute Europe's methods. Picker Institute Europe develops, coordinates and implements healthcare surveys based on the eight Picker dimensions of patient-centred care (see Section 1.1). Information and some findings from a

range of NHS surveys can be found on the Care Quality Commission's website and the Survey Coordination Centre website (see Appendix B).

The UK Department of Health also conducts the General Practice Patient Survey. This survey includes questions on many aspects of primary care patients' experiences, although it focuses strongly on access and has limited questions on experience of the consultation. Various disease-specific patient experience surveys have also been conducted in the UK, including the National Cancer Patient Survey Programme.

United States

In the US, the Centers for Medicare and Medicaid Services (CMS) and the Agency for Healthcare Research and Quality (AHRQ) routinely collect data on patient experience from service providers. This has been expanded under the recently enacted *Patient Protection and Affordable Care Act 2010*.⁵⁸

The US has implemented the Consumer Assessment of Healthcare Providers and Systems survey (CAHPS), developed at Harvard University and based on Picker principles of patient-centred care. The CAHPS program develops and supports a comprehensive and evolving family of standardised surveys that ask patients to report on and evaluate their healthcare experiences. Hospitals use the hospital-CAHPS (H-CAHPS) survey to assess seven domains: communication with doctors; communication with nurses; responsiveness of hospital staff; communication about medicines; pain control; cleanliness and quiet of physical environment; and discharge information. The survey provides an overall rating and assesses the likelihood or willingness of patients to recommend the service to others. Other versions of the CAHPS survey are used by clinician group practices and health insurance plans, and a shorter, real-time version has also been developed.

The National CAHPS Benchmarking Database (also referred to as the CAHPS Database) is the national repository for data from CAHPS surveys. It holds 11 years of data and is one of the key resources for the AHRQ's *National Healthcare Quality Report* and *National Healthcare Disparities Report*. These annual documents help policy makers monitor the nation's progress toward improved healthcare quality.

Various patient experience surveys that focus on specific diseases are also emerging in the US; for example, the National Cancer Institute and the AHRQ are developing a patient care experience survey for cancer patients.

Canada

Some provinces and healthcare organisations in Canada also conduct CAHPS surveys. Statistics Canada measures aspects of patient satisfaction with health services,⁵⁹ but there is no standardised system to compare quality of care between health services in Canada.

Performance reporting and choice of providers

Both the UK and the US have public web-based systems that provide information on health service providers' performance, to allow consumers to choose which provider they wish to access. A brief overview of these systems is presented below.

United Kingdom

Since April 2008 in the UK, all patients who need a specialist referral have had the right to choose to go to any hospital, including many private and independent sector hospitals. The

NHS Choices website^a publishes information on the specialist options available and performance indicators from the national survey data for each hospital. It also allows patients to rate and comment on their healthcare providers online. Regular surveys of patients' experience of choice provide information about the availability and uptake of provider choice.

NHS organisations are now required to obtain real-time patient feedback to improve care and service quality. Several websites are exploring web technology to achieve this. The websites help patients and carers find out what other people think of local hospitals, hospices, mental health services, general practitioners and other individual clinicians. People can submit their stories about their experience when they were ill and their comments on the services, for publication on the website. Providers can automatically direct these to the email of a responsible staff member.

United States

The US CMS has implemented a web-based tool called 'Hospital Compare'^b. This tool sets out information about how well hospitals care for patients with certain medical conditions or surgical procedures, using data from the Hospital Outcomes of Care Measures, CAHPS and H-CAHPS surveys. CMS is also planning to measure individual physicians on quality and patient experience metrics and publish the results on a new Physician Compare site, under the newly enacted *Patient Protection and Affordable Care Act 2010*.⁵⁸

Financial incentives

Public and private healthcare sectors around the world are now linking service quality with provider payment. Patient care experience is a key outcome metric for quality reporting, and financial incentives can now help drive services towards patient-centred care. Both the UK and the US provide financial incentives to some healthcare providers for adopting improved quality practices, including clinical outcomes and some patient-centred care principles.

This section focuses on the role of 'pay for performance' (P4P) in driving organisations to focus on patient experience. P4P is defined as 'financial incentives that reward providers for the achievement of a range of payer objectives, including delivery efficiencies, submission of data and measures to payer, and improved quality and patient safety'.⁶⁰

United Kingdom

In 2004, the NHS began a major P4P initiative — the Quality Outcomes Framework (QOF). In this framework, general practitioners (GPs) receive income increases based on their performance, which is measured using 146 quality indicators that cover organisation of care, clinical care for ten chronic diseases, and patient experience.

Early analysis of the QOF⁶¹ showed that, overall, family practices achieved high scores in their performance indicators in the first year. Practitioners included in the study earned an average of AU\$40 000 more by collecting nearly 97 per cent of the points available. However, a small number of practices achieved high scores by excluding large numbers of patients through exception reporting. More research is needed to determine whether practices like these exclude patients for sound clinical reasons, or to increase their income.⁶¹

It is unclear whether the high performance scores reflect improvements that were already underway, or whether improvement was accelerated by the introduction of the scheme.⁶²

^a www.nhs.uk

^b www.hospitalcompare.hhs.gov

Overall, the QOF has seen modest improvements in measured quality of care,⁶³ but has had little effect on inequalities in chronic disease management.⁶⁴

The NHS introduced a new CQUIN framework to improve the quality of care in hospitals and other healthcare organisations. The CQUIN makes a proportion of providers' income conditional on quality and innovation. To earn from the CQUIN, providers of acute, ambulance, community, mental health and learning disability services that use national contracts must agree on a CQUIN scheme with their funding body. The CQUIN schemes must include goals in the three NHS domains of quality (safety, effectiveness and patient experience) and must reflect innovation. A CQUIN scheme is the agreed package of goals and indicators that, when achieved, earn the provider its full CQUIN payment (1.5 per cent of contract value in 2010–11). From 2011–12, providers that fail to meet agreed patient satisfaction goals may have a proportion of contract payment withheld (up to 10 per cent over time).

United States

The US provides financial incentives to physicians and hospitals that provide data on quality measures, including patient experience, to the CMS.

In 2008, the CMS introduced the Reporting Hospital Quality Data for Annual Payment Update Initiative to strengthen the relationship between payment and quality of service. Under this scheme, hospitals publicly report a range of inpatient data, including quality, mortality and H-CAHPS patient care experience items, via Hospital Compare. In April 2010, the CMS announced that acute care hospitals that choose not to participate in the voluntary reporting program or do not meet the established reporting deadlines, will have a 2 per cent reduction in reimbursement for their Medicare patients (those who are 65 years and over or who meet other special criteria).

For individual physicians, the *Tax Relief and Health Care Act 2006*⁶⁵ established a physician quality reporting system, including an incentive payment for eligible physicians who report on quality measures for services covered by Medicare. Payments are also available for better care coordination between home, hospital and offices for patients with chronic illnesses. Ambulatory surgical centres and other health organisations must also comply with Medicare P4P reporting and performance targets under the *Patient Protection and Affordable Care Act 2010*.⁵⁸

Many private providers and purchasers have embraced P4P approaches as an essential way to meet quality improvement goals. For example, in 2009, the large private insurer, Blue Cross Blue Shield Massachusetts, introduced an 'alternative quality contract' with healthcare providers. Participating providers receive performance-based incentives for a broad set of quality and outcome measures for outpatient and inpatient care. Organisations that meet defined targets can earn up to an additional 10 per cent of their total budget. The same performance incentives and measures are used for every provider, including nationally accepted measures of clinical processes, clinical outcomes and patient experiences.

2.2 Emerging views on the appropriate outcomes of services

Patient-centred health care is part of the emerging views on the appropriate outcomes of services. These views include the need to create public value, the need to focus on the experience of care, and the need to improve efficiency.

Creating public value

One of the common themes resulting from high-profile public inquiries into the health systems in Australia (see Section 4) and the UK was a reported loss of trust in administrators and clinical colleagues from patients and the community.⁶⁶ To regain public trust and confidence, public sector organisations are adopting a ‘public value’ approach to service delivery. Public value is the return created by public services for the taxes that people pay. The expected return is more than simply ‘value for money’. Consumers expect to be able to trust those delivering the services, the actual service delivered, the way they are included in the process of creating and delivering the service, and the measurement of any process or product of delivery from the service.⁶⁷ The power of a public value approach lies in its advocacy of a greater role for consumers in decision making. It also drives public managers to seek out what consumers want and need, creating a quality service.⁶⁸

Research conducted by the Work Foundation in the UK and sponsored by the NHS Institute for Innovation and Improvement and the Quality Improvement Agency cites a range of methods and activities that enable public services to involve consumers and create public value.⁶⁹ These are in line with the patient-centred activities outlined in Section 2.3 and include formal mechanisms such as facilitating patient engagement on committees and boards, client surveys, and providing information and improving communication and interactions with consumers.

In the UK, the NHS uses collaboration with people who use their services to create public value. NHS organisations are required to regularly and systematically collect and analyse feedback from service users to inform decisions about service commission and delivery.⁵⁵ In addition, public services are empowering individual citizens to shape their services by establishing local networks that support the involvement of consumers and patients in commissioning, providing and scrutinising local care services. The *Local Government and Public Involvement in Health Act 2007*⁷⁰ empowers local networks to canvas the views of patients and citizens on their need for and experience of care services, and to make recommendations to health services based on those experiences. Furthermore, overview and scrutiny committees question whether services meet the needs of local people and whether the experience of patients is leading to improvements in service delivery

Valuing the experience

Another approach to seeking out what consumers want and need comes from industry models of business economy theories. In 1999, Harvard Business School published Pine and Gilmore’s book, *The Experience Economy*.⁷¹ This work proposed that society was moving away from the industrial economy view to a modern view, where the ‘product’ that a customer receives in a service economy is ‘the experience’. In this new economy, organisations create engaging, personal and memorable experiences for customers. The application of this approach to the healthcare sector leads to a greater focus on patient care experience as an outcome of the ‘service’ received. Such approaches in health care are typified by work such as *If Disney Ran Your Hospital*,⁷² which emphasises that ‘hospitals would do well to emulate the most vital things that earn Disney the love of their guests and employees’, as Disney does not provide a service — it provides an ‘experience’.

Driving efficiency gains

The need for improved efficiency in service delivery is also driving the engagement of patients and consumers more generally. Limited resources in the form of underfunding, low staffing

levels and low morale in already overstretched systems are a perceived barrier to the practice of patient-centred care.⁹ However, recent research indicates that a patient-centred approach can make health service delivery more efficient.³⁴ By harnessing consumers' contributions, insights and collaboration, patient-centred care is becoming a critical strategy for public services to deal with rising service costs.⁷³⁻⁷⁴

2.3 Approaches and strategies to promote patient-centred care

Internationally, a variety of approaches are used to promote patient-centred care. A review by the Picker Institute Europe identifies the most effective strategies ('best-buys') for facilitating patient-centred care, and numerous other approaches are also available.

'Best buys' for improving patient experience

The Picker Institute Europe reviewed the body of evidence for strategies to engage patients and consumers in health care ('the Picker review').⁷⁵ They evaluated 31 systematic and high-quality narrative reviews on various initiatives to improve patients' experience, including studies of direct and indirect feedback from patients (including patient experience and satisfaction surveys); service user involvement in evaluations; consultation styles; and communication skills training. Each study was graded according to four outcomes: impact on patients' knowledge, impact on patients' experience, impact on service use and costs, and impact on health behaviour and health status.

According to the Picker review, the most effective ways (best buys) to improve patient experience are patient-centred consultation styles and communication training for health professionals; and patient feedback (surveys, focus groups, complaints) with public reporting of performance data. The body of evidence for these strategies includes:

- Impact on patients' knowledge: training health professionals to communicate information about medicines improves patients' knowledge and understanding. Longer consultations in primary care can increase patients' confidence to take action in relation to their health. Educational material can be helpful for carers.
- Impact on patients' experience: patient surveys can stimulate quality improvements, but provider organisations need additional help to implement changes. Patient feedback surveys need to be well planned and carefully implemented. Patient-centred communication and longer consultations in primary care increase patient satisfaction. Communication skills training for clinicians can lead to improved communication, reduced anxiety and greater patient satisfaction.
- Impact on service use and costs: public reporting of hospital performance data can stimulate providers to improve quality. If it is well disseminated and published in a format that patients can understand, this type of information influences public perceptions of a hospital's reputation, making it more likely that patients will want to go there. One review suggested that improved continuity of care reduces costs.
- Impact on health behaviour and health status: communication skills development for clinicians may improve health outcomes, but some reviews have reported conflicting findings. Reviews of patient-centred consultations found mixed results in relation to impact on health status.

