Patient-centred care:

Improving quality and safety through partnerships with patients and consumers

care centred Patient-

Foreword

In a large and complex health care system striving for efficiency, some busy health professionals may tend to treat patient conditions only on the basis of symptoms and scientific evidence. Scientific analysis and treatment is a foundation of modern health care, but it may lead to a reduced consideration of the patient as a person.

The patient-centred movement powerfully demonstrates that fully involving the individual patient as a person at all stages with unique needs, concerns and preferences will lead to more efficacious and satisfying outcomes.

The patient-centred approach to health care treats each person respectfully as an individual human being and not as a condition to be treated. It involves not just the patient, but families, carers and other supporters. It is concerned about the patient's comfort and surroundings as well as their beliefs and values.

A patient-centred approach makes care safer and of higher quality. It provides demonstrable personal, clinical and organisational benefits. It also satisfies an ethical imperative – involving patients in their own care and in the planning and governance of the health system is the right thing to do.

The Commission supports organisations building skills and capacity to involve and engage patients and consumers both in their individual care and in system level improvements.

This paper is our first published commentary. By exploring patient-centred approaches undertaken in Australia and internationally, it provides a comprehensive background for discussion and future initiatives.

I commend the zeal and dedication of our staff involved in preparing this paper and the enthusiastic guidance of the contributing authors.

W J Beerworth
Chairman

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Acknowledgments

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.

Research demonstrates that patient-centred care improves patient care experience and creates public value for services. When health professionals, managers, patients, families and carers work in partnership, the quality and safety of health care rises, costs decrease, 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.

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 may struggle to involve patients, families, carers and consumers and to learn from their experiences.[1]

Patient-centred care is recognised as a dimension of high-quality health care in its own right. It is identified in the seminal Institute of Medicine report, *Crossing the Quality Chasm*,[2] as one of the six quality aims for improving care. Internationally, governments and healthcare services have used a wide variety of strategies to promote patient-centred care. A range of international organisations have also helped to develop and implement these strategies, including Planetree, the Picker Institute and the Institute for Patient- and Family-Centered Care.

Key strategies for building patient-centred care into the systems of healthcare organisations include regular monitoring and reporting of patient feedback data; engaging patients, families and carers as partners; demonstrating committed senior leadership; building staff capacity and a supportive work environment; establishing performance accountability; and supporting a learning organisation culture.

In Australia, a patient-centred approach is supported by the *Australian Charter of Healthcare Rights*, the *Australian Safety and Quality Framework for Health Care*, the *National Safety and Quality Health Service Standards*, other national policies, reports of state-based inquiries, and a range of jurisdictional and private sector initiatives.

National health reform proposals (such as the proposed Performance and Accountability Framework) provide further incentives to improve patient-centred care by linking it to performance and funding. Another driver for improving patient-centred care is the expected establishment of a National Performance Authority, which would report transparently on a range of performance indicators, including 'patient satisfaction' for Local Hospital Networks, public and private hospitals, and Medicare Locals.

Based on these strategies and frameworks — and taking into account Australia's healthcare system, with its mix of public and private sectors — system-oriented and service-oriented recommendations to foster patient-centred care are outlined in this discussion paper. These recommendations may need to be implemented in different ways, depending on the context of the healthcare organisation.

Summary of recommendations

SYSTEM-ORIENTED RECOMMENDATIONS

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:
A core set of nationally endorsed patient survey questions should be developed to facilitate 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:
'Improving patient care experience' should be included as an indicator of quality and reflected in healthcare reporting and funding models.

Recommendation 5:
To improve transparency, Australian policy makers and regulators should make data regarding patient care experience in health services publicly available via websites.

Recommendation 6:
Patient-centred care should be a component of undergraduate and postgraduate education programs for all health professionals.

Recommendation 7:
Education programs should engage patients and families as teachers and collaborators, rather than solely as cases to be studied.

Recommendation 8:
Research funding bodies should acknowledge the importance of patient-centred care to the health system, and this should be reflected in the distribution of funding.

SERVICE-ORIENTED
RECOMMENDATIONS

Health service executives and managers should:

Recommendation 9:
Ensure that organisational systems and processes are designed to be patient-centred.

Recommendation 10:
Ensure their healthcare organisation develops a shared patient-centred mission that senior leaders continually articulate to staff to promote the implementation of patient-centred care.

Recommendation 11:
Develop and implement policies and procedures for engaging patients, families and carers in their own care.