Consultation styles and communication training

Regulators and professionals in the UK, US and Canada are investigating the effects of patient-centred consultation styles on continuity of care, length of consultation and increased support

for patients on nonclinical issues and concerns.⁷⁵ Recent research in Canada found that the degree to which emergency department staff are courteous, particularly to patients in pain, is the key driver of patient ratings of overall quality of care.⁷⁶ Research in the UK and US also demonstrates that overall patient satisfaction strongly correlates with patients' assessment of clinicians' interpersonal skills.⁷⁷⁻⁷⁸

To improve these outcomes, initiatives to develop communication skills, such as training courses and coaching strategies that teach staff about the need to establish a connection with patients, have been introduced successfully in a number of settings.¹² Strategies include developing and using verbal communication guidelines for staff, scripting tools, and cues for effectively communicating with patients. *The Patient-Centered Care Improvement Guide*¹² provides examples of scripting tools and cues. Nonverbal tools include patient and family communication boards with information such as the care team member names and the date and time scheduled for specific procedures.

A successful communication strategy that has facilitated patient-centred care is the 'just ask' campaign conducted at Northern Westchester Hospital in the US. Hospital staff posted a sign in every patient room encouraging patients and families with the message, 'if you're thinking it ask it'. Displaying photographs of care givers, distinguishing clothing for staff, and follow-up discharge phone calls are further examples of communication strategies to support patient-centred care.¹²

Patient feedback reporting

As described in Section 2.1, regulators collect patient experience survey and complaints data to improve patient experience at all levels of health care. One-off patient focus groups can also be used as a source of in-depth information.¹² In hospitals, staff can gather 'real-time' information from patients by engaging them in a conversation about their stay during patient safety rounds. The Dana-Farber Cancer Institute has developed an online toolkit to help organisations initiate patient safety rounds. The UK Department of Health publication, *Understanding What Matters — A Guide to Using Patient Feedback to Transform Services*,⁷⁹ sets out best practice in terms of collecting, analysing and using patient feedback. Links to these resources are provided in Appendix B.

Patient and carer engagement in personal care

Health service providers are adopting strategies that facilitate family and carer engagement to increase their patient-centred practices.⁴⁰ The family or carer knows the patient best and their presence can help reassure patients in times of uncertainty, anxiety or vulnerability. Family members and carers can also provide information about the patient's history, routines or symptoms that may assist in their treatment. Strategies include patient-directed visitation, where restrictions on visiting times are removed and the patient decides the visiting times that best suit them. This strategy benefits overall patient experience and decreases anxiety by 65 per cent.¹² Related strategies include patient or family-initiated rapid response teams, where patients and their families are encouraged to alert staff of changes in a patient's condition; and care partner programs that aim to meet the personal, emotional, spiritual, physical and psychosocial needs of the patient by encouraging members of their support system to be involved in their care.¹²

Patient and carer access to information and education

Patient-centred approaches to empowering patients and families through information can include sharing medical records. Traditionally, medical records have remained the property of the health service providers, but some providers now use medical records as a teaching tool and a tool to encourage patient and carer engagement. The medical record is brought to the bedside during treatment and the results of clinical tests and procedures are shared with the patient. Future treatment plans then involve patients, carers and providers deciding the best course of treatment together.¹² Some providers have also introduced patient progress notes, which give the patient a formal place in the medical record to note any comments or concerns, further encouraging a partnership approach to care.¹²

The Picker review found that printed and electronic information, and educational programs, can benefit patients' knowledge and understanding of their condition. Among cancer patients, question prompt sheets and audiotapes of consultations improve the recall of medical information given in clinical consultations. Providing written and electronic information can increase a patient's sense of empowerment. It can also improve their ability to cope, increase satisfaction and may help to reduce anxiety. Among stroke patients, studies show that information strategies that actively involve patients and their care givers are more effective in reducing anxiety and depression. Telephone help lines, telecounselling and telemonitoring can also reduce social isolation, increase decision-making confidence and self-efficacy, and improve satisfaction.⁷⁵

Pre-operative and pre-discharge information may help to reduce consultations, length of stay in hospital and follow-up visits, with a positive effect on service use and costs. Studies on the effect of targeted information and teleconsultations on diagnostic accuracy, consultation rates, waiting times and out-of-pocket costs to patients show conflicting results. Telephone reminders can help to increase attendance rates and improve medication adherence, and reminder packaging may improve adherence to self-administered long-term medication.⁷⁵

Personalised patient information packets for patients to take with them on discharge are also useful.¹² These provide customised health information to meet the specific needs of the patient and family. Packets may include fact sheets, recent articles, and information on local support groups and relevant complementary modalities.¹²

Implementing rights-based patient constitutions, charters or codes

The UK and US have rights-based constitutions, charters or codes that are provided to patients. These documents facilitate patient-centred health care by informing patients about the level of care they are entitled to expect. The NHS Constitution in the UK⁸⁰ includes the following statements that have a bearing on patients' experience:

- You have the right to be treated with a professional standard of care, by appropriately qualified and experienced staff, in a properly approved or registered organisation.
- You have the right to expect NHS organisations to monitor, and make efforts to improve the quality of health care they provide, taking account of the applicable standards.
- You have the right to be treated with dignity and respect.
- You have the right to privacy and confidentiality.
- The NHS will strive to ensure that services are provided in a clean and safe environment that is fit for purpose, based on national best practice.

- The NHS will strive for continuous improvement in the quality of services you receive, identifying and sharing best practice in quality of care and treatments.

New Zealand has a similar code in place (Code of Health and Disability Services Consumer Rights Regulation 1996).⁴⁷ In the US, the American Hospital Association has developed a *Patient Care Partnership Brochure*.⁸¹ Medicare patients are given a copy of the *Important Message From Medicare Notice*,⁸² outlining patients' rights. There are also many organisation and institution-specific patient rights constitutions or charters operating in the US and Canada.

User-centred design and redesign

In both the US and UK, approaches based on design of the physical care environment are emerging as successful tools to improve patients' experience of care. The approach in the US focuses on user-centred design. User-centred design is based on environmental psychology principles, where spatial design is seen as an important part of the patient experience and wellbeing.⁸³ Typically, a team of architects, psychologists and sociologists are employed to collect data from staff and patients via observations and interviews. The team maps the entire patient journey from the first point of contact to the last point of contact. The team then identifies core patterns and areas for improving the environment to better meet patients' emotional experience of care.⁸³

The leading case-study for user-centred design is Kaiser Permanente's work in the US. By implementing user-centred design, Kaiser Permanente improved interaction and information flow between staff, and between staff and patients; improved staff efficiency; provided examination rooms that could accommodate carers and families; increased attention to privacy and comfort in patient rooms; and provided more comfortable waiting areas and easier check-in procedures and improved signage to help patients orientate themselves more intuitively.⁸³

In the UK, service redesign has been implemented in several NHS services. Service redesign focuses on technical aspects of the patients' journey, such as efficiency. Like user-based design, service redesign is based on insights from observing service users or mapping all the steps of a patient's journey. Service redesign brings together all key staff involved in the patient's journey with the patient themselves, to identify the problems throughout the patient journey.⁸⁴ Solutions are typically generated by staff. This is in contrast to user-centred design, which employs professionals outside the health service to map the patient journey and generate solutions.

Experience-based co-design

Experience-based design (EBD) is a methodology developed by Bate and Robert⁸⁵ for working with groups of patients and staff to improve services. It draws on knowledge and ideas from design sciences and design professions, where the aim of making products or buildings better for the user is achieved by making the user integral to the design process itself. In a healthcare setting, EBD focuses on how patients and staff move (or are moved) through the service and how they interact with its various parts. Unlike user-centred design and service redesign, the focus of co-design is on patients working with staff to 'co-design' improvements in the experience of using the service.

Involving patients and staff on an equal footing in EBD is more integral than in 'patient involvement' projects, where patients are often treated as objects for study, rather than partners. How the service 'feels' or is experienced is seen as equally important as how functional and safe it is. Bate and Robert provide a step-by-step guide to the method and illustrate it with a 12-

month pilot program in head and neck cancer services at Luton and Dunstable NHS Foundation Trust, funded by the NHS Institute for Innovation and Improvement. This method has since been used in other clinical specialties and hospitals in the UK, as well as in Australia.⁷⁴

Patient and carer engagement at the governance level

Patients and carers can be engaged at the governance level by being appointed to advisory councils and committees. Patient and family advisory councils can serve as the ‘patient voice’ and the institutional infrastructure for including the patient and family member perspective in hospital organisational decision making. Councils typically include patients, family members, executive leaders and staff, working in partnership to assure delivery of the highest standard of comprehensive and compassionate care. Patients and carers may be members of existing advisory and governance committees,¹² or new committees being established. Activities may include:

- providing information to hospital leaders and staff about patients’ needs and concerns
- helping plan patient care areas and new programs
- making changes that affect patients and family members
- encouraging patients and families to be involved and to speak up
- strengthening communication among patients, family members, care givers and staff.

The *Massachusetts Health Care Quality Act 2010*⁸⁶ requires all acute, chronic and long-term care hospitals in the US state of Massachusetts to establish a patient and family advisory council. The purpose of these councils is for patient and family members to advise the hospital on matters including, but not limited to, patient and provider relationships, institutional review boards, quality improvement initiatives, and patient education on safety and quality matters, to the extent allowed by state and federal law. Membership of a council is determined by each hospital; and orientation, training, and continuing education must be provided to council members. The legislation also allows physicians and healthcare providers to acknowledge a medical error by offering an apology to a patient without fear of that apology being used in a lawsuit.

Leadership and change management strategies

Enabling patient-centred care may require a change to the way organisations have traditionally provided care. Leadership and change-management strategies, including patient and staff rounding, fireside or chair-side chats, and clinician, employee and board engagement, are successful ways to strengthen the foundation for patient-centred care.¹² Staff rounding involves service-provider leaders moving through their organisation and hearing first-hand from patients and staff about what is happening in that unit. The idea is that patients and staff can express their views in a personalised, dialogue-based way that enables managers to understand the hospital experience.¹² Similarly, staff may be invited to meet with managers to share ideas or express concerns in fireside chats or chair-side chats. The strength of these communication methods is the direct interaction they afford between management, frontline staff and patients.¹²

Engaging staff and clinicians, such as involving them in patient-centred advisory councils, and identifying and recognising role models and champions of other patient-centred practices, are further strategies to establish and sustain patient-centred care.¹²

Board or governance-level strategies to facilitate patient-centred care include starting each board meeting with a patient story, shared by the patient or a staff member; including a board

member on a patient advisory council; and including patient-centredness as a defined and measurable organisational aim.¹²

Staff and practice development

In patient-centred care, the model of care delivery is not limited to a focus on the patient — considerable attention should also be paid to the experience of care providers.¹² In a patient-centred environment, all employees are care givers, each affecting the patient's experience. Accordingly, there is a need to engage employees in fostering an atmosphere of patient-centredness. Successful strategies to recognise and reward employees include public acknowledgment of a staff member in a newsletter for their impact on a patient, family member or another employee; or an employee-of-the-month program.¹² This can also be an opportunity for staff to share their story with the management team. More informal approaches to staff recognition include a simple acknowledgment or thank you during manager rounding.¹² Some providers have successfully adopted a strategy whereby a senior manager writes an inspirational weekly message that is recorded on a dedicated phone line and can be accessed by any employee. Scrolling screen saver messages and staff rounding are further tools to help employees engage in creating a patient-centred culture.¹²

Values training

Another factor associated with success in patient-centred environments is that employees' behaviour consistently reflects the organisation's values. Only when employees' personal values simulate the core values of the organisation can the culture transform to a patient-centred model.¹² At Sharp Coronado Hospital outside San Diego, California, every employee has completed the sentence, 'I come to work to make a difference by...' and the laminated statement is adhered to their name badge as a constant reminder that what they do is meaningful and is making a difference in people's lives.¹² Directly involving staff in determining the organisational values and defining the behaviours that embody those values fosters a culture of patient-centred care.¹² Making the organisation's values visible can remind staff of the patient-centred behaviours expected of them.¹²

Staff satisfaction strategies

According to Shaller,¹⁴ for healthcare organisations to be patient-centred, they need to create and nurture an environment in which their most important asset — their workforce — is valued and treated with the same level of dignity and respect that the organisation expects them to provide to patients and families. An important way to achieve this commitment and engagement is to conduct staff satisfaction surveys and monitor staff experience through staff rounding and experience-based co-design. Directly involving employees in the design and operation of patient-centred processes may also improve staff satisfaction.

Accountability strategies

To encourage and promote staff ownership of the cultural change required in many organisations to become patient-centred, the organisation should create opportunities for staff to be involved in envisaging and engaging in patient-centred care. Approaches that encourage engagement, communication and accountability include a shared governance structure or employee action committees comprised of both management and non-supervisory staff.¹² To define the way patient-centred care is provided, specific commitments and expectations can be outlined in professional codes of conduct. Some patient-centred organisations in the US have

incorporated performance measures to support the behaviours defined in codes of conduct,¹² and performance incentives based on improving quality metrics, including patient experience.⁸⁷

Improved complaints processes

In the UK, complaints about the NHS are a rich source of feedback. The Healthcare Commission and the Parliamentary and Health Services Ombudsman have both commented that the NHS should do more to use complaints feedback to improve services. This is at the heart of the reforms to the complaints process set out in *Listening, Responding, Improving: A Guide to Better Customer Care*.⁸⁸ The aim of the reforms is to enable healthcare organisations to improve the way they listen to, respond to and learn from people's experiences. To ensure that complaints are resolved with a more personal and responsive approach, a single, comprehensive complaints system is in place across health and social care. The UK Department of Health has published a guide and advice sheets on their new approach to complaints;⁷⁹ links to these resources are provided in Appendix B.

In the US, providers have complaints processes in place at the institutional and organisational levels. In addition, the Joint Commission's Office of Quality Monitoring evaluates complaints made by patients, carers and staff about its accredited providers that relate to safety and quality of care issues, such as patient rights, care of patients and safety.

2.4 Case study: Medical College of Georgia Health Inc, Georgia, US

Located in Augusta, Georgia, MCG Health Inc is a non-profit health service affiliated with the Medical College of Georgia. The medical district, including the university hospital, is the largest employer in Augusta, with more than 25 000 staff. MCG Health is a 632-bed tertiary medical centre with more than 22 000 admissions per year and 455 000 outpatients.

MCG Health's focus on patient-centred care started when they built a new paediatric medical centre in 1998. Patients and families were encouraged to participate in their care and were recognised as care team members and partners in improving care delivery. Because of this, MCG Health is considered a pioneer in the field of patient and family-centred care. Once the benefits of a patient-centred focus were recognised in the paediatric area, strategies were broadened to include adult services.

Strategies used by MCG Health include:

- establishing patient advisory councils; MCG Health has the largest patient adviser program in the US, with more than 130 trained patient and family advisers involved in safety and quality, planning, and design throughout the organisation
- removing all visiting hours; family and carers can visit at any time as preferred by the patient (including in the intensive care unit), and they are not viewed as 'visitors', but as 'partners'
- giving patients and family the right to call out rapid response teams
- ensuring that patient advisers sign off on plans for facility redesign and new fitouts
- introducing executives rounding and patient advisers rounding on wards
- providing patients' feedback to staff on a regular basis
- conducting training across the whole organisation in patient-centred customer service values
- redesigning patient accounts based on patient advice.

More recent undertakings include the redesigning of the MCG Medical Center Breast Cancer unit by patients — within three years, patient care experience ratings for the unit moved from the 40th to 74th percentile, rated using surveys administered by Press Ganey (an independent vendor). The neurology intensive care unit was renovated with patients' input and introduced a 24/7 family access policy — within five years, the patient satisfaction ratings increased from the 10th to 95th percentile and the length of stay for patients decreased by 50 per cent. At this point, staff acknowledged that the chief executive officer 'saw the business case' and became a patient-centred care 'convert'. During this time, MCG Health witnessed a number of clinical and operational benefits, including the overall staff vacancy rate falling from 8 per cent to 0 per cent, with a current waiting list of several hundred people. With a continued focus on patients in 2010, planning has begun for a new cancer centre with patient input into the design (Pat Sodomka, Sebrio Vice President, Patient and Family Centered Care, MCG Health Inc and Director, Center for Patient and Family Centered Care, Medical College of Georgia, pers comm, 2009).

2.5 An overview of leading organisations

Several private or not-for-profit organisations advocate specific patient-centred frameworks, or approaches to health service improvement that are built around a combination of the strategies outlined in Section 2.3. Both public and private health service providers have used these frameworks. The leading organisations advocating patient-centred frameworks to health care are described below. Websites and links to resources on strategies to promote patient-centred care are provided in Appendix B.

World Health Organization

The World Health Organization (WHO) is the United Nation's leading authority on global health matters, and their role includes setting standards and developing evidence-based policy.

As stated in Section 1.1, WHO advocates for a 'responsive' healthcare system that meets people's expectations.¹³ In addition, WHO advocates for involving patients and carers as partners in initiatives to improve the safety and quality of care,⁸⁹ particularly through its 'Patients for Patient Safety' (PFPS) program. PFPS works with a global network of patients, consumers, care givers and consumer organisations to support patient involvement in patient safety programs at local, regional and international levels. WHO has established a global network of PFPS 'champions', including 13 Australian champions, who work in partnership with health professionals and policy makers across the world to identify problems, design solutions and implement change.

PFPS is designed to ensure that the perspective of patients and families are a central reference point in shaping the safe and high-quality delivery of health services, including health service decision making. PFPS aims to develop opportunities for patient voices to be heard in creating public awareness about inherent healthcare risks; educate the public about systems approaches to risk management; report errors or healthcare failures in ways that contribute to systemic learning; and disseminate research and share solutions that can prevent patient harm.⁸⁹

Picker Institute

The Picker Institute was established in 1994 as an independent non-profit organisation and is based in Boston, Massachusetts, US. The institute's goal is to foster a broader understanding of the practical and theoretical implications of patient-centred care by focusing on the concerns of

patients and other healthcare consumers. The Picker Institute pioneered the use of scientifically valid, nationwide surveys and databanks on patient-centred care to educate doctors and hospital staff on improving patient services from a patient's perspective. The surveys cover the eight Picker dimensions of patient care (set out in Section 1.1), and patients report on what happened to them rather than rate how satisfied they were, as Picker research has shown that simple patient satisfaction questionnaires do not produce useful results. Picker Institute surveys are used by regulators in the US, UK, Canada and Australia to measure patient-centred care.

In addition to their surveys, the Picker Institute provides education programs, research grants and publications on patient-centred care topics, including *The Patient-Centered Care Improvement Guide*¹² and a self-assessment tool, written in conjunction with Planetree (see below). The Picker Institute has a sister organisation in Europe — the Picker Institute Europe. A variety of resources on patient-centred care is provided on the Picker Institute Europe website^c.

Institute for Patient- and Family-Centered Care

The Institute for Patient- and Family-Centered Care is a non-profit organisation founded in the US in 1992. The institute's mission is to advance the understanding and practice of patient and family-centred care. In partnership with patients, families, and healthcare professionals, the organisation integrates these concepts into all aspects of health care. It provides education, consultation, technical assistance, materials development, information dissemination and research on patient-centred care.

The institute website^d provides numerous practical resources, including assessment tools, guidance publications and multimedia resources produced by the institute and other leading patient-centred care organisations. Notable publications include:

- *Advancing the Practice of Patient- and Family-Centered Care: How to Get Started*³⁰
- *Partnering with Patients and Families to Design a Patient and Family-Centered Health Care System — Recommendations and Promising Practices*⁹⁰ (this publication sets out practical examples of patient-centred care in the US)
- *Partnering with Patients and Families To Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future — A Work in Progress.*²⁷

Studer Group

The Studer Group is a US-based organisation that partners with healthcare providers to increase performance by improving employee and clinician satisfaction and experience. Improved performance is achieved through 'the nine principles': commit to excellence; measure the important things; build a culture around service; create and develop leaders; focus on employee satisfaction to improve patient satisfaction; build individual accountability; align behaviours with goals and values; communicate at all levels; and recognise and reward success.

The Studer Group provides on-site resources to demonstrate their approach. Resources include tools for improving communication interactions between staff and patients, such as 'key words at key times', 'discharge phone calls' and 'patient rounding' tools. Others concentrate on improving patient experience by first improving staff satisfaction and experience, such as the

^c www.pickereurope.org

^d www.ipfcc.org

‘staff rounding for outcomes’ and ‘thank you notes’ tools. There are also several supplemental resources available to nonpartners, including leadership development resources and evidence-based tools.

Planetree

Planetree was founded in 1978 by a patient, Angelica Thierot, who was disheartened by her own experience of hospital care, which she felt was de-personalising. Her vision of a different type of hospital was one in which patients would become active participants in their own care and wellbeing. Planetree began by developing information libraries for patients and has grown into a non-profit organisation providing education and information on patient-centred care. It facilitates efforts to create patient-centred care in healthcare organisations in the US, Canada and Europe.

Based on the feedback of thousands of patients and hospital staff members, Planetree has identified core principles that are essential to practising patient-centred care, published in *Putting Patients First: Designing and Practicing Patient-Centered Care*.⁹¹

The Planetree method for fostering the core principles includes:

- working with senior leaders to develop and share ownership of an organisational strategy to drive improvement in patient-centred care
- multidisciplinary and multiprofessional training for all staff in the core principles, mainly through one and two-day retreats
- expressing the desired culture and values in an accessible language
- positively and continuously reinforcing Planetree values and principles with awards and recognition for individuals
- emphasising the built environment.

Planetree recently partnered with the Picker Institute to produce *The Patient-Centered Care Improvement Guide*.¹² This and other Planetree publications are available on the Planetree website^e.

Institute for Healthcare Improvement

The Institute for Healthcare Improvement (IHI) is an independent not-for-profit organisation, founded in 1991 and based in Cambridge, Massachusetts. The IHI aims to identify best practices and bring about system changes that enable healthcare providers to become and remain patient centred. The IHI has developed tools to assist healthcare providers, including an ‘improvement map’ that sets out the processes for improving patient-centred care in a variety of areas (advanced care planning, communication with patients and families after an adverse event, daily goal setting and planning for treatment and discharge, multidisciplinary patient rounding for coordinated care; shared decision making, patient experience programs, and leadership programs to enable patient-centred care). The IHI provides a variety of publications, resources, tools and improvement stories on its website to help organisations achieve patient-centred care^f.

^e www.planetree.org

^f www.ihl.org

Kenneth B Schwartz Center

The Kenneth B Schwartz Center is a non-profit organisation based at Massachusetts General Hospital. It was founded by the family of a patient (Schwartz) in 1995, with a mission to 'provide support and advance compassionate health care, in which care-givers, patients and their families relate to one another in a way that provides hope to the patient'. The centre runs programs to educate, train and support care givers in 'the art of compassionate health care', and to strengthen the relationship between patients and care givers, including Schwartz Center Rounds, the CarePages website and the Patient Voice for Compassionate Care Program.

Schwartz Center Rounds are a multidisciplinary forum where care givers discuss difficult emotional and social issues that arise in caring for patients. An evaluation of Schwartz Center Rounds⁹² found many benefits, including improving communication and teamwork among care givers, and communication between care givers and patients. This study also found that participating in rounds increased the likelihood of staff attending to the psychosocial and emotional aspects of care, and improved their beliefs about the importance of empathy.

The CarePages website^g contains patient blogs that connect friends and family during a health challenge, helping them support each other. The Patient Voice for Compassionate Care: Schwartz Center Dialogues is a pilot program that brings the experiences and perspectives of patients and their families directly to care givers in a series of facilitated discussions. The program helps patients and their families become stronger advocates and partners in their own care; at the same time, it improves the communication skills of care givers and the quality of compassionate care they deliver. The panel of patients and care givers identify specific changes necessary to improve communication and reconvene over time to ensure that the changes are made and the patient focus is sustained. Information on each of these programs is available on the Schwartz Center website^h.

The King's Fund

The King's Fund is a charity that seeks to understand how the health system in the UK can be improved. The King's Fund Point of Care program aims to transform patients' experience of care in hospital by enabling healthcare staff to deliver the quality of care they would want for themselves and their own families. The King's Fund works with patients and their families, staff and hospital boards to research, test and share new approaches to improving patients' experience. *Seeing the Person in the Patient: Point of Care Review Paper*¹⁵ considered current debates and dilemmas in relation to patients' experience of care in acute hospitals in the UK. Based on this research, The King's Fund developed a framework to analyse the factors that affect patients' experience at four levels: individual interactions with staff members; the 'clinical micro-system' of the team, unit or department; the hospital; and the wider healthcare system, including NHS priorities.¹⁵ These levels are similar to the IOM levels of patient-centred care described in Section 1.4.¹

^g www.carepages.com

^h www.theschwartzcenter.org

3 The relevance of patient-centred care to the Australian health system

Australia has a mixed healthcare system, where funding for, and delivery of, health care is divided between the public (represented by the Australian Government, six states and two territories) and private sectors.⁹³ Despite the complexity of the Australian healthcare system, many of the strategies and approaches to patient-centred care used internationally are highly applicable in Australia. Current policy and reform initiatives address the need for health service organisations to adopt a patient-centred approach to health care. This section describes the applicability of patient-centred care approaches and strategies to the Australian health system; provides an overview of the current policy reform context of patient-centred care in Australia; and highlights national-level initiatives, strategies and policies that promote patient-centred care.

3.1 The relevance of patient-centred care to a mixed healthcare system

Australia's health system is primarily funded through general taxation and a small compulsory tax-based health insurance levy. Medicare, the tax-funded national health insurance scheme, offers patients free public hospital care and subsidised access to their doctor of choice for out-of-hospital care.⁹³ The Australian Government's Pharmaceutical Benefits Scheme provides subsidised access to a wide range of medicines for all Australians. The public system administers public hospitals and a range of other primary and community health services.