Recommendation 12:
Develop and implement policies and procedures for involving patients, families, carers and consumers at a service level, and in policy and program development, quality improvement, patient safety initiatives and healthcare design.

Recommendation 13:
Provide support for patients, families and carers involved in governance to develop the necessary skills and capacity required for effective partnerships with their healthcare organisation.

Recommendation 14:
Ensure that the service meets the National Safety and Quality Health Service 'Partnering with Consumers' Standard.

Recommendation 15:
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 16:
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 17:
Contribute to the evidence base for patient-centred care by recording and publishing changes in key organisational and patient outcome metrics over time.

Recommendation 18:
Provide organisational support to enable staff to partner with patients and consumers, and to implement any necessary changes based on that partnership.

Recommendation 19:
Support staff through training and education activities tailored to building the capacity of all staff to deliver patient-centred care.

Recommendation 20:
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 the work environment.

Recommendation 21:
Integrate accountability for the care experience of patients into staff performance review processes.

Recommendation 22:
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]

Australia ranked highly in a 2010 Commonwealth Fund comparison[4] of seven international health systems, demonstrating our healthcare 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 complaints commissioners were about healthcare 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 needs 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 patient-centred care becomes clearer and our understanding of how to implement patient-centred care improves.

In 2010, Australian Health Ministers endorsed the *Australian Safety and Quality Framework for Health Care*.[7] The framework identifies consumer-centred care as the first of three dimensions required for a safe and high-quality health system in Australia. Including this dimension in the framework reflects a growing recognition of the importance of placing patients and consumers at the centre of the healthcare system. In developing the framework, the Australian Commission on Safety and Quality in Health Care (the Commission) talked to patients, carers, consumers, clinicians,

managers and policy makers, and found strong support for the inclusion of consumer-centred care, as well as for an overall framework that sets the strategic direction for safety and quality in Australian health care over the next decade.

The *Australian Safety and Quality Framework for Health Care* contains strategies for providing care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. The Commission has developed a series of guides[7] that support the use of the framework in practice.

Australia has a widespread and strong commitment to a healthcare system that is based on partnerships with 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 the needs and desires of the patient, as well as their immediate treatment requirements. However, for a range of reasons, people can struggle to carry out patient-centred care in practice. It is clear that more specific and focused guidance in this area may be useful.

Patient-centred care is particularly important among vulnerable or disadvantaged populations, such as the young, elderly, disabled or mentally ill; those from culturally and linguistically diverse backgrounds, or rural and remote areas; and Aboriginal and Torres Strait Islander peoples. For many of these people, communication and collaboration with health professionals can be difficult and necessarily involves carers, friends, family, spiritual and pastoral advisers, or the broader community. Patient-centred care principles and approaches are considered to be an opportunity to go some way towards addressing the inequity people in these populations can experience. It is also seen as a way of supporting greater involvement of all people in healthcare processes, and potentially achieving better health outcomes.

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

To address these needs, the Commission prepared a draft discussion paper as the first review of patient-centred care for Australia, and in 2010 undertook an extensive open consultation process on the paper. Following this consultation, the Commission refined the discussion paper to clarify key issues raised by stakeholders with the intention of providing a comprehensive resource for healthcare organisations wishing to become more patient-centred.

This discussion paper—*Patient-centred care: Improving quality and safety through partnerships with patients and consumers*—provides a broad overview of how to improve the delivery of health care by taking a more patient-centred approach. The target audience includes healthcare professionals, managers and policy makers who want to re-orient their systems and practices to be more patient-centred, and to partner with patients, consumers, families and carers. This paper is the first of a proposed suite of activities by the Commission on patient-centred care. Future work in this area may focus on more specific settings and include resources that target consumers.

This paper provides background information, resources and examples of how to take a more patient-centred approach to healthcare delivery. Also included is 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 that support patient-centred care. Australian examples and case studies have been used to illustrate many of the concepts and approaches described in this paper.

Within this paper, the term 'patient-centred care' is used as it is the most commonly used term in research and literature in this area. The *Australian Safety and Quality Framework for Health Care* used the term 'patient-focused care' when it was released for consultation in 2009; after consultation, the term was changed to 'consumer-centred care'. Other common terms include person-centred care, personalised care, family-centred care and relationship-centred care.