The private sector includes the majority of doctors (GPs and specialists), numerous private hospitals and day hospitals, a large diagnostic services industry, pharmacists and a small number of major private health insurance funds.⁹³ Ownership of private hospitals is centralised, with more than two-thirds of all private beds owned by large for-profit chains or the Catholic Church.⁹³ GPs and pharmacists are largely self-employed and funded by Medicare through a fee-for-service and the Practice Incentive Program (PIP). The PIP offers financial incentives for accredited GPs to improve the quality and accountability of their medical services.

Both the public and private sectors are seeking to improve the overall quality of health care through activities such as patient experience and patient satisfaction surveys. These initiatives are supported and driven at the national policy level via recent national reforms that seek to embed patient experience as a measurable and reportable component of quality. National level service strategies and plans provide a further lever for the government to promote a patient-centred approach to health care in Australia.

Accreditation of health service facilities is another aspect of Australia's healthcare system that could further facilitate patient-centred care by incorporating patient-centred principles into accreditation requirements. The Australian Council on Healthcare Standards is the main accrediting body; others include the Quality Improvement Council, Aged Care Standards and Accreditation Agency, and Australian General Practice Accreditation Limited. To date, accreditation has been largely voluntary; however, most public sector hospitals are required to seek accreditation and most large hospitals seek accreditation.⁹³ Meeting accreditation standards provides financial incentives, because private health insurers pay higher reimbursement rates to accredited facilities.⁹³

3.2 National health reform

Recent national policy reforms set out in the National Health and Hospitals Network Agreement⁹⁴ were focused on the need to improve access to services, quality of service delivery, financial responsibility, patient outcomes and patient experience. The reforms include a new Performance and Accountability Framework that includes national performance indicators, national clinical quality and safety standards developed by the ACSQHC, and new Hospital Performance Reports and Healthy Communities Reports.

The Performance and Accountability Framework builds on the requirement for public reporting on objectives and outcomes of the National Healthcare Agreement (NHA).⁹⁵ The NHA identifies a number of long-term goals for Australian governments to improve health outcomes, including that 'Australians have positive health and aged care experiences which take account of individual circumstances and care needs'.⁹⁵ Progress will be measured by nationally comparative information that indicates patient satisfaction levels on key aspects of the care they received. In the first NHA report in 2010, agreement had not yet been reached on how to measure this progress and no data were included.⁹⁵ In the future, progress reports will be drawn from patients' experience surveys in each jurisdiction (see Section 4.1) and a national population-based survey conducted by the Australian Bureau of Statistics (ABS; see Section 4.1) on the healthcare experiences of individuals in private households.⁹⁵

The national performance indicators set out in the Performance and Accountability Framework provide potential levers for improvement in patient-centred care, and quality more generally. The indicators acknowledge the need to measure traditional operational and clinical performance indicators (such as hospital waiting times and hospital-acquired infections) alongside patient-reported quality based on the patient experience.⁹⁴ They also facilitate transparent monitoring across services and jurisdictions, setting a minimum standard of healthcare quality that each provider should adhere to.

A new, independent National Performance Authority will be established in early 2011 with responsibility for local-level performance reporting. The hospital performance reports prepared by the authority will show how Local Hospital Networks, individual public hospitals, and private hospitals perform against the new national standards. Performance indicators will include public hospital emergency department and elective surgery waiting times, adverse events in hospitals, patient satisfaction and financial management.

Performance will be tied to funding in the form of a 'nationally efficient price'. This is a nationally consistent patient level costing and pricing regime, determined by the Independent Hospital Pricing Authority. The authority will establish nationally consistent funding to providers based on the national efficient price of each public hospital. This is calculated according to reasonable access to public hospital services, clinical safety and quality, efficiency and effectiveness, and financial sustainability of the public hospital system.⁹⁴ By linking this funding to performance, the nationally efficient price will consider clinical indicators and outcomes, as well as patient experience.⁹⁴ Improving the patient experience through patient-centred care therefore has important implications for both patients and providers.

The ACSQHC is exploring options for the national clinical quality and safety standards. These standards will complement the National Safety and Quality Healthcare Service Standards currently being developed by the ACSQHC in their work on accreditation reform. The National Safety and Quality Healthcare Service Standards include a consumer engagement component that encompasses patient-centred care and will become compulsory for high-risk health services, including hospitals, day procedure centres and procedure rooms.

3.3 National strategies and initiatives promoting patient-centred care

A variety of national service-level initiatives, strategies and policies set out a patient-centred approach to health care. National initiatives include the Australian Charter of Healthcare Rights and the National Safety and Quality Framework. National strategies such as the National Primary Care Strategy, the National Chronic Disease Management Strategy, the Fourth National Mental Health Plan and the Fifth Community Pharmacy Agreement, all state that a patient-centred approach to health care is needed to improve the quality of health care in Australia. Current Aboriginal and Torres Strait Islander policies also reflect patient-centred principles and focus on family and community.

Australian Charter of Healthcare Rights

The Australian Charter of Healthcare Rights underpins the provision of safe and high-quality care, and supports a shared understanding of the rights of patients and consumers between those seeking health care and those providing health care.⁹⁶ Since 1993, each Australian state was required to develop public patient hospital charters to inform patients of their rights under the Australian Health Care Agreements.⁹⁷ In July 2008, Australian health ministers endorsed a single national charter as a clear statement of a minimum set of standards, rights, expectations and entitlements that is uniformly applicable across all states and territories and in all settings of care.⁹⁶ The charter and associated information is available on the ACSQHC websiteⁱ.

National Safety and Quality Framework

In 2009, the ACSQHC proposed a National Safety and Quality Framework for health care. The overall aim of the proposed framework is to provide direction for improving the healthcare system. In developing the framework, the ACSQHC recognised that consumer engagement in the health system through patient-centred care is vital to safety and quality improvements and should underpin the strategic plan for the system.⁷ The actions proposed for health systems and providers to achieve patient-centred care are shown in Table 1.

ⁱ www.safetyandquality.gov.au

Table 1 **Actions proposed to achieve patient-centred care under the ACSQHC Proposed National Safety and Quality Framework**

Safe, high-quality health care is always:	What it means for me as a patient or consumer:	Strategies for action by health systems and providers:
<p>1. Patient focused</p> <p>This means providing care that is respectful of and responsive to individual preferences, needs and values. It means a partnership between consumers, family, carers and their healthcare providers. Processes of care are designed to optimise the patient experience.</p>	I can access high quality care when I need it.	<ul style="list-style-type: none"> • Develop service models that improve access to health care for patients.
	I can obtain and understand health information, so that I can make decisions about my own care and participate in ensuring my safety.	<ul style="list-style-type: none"> • Increase health literacy. • Involve patients so that they can make decisions about their care and plan their lives. • Provide care that is culturally safe.
	My health care is co-ordinated because people and systems work in partnership with me.	<ul style="list-style-type: none"> • Enhance continuity of care. • Minimise risks at handover. • Provide case management for complex care. • Facilitate patient-centred service models.
	I know my healthcare rights	<ul style="list-style-type: none"> • Promote healthcare rights.
	If I am harmed during health care, it is dealt with fairly. I will get an apology and a full explanation of what happened.	<ul style="list-style-type: none"> • Inform and support patients who are harmed during health care

Source: ACSQHC 2009⁷

National Primary Health Care Strategy

The National Primary Health Care Strategy is a high-level action plan consisting of 10 elements to improve patient-centred care in Australia. It sets the policy direction to better connect hospitals, primary and community care to meet patient needs, improve continuity of care and reduce demand on hospitals. Key priority areas identified in the National Primary Health Care Strategy include:

- improving access and reducing inequity
- better management of chronic conditions
- increasing the focus on prevention
- improving quality, safety, performance and accountability.⁹⁸

Although the Australian primary healthcare system serves many patients well, it has not been specifically designed to cater for the particular health needs and cultural requirements of some groups, such as people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, or disadvantaged and marginalised populations. These groups may find it difficult to access appropriate services within the system, or to know which services to access and when.⁹⁸ The National Primary Health Care Strategy recognises that an inclusive and patient-centred focus is a key element to all future reforms in primary health care.

National Chronic Disease Strategy and National Service Improvement Frameworks

Promoting patient-centred care is a central aim for improving health service delivery, outlined in the National Chronic Disease Strategy (NCDS) and the National Service Improvement Frameworks (NSIF) for asthma, cancer, diabetes, heart disease, stroke and vascular disease.⁹⁹ NCDS and NSIF place the patient, their family and carers at the centre of a broader health promotion and disease prevention framework. This includes the core principle of achieving patient-centred care and optimising self-management. Self-management helps people to take responsibility for their own health, to make informed decisions, and to maximise their wellbeing and quality of life.⁹⁹

National Mental Health Plan

The Fourth National Mental Health Plan¹⁰⁰ outlines reporting requirements for service providers against agreed standards of care, including consumer and carer experiences and perceptions. A priority in this plan is ensuring that consumers and carers can access information about service provider performance across the range of health quality domains and compare these to national benchmarks. The principles behind this priority include the following patient-centred concepts:

- Consumers, their carers and families should be actively engaged at all levels of policy and service development. They should be fully informed of service options, anticipated risks and benefits.
- Consumers and carers should be able to access information in a language they understand, or have access to interpreters.
- Families and carers should be informed to the greatest extent consistent with the requirements of privacy and confidentiality about the treatment and care provided to the consumer, the services available and how to access those services. They need to know how to get relevant information and necessary support.

The Fourth National Mental Health Plan also calls for the recognition of social, cultural and geographic diversity and experience of consumers and carers.¹⁰⁰

Community Pharmacy Agreement

The Fifth Community Pharmacy Agreement¹⁰¹ commenced on 1 July 2010. It encourages pharmacists to adopt a more patient-centred approach to care by providing support for pharmacists to identify, resolve and document medicine-related issues experienced by patients. The agreement also sets out a new patient service charter that outlines the role and responsibilities of the pharmacist and the pharmacy.

Aboriginal and Torres Strait Islander primary healthcare policy

In addition to the National Primary Health Care Strategy, Aboriginal and Torres Strait Islander policies reflect patient-centred principles and aim to be community and family-centred.

The Office for Aboriginal and Torres Strait Islander Health provides direct grants to approximately 280 Aboriginal community controlled health services and Aboriginal medical services. These organisations are primary healthcare services initiated and operated by the local Aboriginal community. They deliver holistic, comprehensive and culturally appropriate health care to the community that controls it, through a locally elected board of management.

The National Aboriginal Community Controlled Health Organisation (NACCHO) is the national peak Aboriginal health body representing Aboriginal community controlled health services throughout Australia. According to NACCHO, this model of primary health care is in keeping with the philosophy of Aboriginal community control and the holistic view of health that this entails:

Aboriginal health is not just the physical well being of an individual but is the social, emotional and cultural well being of the whole community in which each individual is able to achieve their full potential thereby bringing about the total well being of their community.¹⁰²

In a review on the link between primary health care and health outcomes for Aboriginal and Torres Strait Islander people, Griew¹⁰³ identifies the following patient-centred factors in association with successful local-level primary healthcare interventions:

- genuine local Aboriginal and Torres Strait Islander community engagement to maximise participation, up to and including full community control
- a multidisciplinary team approach employing local community members
- service delivery that harmonises with local Aboriginal and Torres Strait Islander ways of life.

Current reform proposals in relation to Aboriginal and Torres Strait Islander primary health care emphasise the importance of a family-centred approach. Family in this context has a broad community focus and recognises, for example, that Aboriginal and Torres Strait Islander children often have other significant carers in addition to their biological mother and father.¹⁰⁴ Family-centred primary health care takes a life course approach, which, without neglecting adult health, focuses on establishing early life resilience and advantages in child development.¹⁰⁴ Family-centred primary health care is an attempt to draw education and family welfare, usually considered to be part of the social determinants of health, into the foreground of primary healthcare practice.¹⁰⁴

4 Current jurisdictional and other activity in Australia

This section highlights some of the main patient-centred care initiatives in Australia. Many of these evolved from the need to address the safety and quality of health service delivery, revealed by several recent high-profile state-based inquiries. These inquiries involved patient care and adverse clinical incidents at the King Edward Memorial Hospital in Perth,¹⁰⁵ Canberra Hospital,¹⁰⁶ Royal Melbourne Hospital,¹⁰⁷ Campbelltown and Camden Hospitals,¹⁰⁸ Bundaberg Hospital and Queensland Health,¹⁰⁹⁻¹¹⁰ Royal North Shore Hospital,¹¹¹⁻¹¹² and, more generally, acute care services provided by NSW Health.¹¹³⁻¹¹⁴

Hindle et al¹¹⁵ reviewed the common features of the King Edward, Royal Melbourne and Campbelltown and Camden inquiries. They found that quality monitoring processes were deficient, and patients and families were not informed members of the team. Patients were not adequately involved in care planning and did not always have an adequate basis for informed consent; they were unsure of their rights and frequently afraid of exercising them; they were sometimes treated in inconsiderate ways (mainly by doctors); and they seldom received sympathetic and helpful support when they made complaints.