All of these terms are conceptually similar. They emphasise the formation of partnerships and the central roles of not only the patient, but also the family, carers, friends, spiritual and pastoral advisers, community members and staff in individual aspects of care. The importance of acknowledging those who are significant to the patient has been recently enshrined in Commonwealth legislation in Australia in the *Carer Recognition Act 2010*.[8]

As will be seen in this paper, patient-centred care includes a wide range of concepts and ideas about the way in which patients and consumers are involved in the health system and the delivery of health care. The concept of patient-centred care covers partnerships between a patient and a health professional when care is provided. It also covers partnerships between patients, families, carers, consumers and citizens in health service policy, planning and governance. There are large bodies of literature about many of the specific aspects of patient-centred care, such as communication between patients and doctors during a consultation, or strategies to engage consumers in health service planning. This paper does not go into detail about these specific aspects, but instead provides a broad overview of strategies and approaches that health services can use to make their services more patient-centred and to integrate patient-centred care into their business.

Section 1 of this paper discusses the concepts, origins and evidence about patient-centred care. Section 2 examines the drivers, approaches and strategies to patient-centred care, including key international organisations and initiatives. Section 3 examines the relevance of patient-centred care to the Australian healthcare system, and Section 4 highlights current patient-centred activity in Australia. In light of international and current Australian approaches, Section 5 discusses the way forward for patient-centred care in Australia, and provides recommendations for actions that could be taken to make the health system and healthcare organisations more patient-centred. The appendices include checklists to help organisations assess their readiness to implement patient-centred care, an annotated bibliography highlighting key references on the evidence for patient-centred care and a list of patient-centred care resources.

What is patient-centred care?

1

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 'an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families'.[9]

1.1
CONCEPTS OF PATIENT-CENTRED CARE

Numerous proposed definitions of patient-centred care encompass similar core concepts, but there is no globally accepted definition.[10] 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. The research identified eight dimensions of patient-centred care that were originally documented in *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care.*[11] The 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.

The framework clearly defined the patient's perspective for the first time and served as the foundation for the Picker surveys measuring patient experiences of health care.[12]

The concept of patient-centred care clearly recognises the need to include not only the patient in their care, but significant others, including family, friends, carers, spiritual and pastoral advisers, and broader community members.

Patient-centred care also focuses 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.[13]

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 2.5.

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.[14] 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 US [15] (cited in Goodrich and Cornwell[16]) have identified the core elements 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, Cronin[17] (cited in International Alliance of Patients' Organizations[10]) identified the same core elements. Similarly, Robb and Seddon[18] 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.[10] 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.[10]

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.[19] 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.[20]

Carer experience of patient-centred care

...patient-centred is an attitude that is innate in most practitioners — particularly in those that give direct and personal service; [it is] an empathy with the patient and [an ability] to stand in the shoes of the patient, particularly those who, because of old age or disability, cannot answer back. [It is] an inherent attitude that can instinctively consider how another person will react when addressed in words or by some deed. An attitude which accepts that the patient has a mind as well as a body.

Submission received in the consultation on the draft patient-centred care discussion paper

1.2 DEFINITIONS OF ASSOCIATED TERMS

Several terms used interchangeably or associated with 'patient-centred care' are described below. All terms are based around the fundamental concepts of partnership and collaboration between healthcare professionals and patients, families, carers and consumers.

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.[21] The term 'consumer' also aligns with 'client' and 'user' in business and management models of service delivery.[22]

Person-centred care

Terms such as 'person-centred care' and 'person-centredness' are often used interchangeably in primary care settings with 'patient-centred care'. The term 'person-centred care' appears more frequently in literature on the care of older people,[23] and focuses on developing relationships and plans of care collaboratively between staff and patients.[23–24] This term values the needs of patients, carers and staff, with emphasis on the reciprocal nature of all relationships.[25–26]

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.[27]

Family-centred care

The term 'family-centred care' 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.[28] 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.[29–30] In England,

'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.[30]

Relationship-centred care

In 'relationship-centred care', all participants appreciate the importance of their relationships with one another. 'Relationship-centred care' is founded upon four principles:

1. relationships in health care ought to include the personhood of the participants
2. affect and emotion are important components of these relationships
3. all healthcare relationships occur in the context of reciprocal influence
4. the formation and maintenance of genuine relationships in health care is morally valuable.

In 'relationship-centred care', relationships between patients and clinicians remain central, although the relationships of clinicians with themselves, each other and the community are also emphasised.[31–32]

1.3
EVIDENCE FOR PATIENT-CENTRED CARE

Patient-centred care is a broad concept, covering a wide range of different strategies and approaches. The evidence base for patient-centred care is similarly varied: some aspects of patient-centred care have been the subject of large bodies of work, while others are still emerging. Overall, however, it is clear that patient-centred care has significant benefits associated with clinical quality and outcomes, the experience of care, the business and operations of delivering health services, and the work environment.

This section provides a summary of some of the research evidence that supports patient-centred care. Additional information about most of the papers referenced here is included in Appendix B.

There is an increasing body of research about the association between patient experience and perceptions of care, and overall measures of quality and safety.[33–36] Two studies have examined associations among information about the experience of patients collected through the Hospital Consumer Assessment of Healthcare Providers and Systems (H-CAHPS) survey (see Section 2.1), process measures of quality[33–34] and patient safety indicators[33] across a large number of hospitals in the US. Positive associations were found between patient experience and overall technical quality and safety.[33–34]

When looking specifically at patients who have had an acute myocardial infarction (AMI), a number of studies have shown an association between patient-centred care and clinical outcomes, including mortality.[37–40] One study found that better patient-centred care during admission for AMI was associated with a decreased risk of death one year after discharge.[40]

Other clinical benefits that have been found to be associated with better patient experience and patient-centred care include decreased readmission rates,[41] decreased rates of healthcare acquired infections,[42–44] improved delivery of preventive care services,[45] reduced length of stay,[43, 46] improved adherence to treatment regimens[47] and improved functional status.[42–43] One study found that factors such as better communication with doctors, a clean and quiet hospital environment and the responsiveness of medical staff were significantly associated with a decreased likelihood of pressure ulcers and post-operative infections.[33] In addition, participation of hospital patients in their own care, such as asking questions or participating in decision making, has been found to reduce the risk of experiencing an adverse event.[48]

A number of studies have looked at the associations between patient-centred care and outcomes in general practice and primary health care. These studies have often focused on communication and collaboration between patients and providers. In these settings, patient-centred care has been associated with a reduction in the number of diagnostic test orders and other referrals,[49–51] better adherence to treatment regimens,[52–53] greater patient satisfaction[50, 52] and greater patient enablement.[50]

Evidence about the impact of patient-centred care on the business and operation of health services is also beginning to emerge. Some studies have examined the broad effects of the use of patient-centred strategies and approaches within healthcare organisations. Stone[46] 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 patient-centred inpatient unit consistently demonstrated a shorter average length of stay, a statistically significant 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.

In the US, hospitals that have introduced patient-centred approaches have found that inpatient and outpatient throughput increased, community perceptions improved, and the proportion of people reporting that they would be likely to recommend the hospital or to return to it for future care increased.[54] There have also been reports of hospitals experiencing considerable reductions in malpractice claims following

the implementation of patient-centred care practices, despite an increase in patient care activity.[54] Sweeney et al[55] examined the introduction of patient-centred management practices for patients with multiple conditions compared with usual care. A significant decrease in costs was found for the patient-centred group compared with the usual care group, without any shortening of life.

The Medical College of Georgia (MCG) Health System in Augusta, Georgia, was one of the first large health services to explicitly re-orient their systems to be more patient-centred.[56] MCG has found that this patient-centred approach positively affects each of the MCG's business metrics (finances, quality, safety, satisfaction and market share). Outcomes that have been identified by MCG include:[57]

» patient satisfaction scores for the children's hospital among the highest measured by Press Ganey
» patient satisfaction scores for the breast health centre increasing from the 40th percentile to the 90th percentile
» improvements across a range of measures for a new adult neuroscience unit, including increasing the volume of discharges by 15.5 per cent, decreasing length of stay by half, reducing medication errors by 62 per cent and reducing the staff vacancy rate from 7.5 per cent to zero (with a waiting list for nursing positions on the unit).

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.[54] According to Charmel and Frampton,[54] 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.

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 safe, effective, patient-centred, timely, efficient and equitable.[2]

The report 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'. It set out several rules to redesign and improve patient-centred care, including maintaining transparency, sharing knowledge and information freely, customising care based on patients' needs and values, and ensuring that the patient is the source of control and that care is based on continuous, healing relationships.