All the inquiries concerned allegations of poor clinical practice and poor communication between healthcare organisations and patients, their families or other carers. This led to a loss of trust in the health system from patients and the community.⁶⁶

The response to each of these inquiries was an increased focus on patient-centred care. Several strategies to achieve this are in place at the jurisdictional level, including improving communication with patients, improving complaints processes, promoting healthcare rights, increasing reporting of hospital activity and performance in relation to patient safety and quality issues, and increasing consumer involvement in health service planning and design.¹¹⁶⁻¹¹⁷

The need to improve the safety and quality of health care has led to public and private providers adopting a variety of approaches (typically involving patient feedback surveys) to measure the quality of the patient journey and the experience of interactions across different settings. These and other approaches are discussed in this section.

4.1 Listening to patient feedback

Most Australian jurisdictions conduct surveys to measure patients' experience across different settings. In New South Wales, Patient and Care Experience surveys are conducted annually. Condition-specific surveys are also emerging, with a care experience survey for cancer patients conducted through the Cancer Institute NSW.¹¹⁸ Other states' surveys include the Victorian Patient Satisfaction Monitor survey, the Queensland Health Patient Satisfaction survey, the Healthcare Survey (Australian Capital Territory), and the Patient Evaluation of Health Services survey (South Australia and Western Australia). Tasmania has a Patient Satisfaction System in place.¹¹⁹ Links to some of the state and territory survey websites, which contain information about the surveys and some results, are provided in Appendix B.

Survey results are used to identify trends, monitor performance, benchmark results against similar service providers, and inform health service planning and patient safety and quality initiatives.¹²⁰ For example, NSW Health requires each of its area health services to produce action plans based on their survey results.

The Australian Bureau of Statistics (ABS) also collects population-based information about healthcare experiences from private households. Part of the annual Multipurpose Household Survey identifies healthcare issues at a national level across a range of key delivery areas, including hospitals (inpatient and emergency), general practice, specialists, pathology and imaging tests, and dentistry. Unlike the state and territory surveys, the ABS asks household members to recall a range of experiences over the preceding 12-month period, rather than a specific service experience. This survey of consumer experience, first conducted in July–December 2009 on a sample of around 6500 people, has the advantage of capturing information about people who could not access services and exploring underlying reasons. Future ABS surveys will be expanded to capture the experiences of more than 20 000 people from 2010–11.

The Council of Ambulance Authorities has conducted annual national patient satisfaction surveys since 2002,¹²¹ which measure the quality of the ambulance service as perceived by its customers. The survey results are compared across states and territories and are used to set performance benchmarks.

The private sector, including GPs, insurers and hospitals, also conduct surveys to capture patients' experiences and feedback. There is little publicly available information on the content or scope of private sector surveys. The draft fourth edition of the Royal Australian College of General Practitioners Standards (due for release in late 2010) requires GPs to obtain feedback from patients by both establishing and maintaining an ongoing feedback mechanism (such as a suggestion box or complaints management system); and collecting patient feedback information every three years (such as through written patient questionnaires, focus group discussion or patient interviews).

4.2 The Australian Institute for Patient- and Family-Centred Care

The Australian Institute for Patient- and Family-Centred Care was recently formed by a group of interested individuals and healthcare professionals. The institute is based on the American Institute for Patient- and Family-Centered Care (see Section 2.5). The purpose of the institute is to:

- advance the understanding and practice of patient and family-centred care
- improve the healthcare experience and outcomes for patients, families and healthcare professionals
- provide onsite training, technical assistance and education packages to all healthcare professionals and students
- undertake research and evaluation
- develop policy statements
- advise healthcare program planners and decision makers.

4.3 Examples of state and territory initiatives

State and territory health departments have made a range of advances in driving and supporting patient-centred care. These are summarised below.

ACT Health

In 2003, ACT Health established the Consumer Feedback Project, which involved comprehensive consultation with the community and resulted in the report *Listening and Learning, ACT Health's Consumer Feedback Standards*.¹²² The standards encourage consumers to provide feedback, both positive and negative, on their health experience. The importance of the standards was reinforced with the release of ACT Health's *Consumer Feedback Management Policy*¹²³ in 2008. The policy outlines the general principles and approach of all ACT Health staff to manage consumer feedback.

ACT Health provides consumer information on its website^l. This includes the ACT Healthcare Survey, details of how to access medical records, and information on consumer involvement, community consultation, surgery, interpreter services, freedom of information, interstate patient travel, and maps of the campuses.

A patient experience program and a redesign program are currently underway in the ACT. More than two hundred patients and carers across a wide range of clinical settings have told their stories through these programs. This information is used for planning and designing new facilities, redesigning processes, and identifying gaps and barriers to healthcare delivery. ACT Health is developing a framework for partnering with patients in all aspects of the redesign program.

Information from the patient experience and redesign programs is a valuable educational tool. Staff are directly involved in documenting the information received from interviews, and the patient experience reports are provided to senior staff and executives. Furthermore, ACT Health partners with the University of Canberra to educate nursing students about patient experiences and the importance of a patient-centred approach to care delivery.

Since 2006, ACT Health has implemented the Respecting Patient Choices Program, a national advance care planning program developed by Austin Health in Victoria. The Respecting Patient Choices Program enables individuals to discuss and document decisions about their future health care, to prepare for a time when they are unable to participate in their medical care decisions. There is significant community support for this program and the program coordinator has built networks within the residential aged care sector, as well as with other groups, to increase community awareness of advance care planning.

ACT Health has adopted the Australian Charter of Healthcare Rights and is working with the Human Rights Commission and the Health Care Consumers Association of the ACT to implement the charter.

NSW Health

NSW Health has implemented two experience-based co-design programs.^{74 124-125} Evaluations of these programs revealed that co-design was successful in:

- enabling frontline staff to better appreciate the impact of healthcare practices and environments on patients and carers
- engaging consumers in 'deliberative' or in-depth processes that were qualitatively different from conventional consultation and feedback

^l www.health.act.gov.au

- achieving practical solutions that realise the wishes, advice and insights of consumers and frontline staff
- enabling staff to reflect on and improve their work practices
- involving consumers in developing or reviewing clinical pathways, leading to better experiences and patient flow.^{74 124-125}

NSW Health has implemented a variety of other patient-centred initiatives. For example, the Essentials of Care Program aims to:

- encourage patient participation in decisions about their care
- focus on patients' needs and their experiences of care provided
- value the contributions from all involved in care
- support the ongoing review and development of practice
- use relevant research and evidence that is generated from practice and care settings.

The Clinical Leadership Program, an initiative of the Clinical Excellence Commission in NSW, helps healthcare professionals develop leadership strategies to introduce more patient-centred principles into their practice.

In response to the New South Wales inquiries, the NSW Health *Caring Together: Health Action Plan*¹¹⁶ focuses on the patient as the centre of the healthcare system. This includes strategies to improve communication with patients, such as identifying categories of staff and types of uniforms worn, and developing patient fact sheets to support care in emergency departments. Nurse positions have been established and filled in the emergency department that focus on the needs of the patients in the waiting room, providing better communication on waiting times, initiating basic treatments and completing required admissions documentation.¹¹⁶ The 'Take the Lead' project is designed to further facilitate the roles of the Nursing Unit Manager and Midwifery Unit Manager in improving the patient journey and carer experience. Some health services in NSW have also implemented Studer Group training and programs.

Queensland Health

Queensland Health acknowledges that measuring and reporting on the quality of care from a patient's perspective is essential to providing a high-quality healthcare system.

The Queensland Health strategy for improving the patient experience is informed by collecting consumer feedback through surveys, collecting patient stories and using an enterprise-wide computer-based information system to record and manage complaints and compliments. This information allows Queensland Health to assess performance along the patient journey at the service delivery level and to determine where it may be appropriate to concentrate improvement activities. It also allows the impact of these improvement activities to be measured over time. Management action plans developed in consultation with local Health Community Councils identify areas and activities for improvement, and state-wide trend analysis informs organisational strategic planning.

The Productive Ward and Transforming Care programs are key quality and safety improvement initiatives sponsored by the Patient Safety and Quality Improvement Service. Both focus on patient-centred care as a core pillar of their improvement strategy. The programs promote practice that improves the amount of time nurses spend delivering direct patient care (typically doubled). They provide strategies to improve the quality of patient-centred care and have

established links with priority state and national safety initiatives. These include clinical handover, recognition and management of the deteriorating patient, malnutrition, patient identification, and falls and pressure ulcer prevention. Both programs have developed patient satisfaction and patient experience assessments to measure improvement in these indicators. The programs are spreading across all health service districts in Queensland.

Queensland Health actively engages consumers in service planning, design implementation and assessment, from executive committee membership to consultation in the assessment of survey outcomes. Health Consumers Queensland was established in 2008 to contribute to the continued development and reform of health systems and services in Queensland, by providing the Minister for Health with information and advice from a consumer perspective and by supporting and promoting consumer engagement and advocacy.

Victorian Department of Health

In 2006, the Victorian Department of Health developed the consumer participation in health policy, *Doing it With Us Not For Us*.¹²⁶ A strategic framework advocating a patient-centred approach to implementing this policy was drafted in 2009.¹²⁷ In addition, *The Victorian Mental Health Reform Strategy 2009–19* was developed in partnership with patients and carers.¹²⁸ The strategy and accompanying action plan and draft quality framework promote mechanisms to support patient-centred care in mental health services.

The Victorian Department of Health currently has several patient-centred projects and initiatives in place. For example:

- A series of 'productive ward' projects developed by the NHS in the UK are currently being piloted. The aims of the projects are to increase the time staff spend caring for patients, staff morale and retention and safety. The pilots also aim to reduce length of stay and patient complaints.
- In 2008, a stroke project aimed at improving the care pathway for people who have had a stroke and their carers was developed and implemented in consultation with patients and carers.
- A paediatric palliative care parent reference group is being established to ensure the needs and views of parents are included in the government's policy for paediatric palliative services.

Several health services have conducted process-redesign projects as part of a broader Improving the Patient Experience Program. Under this program, emergency departments in Victoria had physical amenity upgrades and reviews of their internal environment. Three complementary activities to improve communication were initiated, including consistent patient-friendly signage improvements, consistent consumer-focused information materials, and communication workshops for frontline emergency department staff. Workshops were also held to improve clinicians' understanding of the patient's perspective of emergency department care and consumer communication needs.

The Ministerial Advisory Council on Safety and Quality, the Victorian Quality Council, has introduced an initiative to improve the patient journey. Objectives of this initiative are to promote the principles of patient-centred care across the Victorian health sector, improve and standardise information flow, and provide decision support tools to assist interfacility transfer of non-critical patients.

The Victorian Quality Council has also introduced the Consumer Leadership Program to develop patient-centred care at the system level. This program is based on research commissioned by the Rural and Regional Health and Aged Care Services Division¹²⁹ that cites the need for structured education and training for staff to develop and improve leadership, and effective consumer participation to improve the safety and quality of care. The most effective strategies were:

- consumer leadership programs that incorporate elements of formal learning, peer support and mentoring
- peer support networks (including local, regional and statewide meetings) for consumer leaders involved in safety and quality activities, in partnership with statewide and major metropolitan and rural health consumer organisations and networks
- guidelines for development and support of consumer leadership within the health system to ensure effective participation and leadership.¹²⁹

Based on this research, the Victorian Quality Council has now contracted the Health Issues Centre to design a pilot program in health literacy and consumer leadership that meets the needs of health consumers and staff with varying experience levels in consumer participation, from beginner to experienced board member or health services staff. The pilot is expected to be completed by April 2011.

WA Health

WA Health has developed the Patient First Program.¹³⁰ This program places patients and their carers at the forefront of clinical processes by increasing patients' understanding of their condition, which facilitates better decision making through informed consent. The program aims to increase patients' health literacy and facilitate a quicker recovery time. Increasing patients' awareness of the risks inherent in their health care was seen to minimise the potential for adverse events and give them the ability to self-manage their health issues.

The program involved volunteer consumers ('Patient First Ambassadors') distributing a *Patient First* booklet directly to patients. The booklet provides information for patients on topics such as informed consent, issues to consider when making decisions about treatment, understanding the risks associated with treatment and procedures, patients' rights and responsibilities, medication safety, falls prevention, avoiding infection, improving emotional wellbeing, maximising recovery, health records, information and privacy.¹³¹

Using a Patient First Ambassador to distribute the booklets improved communication with patients, and the idea of one consumer talking to another consumer was a powerful tool. The ambassador was not affiliated with the hospital or health department, but identified with the health consumer and was therefore able to discuss the topics in the booklet in a non-threatening way.¹³⁰

In 2009, the inaugural Australian PFPS Workshop was held in Perth. The workshop was a collaboration between the WHO Alliance for Patient Safety; the London, Chicago and Australian networks for PFPS; the Health Consumers Council WA; and the Office of Safety and Quality of the WA Department of Health. The workshop brought together a group of 40 health consumers, many of whom had experienced medical error or health system failure, healthcare providers and health policy makers from around Australia. The workshop resulted in the Perth Declaration for Patient Safety. The Perth Declaration builds on the London Declaration drafted at a similar workshop in London in 2005. The London Declaration is a pledge of partnership between consumers and providers. The Perth Declaration for Patient Safety continues and aligns with

this Pledge of Partnership to form an Australian community of committed people who seek to ensure future health users are not harmed.