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, assures the candid sharing of useful information in an ongoing manner, and 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. This could be 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, families, carers and consumers 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, families, carers and consumers 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,[54] 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 England became a dimension of high-quality health care over time. From 1997, when the 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'.[24]

By 2004, the NHS had set out its priorities for the following four years in its *NHS Improvement Plan: Putting People at the Heart of Public Services.*[24] 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[24]). *Creating a Patient-led NHS: Delivering the NHS Improvement Plan*[58] outlined how the quality agenda could be delivered: patient-led services would ensure that patients were treated with respect, dignity and compassion.[24]

The 2008 *NHS Next Stage Review*[59] 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[24]). In his introduction to the Next Stage Review, Lord Darzi stated that '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'.[59]

In 2010, The King's Fund[60] assessed the effect of the former Labour government's reforms to the NHS on various factors within the service (safety, equity, accessibility, accountability, efficiency, clinical effectiveness, patient experience, promoting health and managing long-term conditions). 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 routinely monitoring survey results. 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.[60]

In New Zealand, the *Code of Health and Disability Services Consumers' Rights Regulation 1996*[61] (the Health and Disability Code) and the New Zealand Ministry of Health's *Improving Quality* document[62] established patient-centred care as a priority.[18] *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, adherence to the Health and Disability Code, and adherence to other consumer protections such as the Health Information Privacy Code 1994.[18, 62] According to Robb and Seddon,[18] 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, consumers, healthcare practitioners and hospital leaders in all aspects of health care and at all levels of the healthcare system.[18]

At the federal level in Canada, the term 'collaborative patient-centred care' is used to describe Health Canada's initiatives in the primary healthcare sector to increase patients' self-care[63] and educate professionals about working together to achieve patient-centred care.[64] At the state and provincial level, many jurisdictions are adopting a patient-centred approach as part of their aim to increase healthcare quality.[65–66]

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, England, 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.[67] One study found that in addition to the US, England, 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.[68]

Drivers, approaches and initiatives for patient-centred care

2

This section presents an overview of the policies and approaches that drive patient-centred care. It also examines the strategies and initiatives that have been used successfully by healthcare regulators and organisations to put patient-centred care into operation at different levels and in different sectors of the healthcare system.

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, healthcare organisations often have difficulty implementing the type of change necessary to sustain patient-centred care. As a consequence, many organisations are seeking guidance on appropriate strategies for building and maintaining partnerships with patients, families, carers and consumers.

This section provides information on key policy, legislative and theoretical approaches that have driven the emergence of patient-centred care, followed by specific strategies that have been used to promote and embed patient-centred care in health services and health system policy. The section concludes with a summary of leading international organisations that provide tools and resources to support patient-centred care. Case studies of patient-centred approaches that have been adopted by different organisations, including some Australian examples, are provided to illustrate these strategies.

A list of the leading organisations' websites and other relevant websites and resources are included in Appendix C.

2.1
INTERNATIONAL 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 England. 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 of these policies are discussed below.

Collecting and publishing patient experience data

The US, England and some European countries have implemented patient survey programs to systematically collect patient and carer experience feedback at a national level. In general, the purpose of these programs is to provide a comprehensive picture of quality, monitor trends and drive system change.

England

In England, the former Labour government's vision was for patients and the public to drive the design and delivery of high-quality services. In health care, this was to be achieved by 'putting patient experience centre stage', and a number of regulatory requirements were put in place to meet this aim.[59, 69]

The coalition government has continued this commitment to patient experience. The government's National Health Service (NHS) White Paper, *Equity and Excellence: Liberating the NHS*, published in July 2010,[70] sets out three key objectives for health care in England: to create a patient-led NHS, to improve healthcare outcomes, and to increase autonomy and accountability within the NHS.

To achieve these objectives, the *NHS Outcomes Framework 2011/12*[71] sets out 10 overarching indicators and 31 'improvement area' indicators, divided between five domains of health care. The first three domains make up the 'clinical effectiveness' component of quality, Domain 4 ensures that people have a positive experience of care and Domain 5 is 'patient safety'.

While some indicators are yet to be developed, most of the indicators under Domain 4 are based upon patient experience surveys, including the General Practice Patient Survey, the Inpatient Survey, the Maternity Survey, and the Outpatient Survey, and the Accident and Emergency Survey.

These surveys are conducted using standardised questionnaires. All of the hospital-based surveys use methods based on the work of Picker Institute Europe, which 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 C). Various disease-specific patient experience surveys have also been conducted in England, including the National Cancer Patient Experience Survey Programme.

Patient experience was also a standard measure in the *2010/11 Quality and Outcomes Framework*, and will be a feature of *Quality Accounts 2011/12* and local Commissioning for Quality and Innovation (CQUIN) schemes. In late 2010, the National Institute for Health and Clinical Excellence commenced the development of a quality standard for patient experience, which is due to be published in October 2011.

The government's overall objectives in setting these outcomes are to reduce mortality and morbidity, increase safety, and improve patient experience and outcomes for all.[70] *The Operating Framework for the NHS in England 2011/12*[72] situates patient experience as 'a key arbiter of all NHS services.' The framework states that the 'core purpose remains the delivery of improved quality for our patients, by improving safety, effectiveness and patient experience'.

The framework requires providers to ensure that appropriate systems are in place to capture the views and experiences of patients, service users and carers. This includes the use of locally and nationally coordinated patient surveys, and a range of additional approaches or sources, such as the use of real-time feedback collected at the point of care (e.g. text messaging, patient experience trackers), and use of complaints data and patient-reported outcome measures. In addition, the framework requires service providers to raise awareness of local feedback options, encourage feedback, and demonstrate to the public how their feedback has been used to improve service quality and patient experience. Furthermore, providers need to ensure that patient experience and feedback are inherent parts of service design, delivery and improvement.

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 *Patient Protection and Affordable Care Act 2010*.[73]

The US has implemented the Consumer Assessment of Healthcare Providers and Systems survey (CAHPS), developed at Harvard University and based on the 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. 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*.[74] 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.

Performance reporting and choice of providers

Both England 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.

England

Since April 2008, 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 that are contracted to provide NHS-funded care. The NHS Choices website 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.

The website enables consumers to find both primary and acute care services in their area. It also allows consumers to compare hospitals by various criteria, including cleanliness, car parking arrangements,

general facilities, availability of Accident & Emergency departments, experience of a particular procedure and, in some cases, survival rates.

In addition, the NHS Choices website has a number of areas to which consumers can contribute. Consumers can comment on almost any NHS service, including hospitals, general practices and dentists. Comments will eventually become part of an overall 'ranking' showing the public's opinion of every hospital and general practice that does NHS work in England.

The Coalition government's plan for the NHS sees patient choice as a key mechanism to create a high-quality, patient-centred NHS. The proposed arrangements under the *Health and Social Care Bill 2010–11* would extend patient choice to include choice of specialist team, general practice and treatment.[75]

United States

The US CMS has implemented a web-based tool called Hospital Compare, which uses data from the Hospital Outcomes of Care Measures, CAHPS and H-CAHPS surveys. This tool sets out information about how well hospitals care for patients with certain medical conditions or surgical procedures.

CMS also launched the Physician Compare web-based tool in December 2010, under the *Patient Protection and Affordable Care Act 2010*.[73] This tool serves as a healthcare professional directory on the official US Government Medicare website, and currently allows individuals to search for a physician or other healthcare professional by specialty, type of professional and location. Additional search criteria allow the user to search by gender, and whether or not the healthcare professional accepts the Medicare-approved amount as payment in full on all claims. Other information available includes languages spoken, group practice locations, education and hospital affiliation. Information on the site is updated monthly.

The Physician Compare web-based tool also includes information about physicians and other professionals who satisfactorily participated in the Physician Quality Reporting System (formerly known as the Physician Quality Reporting Initiative). The tool does not yet contain physician and eligible professional performance information. CMS is required to make information on physician performance publicly available through Physician Compare by January 2013.[76]

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 England and the US provide financial incentives to some healthcare providers for adopting improved quality practices, including clinical outcomes and some patient-centred care principles. A recent study of CAHPS data for the primary care sector found that the use of public reporting and performance-based financial incentives can potentially improve patients' experiences of care.[77]

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'.[78]

England

In 2004, the NHS began a major P4P initiative — the *Quality and Outcomes Framework*. Under the 2010/11 framework, general practitioners (GPs) received income increases based on their performance. This was measured using 134 quality indicators that cover patient experience, organisation of care and clinical care for ten chronic diseases.

Early analysis of the *Quality and Outcomes Framework*[79] 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 such as these exclude patients for sound clinical reasons, or to increase their income.[79]

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.[80] Overall, the *Quality and Outcomes Framework* has seen modest improvements in measured quality of care,[81] but has had little effect on inequalities in chronic disease management.[82]

The NHS introduced a new CQUIN framework in April 2009 to improve the quality of care in hospitals and other healthcare organisations. The CQUIN makes a proportion of providers' income (1.5 per cent of contract value in 2011/12) conditional on an agreed package of goals and indicators that address quality, safety, innovation and patient experience. 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 2011/12 CQUIN schemes must include locally agreed quality improvement and innovation goals. In addition, acute providers must include two national goals in 2011/12: to improve responsiveness to personal needs of patients, and to reduce avoidable death, disability and chronic ill health from venous thromboembolism (VTE)

by engaging patients and carers in understanding the risk of VTE and how this can be reduced.[83] 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).