4.4 Case study 1: Australian Capital Territory — Calvary Health Care Simply Better Program

In 2006, staff at Calvary Health Care in the ACT — a mixed public and private service — reviewed their patient care experience results and identified a need for significant improvement. Analysis of surveys conducted through private vendor Press Ganey highlighted that patient satisfaction had fallen below the 10th percentile and that staff satisfaction was similarly poor. Assessment by Better Practice Australia identified a ‘culture of blame’ in the service.

In recognition of the link between patient satisfaction and staff satisfaction, Calvary launched the Simply Better Program using the Studer Group model to develop strategies to improve both the care experience of patients and the work environment experience of staff. Targets for performance improvement were established in both areas at the outset. Importantly, the Simply Better Program was linked to Calvary’s strategic plan, organisational mission, and values and service accreditation processes.

Using the Studer Group principles for improvement, the program:

- obtained commitment from the executive team and departmental managers
- developed measurable goals and performance indicators (eg in preventable harm of patients and unplanned employee leave)
- built a service culture through training and coaching of staff and regularly providing staff with patient feedback
- developed leaders through providing managers with executive leadership training
- focused on staff satisfaction including staff rounding to engage staff in the improvement processes
- built accountability through review of measurable goals and meetings with line managers to identifier barriers and enablers
- aligned behaviours with goals and values
- provided open communication about strategies and program orientation for new staff
- instituted a process of formal recognition of staff excellence.

Specific strategies to improve patient care experience included rounding on patients (which is the systematic monitoring of patients that incorporates specific actions, done at specific intervals) and using patient whiteboards. Communication skills were improved through discharge calls and use of the AIDET tool (Acknowledge, Introduce, Duration, Explanation, Thank you) for all patient communication.

Calvary Health Care considers the Simply Better Program an organisational success, as witnessed through a range of improved outcomes. Improvements in patient care experience data occurred across the organisation, including the public mental health hospital (increased from 69th to 99th percentile), public day surgery (from 56th to 74th percentile) and private day surgery (from 47th to 88th percentile). In three years, employee satisfaction significantly improved from a ‘culture of blame’ to one of ‘reaction/consolidation’. Following the implementation of the Simply Better program, Calvary achieved its best ever accreditation survey results and the program was awarded an ‘outstanding achievement’ during the

accreditation. Other health services across the country have liaised with Calvary and are now adopting similar strategies.

In 2009, Calvary Health Care's Simply Better Program was awarded the Overall Winner of the ACT Quality in Healthcare Awards (Naree Stanton, Support Services Manager, Calvary Hospital, Canberra, ACT, pers comm, 2009).¹³²

4.5 Case study 2: South Australia — Flinders Medical Centre Emergency Department Redesign project

Flinders Medical Centre established the Redesigning Care Program in 2003. The primary objective of this program was to address the increasing demand for emergency services in the hospital. The program used 'lean thinking' (ensuring that every step of a process adds value and serves the customer's needs) to redesign hospital processes across the entire spectrum of clinical care. Using these principles, Redesigning Care aimed to eliminate duplication and delays, and redesign patient flow to ensure that each step in the process added value and improved outcomes for patients and staff.¹²⁴ The program focused on the patient journey from admission to discharge, and one of its basic rules was to 'see things through the patient's eyes'. The work at Flinders Medical Centre has been undertaken in the emergency department, under the banner of experience-based design (EBD) based on Bate and Robert.⁸⁵

In 2007, the Flinders Medical Centre Redesigning Care Program designed and implemented an approach to capture patient, carer and staff experience in the emergency department. The aim was to understand and improve patient, carer and staff experience when accessing the emergency department at Flinders Medical Centre; and to trial the EBD methodology as a sustainable approach to patient and carer participation within the Flinders Medical Centre management system.¹²⁴ In 2007–08, data were generated through observations of 22 patient and carer real-time experiences, 14 patient and carer reflective interviews and 29 staff interviews.

Some of the solutions for action related to recommendations for physical changes and resulted in a capital works redevelopment of the emergency department at Flinders Medical Centre to increase patients' comfort and improve their environment. These solutions included a physical redevelopment that reduced noise levels and improved visual management by staff. The main solutions outside of the redevelopment involved communication processes and team work. The program was considered successful in improving team work and improving communication between staff and patients.⁷⁴

5 Making progress on patient-centred care in Australia

Current and emerging policy points to the need for health services to be patient centred, but healthcare services can often find it difficult to transform care delivery. Most services can readily put patient charters and informed consent policies in place, but many also find it hard to actively change the way care is delivered, and struggle to involve patients and learn from their experience.² There is little guidance on how to implement patient-centred care in health services in Australia.

This section highlights strategies and makes recommendations that practitioners, managers and policy makers can use to establish and maintain patient-centred care. Sections 5.1 and 5.2 consider the key issues of redefining quality in health care and in performance monitoring, and give policy-level recommendations. Practical strategies and service-level recommendations are discussed in Section 5.3, and checklists to help organisations assess their readiness to implement patient-centred care are presented in Appendix A.

5.1 Refocusing the way we look at quality in health care

Patient-centred care necessitates a change in the way policy makers and regulators think about the quality of health care. The traditional approach to health care focuses on clinical, therapeutic and diagnostic effectiveness, and cost-effectiveness as measures of health outcomes.⁹ By contrast, patient-centred care takes a broader view; for example, the Next Stage Review defines quality as consisting of patient safety, clinical effectiveness and patients' experience.

In the US, the IOM report identified patient-centred care as one of six quality aims for improving care.¹ Berwick¹³³ states that incorporating patient-centred care into health care as we currently know it will involve some radical, unfamiliar, and disruptive shifts in control and power, out of the hands of those who give care and into the hands of those who receive it. The starting point for change will therefore be affirming patient-centred care as a dimension of quality in its own right, and not just through its effect on health status and outcomes.¹³³

In Australia, it is recognised the traditional model of patient safety, drawn from high-risk industries, is not patient-centred enough to be used as a comprehensive approach to improving safety and quality.¹³⁴ Patient-centred care is now considered to be an integral dimension of quality health care in Australia: the ACSQHC's proposed National Safety and Quality Framework, described in Section 3.3, positions patient-centred care as one of three dimensions of safety and quality.⁷ Various state and territory safety and quality frameworks acknowledge the importance of patient-centred concepts as a dimension of quality, although they do not generally define patient-centred care as a dimension of quality in its own right.

Recommendation 1

Policy makers and regulators should include patient-centred care as a dimension of quality in its own right in strategic and other policy documentation.

5.2 Performance monitoring — towards standardised measurement

All states and territories in Australia are increasing their activity in measuring healthcare quality, especially patient experiences. Most jurisdictions collect a variety of patient feedback, including national and local surveys, complaints data and web-based feedback.

In the US, the IPFCC⁹⁰ states that processes and outcomes associated with quality, safety and experience of care should be measured in order to embed patient-centred care in the health system. They also suggest that there is a need to link funding and accreditation to patient satisfaction measurements and to assure accountability by requiring accurate public reporting.⁹⁰

According to the International Alliance of Patients' Organizations,⁹ the traditional approach to defining quality has lacked the necessary concepts of patient-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.

In Australia, approaches to the measurement of quality in health care are increasingly being standardised across the country. There is also a need to standardise measures of patient care experience and indicators that can be used at the service level across the states and territories, and healthcare sectors.

Steps are being made in this direction. The new national-level Performance and Accountability Framework indicators will measure traditional operational and clinical performance indicators, as well as patient-reported quality based on the patient experience⁹⁴ (outlined in Section 3.2). These performance indicators will facilitate transparent monitoring across services and jurisdictions, setting a minimum standard of healthcare quality that each provider should adhere to. Adherence to the standards will be tied to funding.⁹⁴

Currently, different organisation, jurisdictions, and healthcare sectors use different survey tools, preventing the compilation of national-level data. In standardising the collection of patient experience data, the data collection tools should address the principles of patient and family-centred care, including responsiveness, respect, information sharing and collaboration.

Recommendation 2

Patient survey tools should include a core set of items standardised at a national level to enable the collation and comparison of patient care experience data in key healthcare settings.

Recommendation 3

Patient surveys used to assess patient care experience need to include questions specifically addressing recognised patient-centred care domains and assess more than patient 'satisfaction'.

Recommendation 4

Implementation of healthcare funding models incorporating performance-based payments should include ‘improving patient care experience’ as an integral indicator of health service quality improvement.

Australia is also improving transparency. State and territory health departments are increasingly reporting patient survey and experience data publicly, with survey results available on departmental websites. In May 2010, the New South Wales Bureau of Health Information released a detailed report of patient care experience data for overnight and day-only patients. Data on specific area health services and individual hospital performance were made publicly available.

Some international initiatives may be useful models for Australia to follow to improve transparent data reporting. For example, in the UK, individual stories of patient and family perceptions of care complement survey data (see Section 2.1). In the US, the Department of Health and Human Services publicly reports all hospital data for patient care experience, processes of care (eg infection prevention) and outcomes of medical conditions and surgical conditions (eg mortality and surgical readmission rates) through the Hospital Compare website.

Recommendation 5

To improve transparency, Australian policy-makers and regulators should make data regarding patient care experience in health services publicly available via websites.

5.3 Organisational strategies

This section considers practical strategies that healthcare service providers can introduce to improve patient-centred care, as well as tools for assessing current care delivery. Key characteristics of organisations that have successfully transformed care delivery to patient-centred care include:

- having committed senior leadership
- using data to drive change — using regular collection and feedback of patient care experience
- engaging patients, family and carers as partners
- resourcing change responsively
- building staff capacity and a supportive work environment
- ensuring accountability at all levels for improving patient care experience
- fostering an organisational culture that strongly supports learning and improvement.^{14 87}

Each organisation needs to reflect on its current care provision and feedback from patients before deciding on strategies to put in place to improve patient-centred care and how this should be done.

Data driving change: using regular collection and feedback of patient care experience

Internationally, few organisations have adequate systems for coordinating patient experience data collection and assessing its quality, or for learning from and acting on the results in a systematic way.²³ To gain a clear picture of patient care, it is important to use a range of sources to collect information about patient experience. Patient surveys that are conducted on a regular basis and reported throughout the organisation, from executive level to the ward, provide staff and management with feedback about care from the service users' perspective.

Patient surveys and complaints data are useful to reveal large-scale trends,²³ and help those responsible for service planning and governance. Although they are an important foundation, patient experience survey scores can present a limited picture. Detailed information about specific aspects of patients' experiences is likely to be more useful for monitoring performance of hospital departments and wards.¹³⁵

These measures need to be complemented with patients' personal stories, which can have a direct impact on those responsible for care.⁷⁴ The stories allow carers to 'see the person in the patient': they bring patients' experiences, feelings and concerns to life in a way that connects with service providers' own experiences, feelings and concerns.^{15 74} Other methods for collecting care experience information include conducting focus groups, providing patient journals, having patient advisers round on wards, using 'mystery shoppers' who report to governance committees, and asking patients to tell their story at executive meetings.

Recommendation 6

Healthcare service executives and managers should ensure that systems are in place for the regular collection and reporting of patient care experience data through quantitative patient surveys and qualitative, narrative-based sources.

Recommendation 7

Healthcare service executives and managers should ensure that organisational approaches to quality improvement include feedback about patient care experience — alongside clinical and operational data — when determining health service action plans.

Recommendation 8

Healthcare service executives and managers should contribute to the evidence base for patient-centred care by recording and publishing changes in key organisational and patient outcome metrics over time.

The importance of committed senior leadership

Schall et al¹³⁶ state that one of the best lessons learned at their facility in implementing patient-centred care is that 'leadership matters'. At the organisational level, the way in which leaders set policies and reinforce the importance of improvement greatly affects progress towards improvement. When leadership and staff priorities do not align, poor quality is likely.

Key characteristics of successful patient-centred care organisations are a strategic vision and mission that clearly articulate the organisation's focus on patients, and organisation leaders who continuously convey this message at all levels of the service.^{14 87} Effective senior leaders often use a personal story to engage staff in the organisational mission.⁸⁷

Changing organisational culture from a provider focus to a patient focus can be one of the most difficult barriers to establishing a patient-centred approach to care. Various change-management strategies can be used to shift culture over time, including Kotter's Eight Steps incorporating creating a vision for change, communicating the vision, removing barriers, creating short-term wins, and anchoring the change in organisational culture.¹³⁷ Programs by organisations such as the Studer Group (highlighted in Section 2.5) may help engage staff, particularly those in priority areas for improvement.

Designating a senior manager or executive with responsibility for implementing patient-centred care and designating champions who model patient-centred behaviours also sends a clear message to the organisation about the importance of this approach.

Recommendation 9

Healthcare service executives and managers should develop a shared patient-centred mission that senior leaders continually articulate to staff to promote the implementation of patient-centred care.