From April 2012, the NHS Commissioning Board will assume responsibility for leading the use of the CQUIN framework. The Board's work will be informed by an independent evaluation report, expected in March 2012.

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 aged 65 and over or who meet other special criteria).

For individual physicians, the *Tax Relief and Health Care Act 2006*[84] established a physician quality reporting system. This includes 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*.[73]

Many private providers and purchasers have embraced P4P approaches as an essential way to meet quality improvement goals. For example, in 2009, a 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
PUBLIC VALUE AND EXPERIENCE AS DRIVERS FOR PATIENT-CENTRED CARE

There is strong support for viewing patient-centred care as a core component in ensuring appropriate outcomes from health service delivery. A range of emerging views regarding the need to create public value, focus on the experience of care, and improve efficiency as part of the context for improving patient-centred care are described below.

Creating public value

One of the common themes resulting from high-profile public inquiries into the health systems in Australia (see Section 4) and England was a reported loss of trust in administrators and clinical colleagues from patients and the community.[85] 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.[86] 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.[87]

Research conducted by the Work Foundation in England, 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.[88] These are in line with the patient-centred activities outlined in Section 2.4, and include formal mechanisms such as client surveys, facilitating patient engagement on committees and boards, providing information to consumers, and improving communication and interactions with consumers.

In England, the NHS collaborates 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.[69] 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*[89] and the proposed *Health and Social Care Bill 2011*[90] empower local networks to canvass 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 *The Experience Economy*.[91] This book 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*.[92] Based on the idea that Disney does not provide a service, but instead provides an 'experience', this work emphasises that 'hospitals would do well to emulate the most vital things that earn Disney the love of their guests and employees'.[92]

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.[10] However, recent research indicates that a patient-centred approach can make health service delivery more efficient.[54] By harnessing consumers' contributions, insights and collaboration, patient-centred care is becoming a critical strategy for public services to deal with rising service costs.[93–94]

2.3
CONSUMER ENGAGEMENT AND PATIENT-CENTRED CARE

The importance of involving people in all levels of the healthcare system has been recognised for some time, particularly since the *Declaration of Alma Ata* in 1978. This declaration states that 'people have the right and duty to participate individually and collectively in the planning and implementation of their health care'.[95]

Consumer engagement is a broad and complex field, with different types and levels of engagement that reflect the different goals, audiences and purposes for seeking engagement.[96] Different types of consumer engagement range from processes to inform or disseminate information, which have a low level of engagement, to formal partnerships with a high level of public involvement and influence.[97] In addition to engagement as patients at the individual service provision level, people are often engaged as consumers of health care, or as citizens, to represent the views of patients and the broader community at the service, program, policy and governance levels of organisations.

All of us are patients or potential patients, and citizens or members of the wider community. However, a distinction can usefully be made between what we want when we are using the health service and what we hope for as citizens or taxpayers.[98] Involving consumers as patients means tackling the clinical agenda and changing the culture of care, while involving consumers as citizens means opening up debate about the pattern and nature of service provision.[99]

Involving consumers as citizens has been described as:[97]
» an ethical and democratic right
» a way of adding legitimacy to decision-making
» a way of improving health outcomes and policy outcomes
» a way of improving relationships with consumers
» a way of serving political or democratic processes.

There are clear differences between the processes that empower individuals to contribute to improving the safety and quality of health care, and the processes that enable the public to hold the health system to account. However, without engaging patients in making decisions about their own care and in improving the safety and quality of the health system as a whole, consumer engagement can be seen as little more than tokenistic. Coulter suggests it makes little sense to encourage people to get involved in collective action while treating them merely as passive recipients of health care in day-to-day interactions.[99] If people are disengaged and disempowered when they are patients, they are unlikely to feel encouraged to participate as active healthy citizens; most will just want to forget about their experiences of the health service and get on with their everyday lives. Involving patients more actively is the basic building block for consumer engagement.[99]

Aiming to have active and informed consumers as equal partners in decision-making processes at all levels of the healthcare system is therefore the central concept for both consumer engagement and patient-centred care.

CASE STUDY 1: VICTORIAN COMMUNITY ADVISORY COMMITTEES

In Australia, Victoria was the first jurisdiction to enact legislation mandating community involvement committees to advise area health board governors on

health service decision making. This occurred in 2002 under amendments made to the *Health Services Act 1998*.