Engaging patients, families and carers as partners

Promoting patient engagement can focus on service-level improvement and individual care. For example, a service aiming to improve safety by partnering with individual patients may actively engage patients in handovers, medication reviews, and planning and managing their own care. Strategies for partnering with patients, family and carers at the service level include:

- partnering in service redesign and co-design projects
- involving patients, families and carers in educational programs for healthcare professionals and administrative leaders
- establishing a patient liaison office involving patient representatives
- establishing patient and family advisory councils or committees
- involving patients, families and carers in key organisational committees such as
 - strategic planning
 - safety and quality improvement
 - medical review
 - risk management

- facility planning and design
- staff interview panels and induction
- information technology
- ethics and research.

Appointing patients to advisory or governing structures is emerging as a successful consumer involvement activity that links the individual experience level of health care to the organisational and systems levels. For example, in the UK, experience-based co-design facilitated patients provision of feedback to the board of governors by telling their stories at board meetings.¹³⁸ In Canada, Patients For Patient Safety champions are appointed to consumer advisory committees of safety and quality structures,¹³⁹ and at the provincial level patients and families are being invited onto patient safety advisory committees at hospitals. In the UK, the *Local Government and Public Involvement in Health Act 2007*⁷⁰ empowers local networks to assess the healthcare needs and experiences of patients and citizens, and make recommendations to governors of health services.

Implementing organisational procedures and policies to support these patient-engagement strategies will ensure that the strategies are sustainable.⁸⁷ In this regard, the ACSQHC is developing a service-level standard for healthcare providers that outlines principles for partnering with patients, family and carers to improve quality of care within services. All the standards being developed as part of the set of National Safety and Quality Healthcare Service Standards need to be considered in the context of partnering with patients.

Healthcare services should be encouraged to evaluate the effect of these partnerships to build the evidence base for partnering with patients, families and carers to improve quality of care.

Recommendation 10

Healthcare service executives and managers should develop and implement policies and procedures for involving patients, families and carers in their own care and, at a service level, in policy and program development, quality improvement, patient safety initiatives and healthcare design.

Recommendation 11

Healthcare service executives and managers should ensure that the service meets the ACSQHC National Safety and Quality Healthcare Service Standard for ‘Partnering with Consumers’.

Resourcing improvement of care delivery and environment

To successfully establish a patient-centred care approach, organisations need to address changes in response to the areas of need identified through patient feedback,⁸⁷ and consult with patient advisers and other relevant experts before deciding on strategies. Surprisingly, in successful patient-centred services, the improvements that patients suggested were not

necessarily expensive,⁸⁷ and patient advisers in a number of US services are viewed as the force for making health care more affordable.

Examples of responsive changes made by hospitals to improve patient-centred care include:

- nurses hourly rounding on wards
- providing welcoming facilities for families
- reviewing hospital signage from a patient perspective
- providing a new style of hospital gown to afford dignity to patients
- engaging volunteers to act as concierges or patient navigators
- redesigning waiting areas
- introducing communication strategies to keep patients and families informed.⁸⁷

These examples demonstrate the types of responsive changes that organisations can make and are not an exhaustive list. Other strategies are presented in sections 2 and 4, along with resources to help foster a patient-centred approach. Other resources, including checklists, are summarised in the appendices to this discussion paper.

Resourcing the improvement of the quality of the physical care environment strongly correlates with improved patient care experience and other health and business outcomes.¹⁴⁰ The Planetree approach in the US links architecture and physical space with healing, and outlines principles for healthcare service design (see Appendix B). When considering new healthcare facilities, or when renovating or reviewing existing facilities, organisations should consider patient-centred principles and seek patient adviser input; for example, through experience-based redesign and co-design strategies (see Section 2).

Recommendation 12

Healthcare service executives and managers should resource patient-centred changes to care delivery based on patient feedback and consumer input.

Building staff capacity and a supportive work environment

The strategies highlighted in Section 2 to support staff, such as staff and practice development, values training, communication skills training and staff satisfaction programs, will also help establish patient-centred care in Australia. This has already begun in New South Wales, where NSW Health is using a Studer Group program to improve communication between staff and patients.

According to Coulter,¹⁴¹ the basic competencies required by individual health professionals to be patient-centred include:

- understanding the patient's perspective, expressing empathy and providing appropriate support
- guiding patients to appropriate sources of information on health and healthcare
- educating patients on how to protect their health and prevent occurrence or recurrence of disease

- eliciting and taking account of patients' preferences
- communicating information on risk and probability
- sharing treatment decisions
- providing support for self-care and self-management
- working in multidisciplinary teams
- managing time effectively.

Patient-centred organisations focus on increasing their staff skills to support patient-centred care delivery.⁸⁷ Strategies to achieve this include:

- training staff in communication skills
- adopting communication techniques such as AIDET (Acknowledge, Introduce, Duration, Explanation, Thank you)
- training all staff in patient-centred values
- training all staff in customer service techniques
- tailoring the workforce through selection of staff with a commitment to the mission of the organisation
- integrating discussion of patient-centred values into staff orientation sessions (for example, the chief executive could open the induction session with a discussion of values)
- actively involving patients and families in education programs for healthcare professionals, managers and executives
- holding education sessions for healthcare professionals where patients and families share their experience of care
- involving patients and families in educating junior healthcare professionals and in affiliated programs for undergraduates.

Focusing on the staff work environment is an important component of 'caring for the care givers'. Exemplary patient-centred health services achieve this by visibly celebrating the successes of staff in improving patient care experience (such as public acknowledgment by the chief executive, awards for achievements, or features in annual reports, hospital intranet and newsletters).⁸⁷ This approach recognises that the workforce is the healthcare service's most important asset and aligns with the move towards 'person-centred' organisations, where both patients and staff are valued.¹⁴ Person-centred organisations also use feedback from staff surveys on the work environment to improve the work culture and processes. Giving significant attention to staff satisfaction also acknowledges the link between employee satisfaction and patient satisfaction.¹⁴²

Recommendation 13

Healthcare service executives and managers should implement training strategies tailored to building the capacity of all staff to support patient-centred care.

Recommendation 14

Healthcare service executives and managers should focus on work environment, work culture and satisfaction of staff as an integral strategy for improving patient-centred care. Workforce surveys and review of staff recruitment and retention rates should be undertaken at regular intervals to monitor work environment.

Accountability at all levels for improving patient-centred care

Successful patient-centred care organisations establish clear lines of accountability for staff at all levels, making each person responsible for improving patient care experience.⁸⁷ Individual accountability can be reinforced through performance reviews. A range of strategies can be put in place to promote staff accountability, including:

- incorporating responsibility for improving patient care experience in job descriptions
- explaining at orientation for new staff that they are responsible for the experience of care that a patient has
- considering patient feedback during staff performance reviews, including sharing patient stories
- linking promotions or performance bonuses to improving quality indicators, including care experience
- incorporating patient care experience metrics into unit, departmental and organisational performance monitoring and reporting
- adopting a motto that embodies accountability (eg 'Every patient — Everyone's responsibility' [Pat Sodomka, Sebrio Vice President, Patient and Family Centered Care, MCG Health Inc and Director, Center for Patient and Family Centered Care, Medical College of Georgia, pers comm, 2009])
- linking quality metrics, including patient care experience, to performance reviews of organisational governance bodies and chief executives
- ensuring that the agenda for boards or governance committee meetings includes a strong emphasis on reviewing quality issues and quality performance data, including patient care experience.⁸⁷

Although a number of options are outlined here, linking improvement of care experience to individual accountability through performance review is a starting point relevant to all staff.

Recommendation 15

Healthcare service executives and managers should integrate accountability for the care experience of patients into staff performance review processes.

An organisational culture that strongly supports learning and improvement

The leading organisations in patient-centred care have a culture of learning and strongly support change and improvement.⁸⁷ These organisations use many aspects of ‘learning organisation’ theory and have characteristics described in ‘learning culture’ frameworks. Learning organisations have systems, mechanisms and processes in place that are used to continually enhance the capabilities of those who work with it or for it, to achieve sustainable objectives.¹⁴³ They adapt to external environmental forces, constantly improve their own ability to change, promote individual and collective learning, and use these lessons to improve outcomes.

Healthcare organisations can commit to continuous quality improvement using approaches such as Deming’s cycle of ‘Plan, Do, Study, Act’. Focusing on needs analysis, performance measurement and improvement is crucial. Learning organisations also support a culture that values people, stimulates new ideas, develops teamwork and adopts staff recognition systems. Successful patient-centred organisations often take the next step of linking individual performance accountability with organisational performance.

Learning organisations are also open to learning from past failures.¹⁴⁴ A number of healthcare services have refocused care delivery for patient-centred care in response to tragic events in their facility, such as the death of a patient or severe harm of a patient during care. Such tragic events can cause an organisation to examine its own values and its processes for promoting safety and quality improvement. Listening to patients and involving patients and families in improving care delivery is a positive response to these tragedies.

Events at the Dana Farber Cancer Institute, Boston, US, are well known in the area of ‘turning tragedy into a positive outcome.’ In 1994, Betsy Lehman, a health journalist from the Boston Globe newspaper, died after she was accidentally given an overdose of cyclophosphamide, a chemotherapy drug she was receiving for breast cancer treatment. The institute began asking patients and families ‘how can we do better?’ The incoming chief operating officer, James B Conway, organised town hall meetings for patients and was inundated with people providing feedback about improving care delivery. Sixteen years on, the Dana Farber Cancer Institute is a leader in patient-centred care, with patient advisers involved throughout the organisation.

Learning from others’ experiences can be invaluable and healthcare organisations can link with service providers who have experience of learning from patients and families.

Recommendation 16

Healthcare service executives and managers should foster a culture of learning within the organisation, equally learning from successes and failures, including tragic events, to promote patient-centred care.

6 Next steps

A patient-centred focus can improve healthcare quality and outcomes by increasing safety, cost-effectiveness, and patient, family and staff satisfaction.¹⁴⁵

The ACSQHC developed this paper as a first step in a discussion of the concepts of, and evidence for, patient-centred care, and the applicability of international models to the Australian context.

The paper is aimed at practitioners, managers and policy makers and outlines the background, context, evidence and impetus for improving quality and safety through patient-centred care. It gives examples of both local and international success stories, where systems and practices have become more responsive to the needs and desires of patients. It also provides examples of models and tools, and recommendations that focus on what organisations can do to foster a patient-centred approach to health care.

To support and facilitate patient-centred care, the ACSQHC will work with consumers, patients and the general public to ensure that the principles, models and approaches it supports and endorses, including the work of other organisations, are appropriate, effective and modelled by the organisation's actions.

To this end, the ACSQHC is holding an open consultation on this discussion paper, and is seeking the views of a broad range of stakeholders including health services, practitioners, patients, consumers and policy makers on:

- the discussion paper itself, including the content, relevance and accuracy of the issues and examples raised in the paper; any gaps in the information or examples provided; and any areas that could be strengthened
- future directions, including opportunities for developing or supporting initiatives to improve the uptake of patient-centred care approaches within health services.

After the consultation process, the ACSQHC will prepare a consultation report that outlines the themes and key issues raised in the submissions and the overall response to the discussion paper. This report will be publicly available and information from the consultation process will contribute to further refinement of the discussion paper.

Both the discussion paper and the outcomes of the consultation process will be used to inform activities to improve patient-centred care in Australia, including the work of the ACSQHC and other organisations in this field.

Your views

The ACSQHC is seeking responses to this discussion paper. Questions of particular interest include:

The discussion paper

- Did you find the discussion paper useful?
- Were the principles of patient-centred care clear and understandable?
- Is there any terminology that needs further exploration or explanation?
- Are there any concepts that need further exploration or explanation?
- Would any of the approaches or strategies outlined in the discussion paper be particularly suitable or unsuitable for you or your organisation?
- Is the section on support provided by leading international organisations and their resources applicable to you or your organisation?
- Are there additional significant Australian or international initiatives or strategies that need to be highlighted in the discussion paper?
- Are there barriers to implementing patient-centred care in the Australian context that need to be explored in the discussion paper?
- How do the contents of the discussion paper, including the recommendations, apply to your service?

Future directions

- How could you or your organisation work better in partnership with patients?
- How do you promote greater uptake of patient-centred care models? Who needs to be involved in this?
- Is there more work that needs to be done in this field, specific to the Australian context?
- What type of tools or support would you need to make your organisation more patient centred?
- Are there activities, frameworks, strategies or protocols that could be provided that would help your organisation become more patient centred?
- Is there infrastructure or support that could be provided that would help your organisation become more patient centred?
- How could the ACSQHC or other organisations support or facilitate greater use of patient-centred care models?

Submissions do not have to address these questions and may respond to other issues raised in the discussion paper.

All submissions are welcome and will be accepted up to 17 December 2010. Submissions should be marked 'Patient-and Consumer-Centred Care' and forwarded to:

GPO Box 5480
Sydney NSW 2001

or emailed to:
mail@safetyandquality.gov.au

Appendix A Assessing organisational readiness to implement patient-centred care

Appendix A contains:

- Tool 1: a checklist for assessing organisational readiness for implementing patient-centred care, written by Dr Karen Luxford in the context of the Australian healthcare system.
- Tool 2: an assessment tool written by the Institute for Patient- and Family-Centered Care in 2008, entitled *Where do we stand? An Assessment Tool for Hospital Trustees, Administrators, Providers and Patients and Family Leaders*.

Tool 1: Patient-centred care organisational status checklist

Check your organisational readiness for improving patient care experience

1. Are you collecting patient care experience data? Yes No (go to Q8)
2. How are you collecting patient care experience data?
3. Why are you collecting patient care experience data?
4. How often are you collecting patient care experience data?
5. How are you using the data/information collected?
6. Is the data about patient care experience being reported?
7. To whom is it being reported?
8. Is staff satisfaction monitored?
9. Is there a 'dashboard' of performance metrics monitored by the organisation?
10. Does the 'dashboard'/set of metrics include patient care experience indicators?
11. What is the mission/vision of the organisation?
12. What is the main message to staff from the leadership? CEO? Organisational governance?
13. Is the culture of the organisation supportive of change? Open to learning?
14. Are successes by staff visibly celebrated?
15. What is the current area of focus for staff development?
16. Have staff training activities included communication skills training or patient-centred values?
17. Are patients and families considered 'partners' in care?
18. Are any patient or family/carer representatives involved in any organisational committees?
19. If so, which areas do these committees cover?
20. Any future plans for engaging patients at a service level within the organisation?
21. Have there been any tragic events within the service from which lessons have been learnt? What did the organisation learn from these events?
22. Are families/carers considered 'visitors' to the service (ie restricted 'visiting' hours)?

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Tool 2: Where do we stand?

An assessment tool for hospital trustees, administrators, providers, and patient and family leaders (IPFCC 2008)

Initial assessment

Organisational culture and philosophy of care

- Do the organisation's vision, mission, and philosophy of care statements reflect the principles of patient- and family-centered care and promote partnerships with the patients and families it serves?
- Has the organisation defined quality health care, and does this definition include how patients and families will experience care?
- Has the definition of quality and philosophy of care been communicated clearly throughout the healthcare organisation, to patients and families, and others in the community?
- Do the organisation's leaders model collaboration with patients and families?
- Are the organisation's policies, programs, and staff practices consistent with the view that families are allies for patient health, safety, and well-being?

Patient and family participation in organisational advisory roles

- Is there an organisational Patient and Family Advisory Council?
- If there is a Patient and Family Advisory Council, is patient safety a regular agenda item?
- Are patients and families members of committees and are they involved in initiatives for:
 - patient safety?
 - quality improvement?
 - facility design?
 - use of information technology?
 - pain management?
 - patient/family education?
 - discharge/transition planning?
 - palliative/end-of-life care?
 - staff orientation and education?
 - service excellence?
 - ethics?
 - diversity/cultural competency?
 - architecture and design
- Does the healthcare organisation's architecture and design:
 - create welcoming impressions throughout the facility for patients and families?
 - reflect the diversity of patients and families served?

- provide for the privacy and comfort of patients and families?
- support the presence and participation of families?
- facilitate patient and family access to information?
- support the collaboration of staff across disciplines and with patients and families?

Patterns of care

- Are family members always welcome to be with the patient, in accordance with patient preference, and not viewed as visitors?
- Are patients and families viewed as essential members of the healthcare team? For example, are they encouraged and supported to participate in care planning and decision-making?
- Do physician and staff practices reinforce that care will be individualised for patient and family goals, priorities, and values?
- Are patients and families, in accordance with patient preference, encouraged to be present and to participate in rounds and nurse change of shift?
- Is care coordinated with patients and families and across disciplines and departments?

Patient and family access to information

- Are there systems in place to ensure that patients and families have access to complete, unbiased, and useful information?
- Do patients and families, in accordance with patient preference, have timely access to medication lists, clinical information (e.g., lab, x-ray, and other test results), and discharge or transition summaries?
- Are informational and educational resources available in a variety of formats and media and in the languages and at the reading levels of the individuals served?
- Are patients and families encouraged to review their medical records and work with staff and physicians to correct inaccuracies?
- Are patients and families provided with practical information on how to best assure safety in health care?
- Are there a variety of support programs and resources for patients and families, including peer and family-to-family support?

Education and training programs

- Do orientation and education programs prepare staff, physicians, students, and trainees for patient- and family-centered practice and collaboration with patients, families, and other disciplines?
- Are patients and families involved as faculty in orientation and educational programs?

Research

- In research programs, do patients and families participate in:
 - shaping the agenda?
 - conducting the research?
 - analysing the data?
 - disseminating the results?

Human resources policies

- Does the organisation's human resources system support and encourage the practice of patient- and family-centered care?
- Are there policies in place to ensure that:
 - individuals with patient- and family-centered skills and attitudes are hired?
 - there are explicit expectations that all employees respect and collaborate with patients, families, and staff across disciplines and departments?
- Are there strategies in place to reduce the cultural and linguistic differences between staff and the patients and families they serve?

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Appendix B Supportive resources

A variety of resources including assessment tools and checklists for health service providers are available online. Leading organisations and their resources are listed below in alphabetical order.

Leading organisations and their resources

Dana-Farber Cancer Institute (DFCI)

- Website:
www.dana-farber.org
- *A Toolkit to Assist Organisations in Initiating Patient Safety Rounds:*
www.dana-farber.org/pat/patient-safety/patient-safety-resources/patient-rounding-toolkit.html

Institute for Healthcare Improvement (IHI)

- Website:
www.ihl.org
- *Partnering with Patients and Families to Design a Patient and Family-Centred Health Care System — Recommendations and Promising Practices* (2008):
www.ihl.org/IHI/Topics/PatientCenteredCare/PatientCenteredCareGeneral/Literature/PartneringwithPatientsandFamilies.htm
- Resources, tools and improvement stories:
www.ihl.org/IHI/Topics/PatientCenteredCare/PatientCenteredCareGeneral/PatientCenteredCareGeneralHome.htm

Institute for Patient- and Family-Centered Care (IPFCC)

- Website:
www.ipfcc.org
- *Advancing the Practice of Patient - and Family-Centred Care — How to Get Started* (IPFCC 2008).
www.ipfcc.org/pdf/getting_started.pdf
- *Partnering with Patients and Families to Design a Patient and Family-Centred Health Care System — Recommendations and Promising Practices* (Johnson, Abraham, Conway et al 2008 in conjunction with the Institute for Healthcare Improvement)
www.ipfcc.org/pdf/PartneringwithPatientsandFamilies.pdf
- *Partnering with Patients and Families To Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future — A Work in Progress* (Conway, Johnson, Edgman-Levitan, et al 2006 in conjunction with the Institute for Healthcare improvement)
www.ipfcc.org/pdf/Roadmap.pdf
- Other IPFCC resources are available at:
www.ipfcc.org/tools/downloads.html

Kenneth B Schwartz Center

- Website:
www.theschwartzcenter.org
- Publications:
www.theschwartzcenter.org/bibliography/index.html
- Schwartz Center Rounds:
www.theschwartzcenter.org/programs/rounds.html
- Carepages website:
www.carepages.com

The King's Fund

- Website:
www.kingsfund.org.uk
- *Seeing the Person in the Patient: Point of Care Review Paper* (Goodrich and Cornwell 2008)
www.kingsfund.org.uk/current_projects/the_point_of_care

Picker Institute

- Website:
www.pickerinstitute.org/
- *The Patient-Centered Care Improvement Guide* (2008) (in conjunction with Planetree):
www.patient-centeredcare.org/title.html
- *Self-assessment Tool*:
www.patient-centeredcare.org/inside/selfassessment.html

Picker Institute Europe

- Website:
www.pickereurope.org/
- A comprehensive review of the worldwide evidence of what works to engage patients and the public in healthcare.
www.investinengagement.info

Planetree

- Website:
www.planetree.org
- *The Patient-Centered Care Improvement Guide* (2008) (in conjunction with the Picker Institute):
www.planetree.org/publications.html
- Other Planetree publications are available at:
www.planetree.org/publications.html

Studer Group

- Website:
www.studergroup.com

World Health Organization

- Patients for Patient Safety:
www.who.int/patientsafety/patients_for_patient/statement/en/index.html

Patient-centred care strategies

Collecting patient feedback

United Kingdom

- UK Care Quality Commission's website:
www.cqc.org.uk/usingcareservices/healthcare/patientsurveys.cfm
- UK survey coordination centre website:
www.nhssurveys.org
- UK General Practice Patient Survey results:
results.gp-patient.co.uk/report/main.aspx
- UK National Cancer Action Team Patient Experience:
www.cancerinfo.nhs.uk/
- *Understanding What Matters — A Guide to Using Patient Feedback to Transform Services*, UK Department of Health (2009b)
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099780

United States

- AHRQ CAHPS survey website:
www.cahps.ahrq.gov/default.asp
- AHRQ National CAHPS Benchmarking Database:
www.cahps.ahrq.gov/content/ncbd/ncbd_Intro.asp?p=105&s=5

Australia

- NSW Health patient survey website:
www.health.nsw.gov.au/hospitals/patient_survey/index.asp
- NSW Bureau of Health Information website:
www.bhi.nsw.gov.au
- Victorian Department of Health Patient Satisfaction Monitor survey website:
www.health.vic.gov.au/patsat/
- ACT Health Healthcare Survey website:
www.health.act.gov.au/c/health?a=da&did=10101609&pid=1254789026
- Queensland Health Patient Satisfaction survey website:
www.health.qld.gov.au/quality/pat_sat_survey/patsat.asp
- SA Health Patient Evaluation of Health Services (PEHS) survey website:
www.health.sa.gov.au/pros/Default.aspx?PageContentMode=1&tabid=44,

- *WA Health Toolkit for Collecting and Using Patient Stories for Service Improvement in WA Health*
www.health.wa.gov.au/hrit/docs/A_toolkit_for_collecting_and_using_patient_stories.pdf

Real-time patient feedback

- UK website offering patient reviews for healthcare services:
www.iwantgreatcare.com
- UK website offering patient reviews for healthcare services:
www.patientopinion.org.uk

Patient choice of provider

- NHS Choices:
www.nhs.uk/Pages/HomePage.aspx
- NHS survey results for patients' experience of choice
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_085329
- US Department of Health and Human Services Hospital Compare website:
www.hospitalcompare.hhs.gov

Rights-based charters and codes

- *The NHS Constitution*:
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113613
- American Hospital Association (AHA) Communicating with patients website:
www.aha.org/aha/issues/Communicating-With-Patients/index.html,
- CMS *Important Message From Medicare Notice*: www.virginia.edu/uvaprint/HSC/pdf/CMS-R-193.pdf,
- *Australian Charter of Healthcare Rights*:
[www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/com-pubs_ACHR-pdf-01-con/\\$File/17537-charter.pdf](http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/com-pubs_ACHR-pdf-01-con/$File/17537-charter.pdf)
- Australian Commission on Safety and Quality in Healthcare publications and other information about the Australian Charter of Healthcare Rights:
www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/PriorityProgram-01
- *London Declaration for Patient Safety*:
www.who.int/patientsafety/patients_for_patient/London_Declaration_EN.pdf

Redesign and experience-based design

- NHS Institute for Innovation and Improvement Case Studies:
www.institute.nhs.uk/quality_and_value/experienced_based_design/case_studies.html
- ACT Health Access Improvement Program:
www.health.act.gov.au/c/health?a=&did=10109188
- NSW Health patient and carer experience:
www.health.nsw.gov.au/performance/pcexperience.asp

- Victorian Department of Health Improving the patient experience program:
www.health.vic.gov.au/managementinnovation/resources
- Queensland Health redesign projects:
www.health.qld.gov.au/cpic/service_improve/projects.asp

Improving complaints processes

- UK Department of Health guide and advice sheets:
www.dh.gov.uk/en/Publicationsandstatistics/Publications/index.htm
- *Listening, Responding, Improving: A Guide to Better Customer Care*, UK Department of Health (2009):
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_095408

Australian state and territory programs and initiatives

- ACT Health website:
www.health.act.gov.au/c/health?a=&did=10101609
- Health Consumers' Council website:
www.hconc.org.au/
- NSW Health Essentials of Care program: www.health.nsw.gov.au/nursing/projects/eoc.asp;
- NSW Health Clinical Leadership Programme:
www.clinicalleadership.com/index.php?option=com_frontpage&Itemid=1,
- NSW Health 'Take the Lead' project:
www.health.nsw.gov.au/nursing/projects/take_the_lead.asp
- Queensland Health Healthcare Experience Improvement Homepage for consumers:
www.health.qld.gov.au/cpic/hlthcr_exp_improve/hlthcr_exp_improve.asp
- Victorian Quality Council website: www.health.vic.gov.au/qualitycouncil/activities/index.htm
- WA Office of Safety and Quality in Healthcare WA Patient First program:
www.safetyandquality.health.wa.gov.au/involving_patient/patient_1st.cfm

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