Community advisory committees have a broad remit to provide direction and leadership in relation to the integration, recognition and reflection of consumer views in all areas of health service operations, planning and policy development.

An external evaluation of community advisory committees revealed that facilitators for the success of the community advisory committees included:[100]

» adopting diverse approaches to consumer involvement
» allocating adequate time
» having clear lines of accountability
» ensuring appropriate and reliable resourcing and support for the advisory committee towards achievement of the committee's agreed role
» providing appropriate information and training to all participants and ensuring that members had a clear understanding of the health sector and health service bureaucracy
» ensuring meetings were open and inclusive
» appreciating the circumstances of those participating (e.g. that the meeting environment may be intimidating)
» reporting to participants so that they know what resulted from their involvement.

The evaluation found that a community advisory committee-type forum could only facilitate part of the required agenda for strategic and operational involvement between health services and consumers. There was a need to clarify the facilitative role of community advisory committees in relation to where they fit in the overall strategy of consumer engagement at all levels of the health service. Without this broader context, community advisory committees risked attempting an unmanageable and perhaps inconsistent agenda, resulting in frustration for council members and other consumer involvement stakeholders.[100]

2.4
APPROACHES AND STRATEGIES TO PROMOTE PATIENT-CENTRED CARE

A variety of approaches have been used internationally and in Australia to promote patient-centred care. A review by the Picker Institute Europe identified the most effective strategies, or 'best buys', for facilitating patient-centred care. Links to many of the strategies, approaches and resources discussed in this section are provided in Appendix C.

'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.[101] They evaluated 31 systematic, high-quality narrative reviews on various initiatives to improve patients' experience, including consultation styles, communication skills training, service user involvement in evaluations, and studies of direct and indirect patient feedback (including patient experience and satisfaction surveys). 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, or 'best buys', to improve patient experience are patient-centred consultation styles, communication training for health professionals and patient feedback (e.g. 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.

Implementing rights-based patient constitutions, charters or codes

Several countries provide patients with rights-based constitutions, charters or codes. These documents facilitate patient-centred health care by informing patients about the level of care they are entitled to expect. The NHS Constitution in England[102] 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*).[61] In February 2011, Scotland passed the *Patient Rights (Scotland) Bill (SP Bill 42)*.[103] The Bill aims to create new statutory rights for those using the NHS (Scotland), including a statutory maximum treatment time guarantee, the introduction of a legal right to complain and the creation of a national Patient Advice and Support Service.

In the US, the American Hospital Association has developed the *Patient Care Partnership Brochure*.[104] Medicare patients are given a copy of the *Important Message From Medicare Notice*,[105] outlining patients' rights. Many organisation- and institution-specific patient rights constitutions or charters also operate in the US and Canada.

In Australia, the *Australian Charter of Healthcare Rights* provides a national statement of the rights of patients and people using the healthcare system.[106] In addition, a number of Australia's states and territories have legislated charters of healthcare rights and human rights in place.[107–109]

Patient feedback

One method of driving improvements in the overall quality of an organisation is the collection and reporting of patient feedback.

Surveys are one of the most common tools for collecting patient feedback. Rather than relying on paper-based or telephone surveys, innovative methods such as hand-held devices, bedside terminals and online tools are now being used to survey patients.[110] Further information about Australian patient experience surveys is provided in Section 4.1.

When conducting surveys, it is important to ensure that survey participants reflect the entire population range and include people with disabilities, people from different cultures and age groups, and people from vulnerable populations.[111] Surveys must also be accessible to these groups, and capture meaningful data that can be used to identify and address processes and practices that may compound any disadvantages or unique issues experienced by these populations.

In addition to surveys, deeper, qualitative methods of obtaining patient feedback can include:[13, 110]

» collection of patient stories, interviews and focus groups in which participants share their experiences and insights on a one-time basis
» use of patient diaries to record healthcare experience through illness and treatment
» panels of volunteers (e.g. patients, families, carers) to obtain views on a particular topic, concept or idea, such as hospital service changes, services provided in the community, ambulance services or intermediate care
» staff-accompanied patient walk-throughs during their visit to a department to understand the whole patient journey from the user's perspective
» anonymous shoppers reporting to management on processes of care.

In 2006 in New Zealand, the Health and Disability Commissioner began inviting the public to provide stories about great healthcare experiences, which were complied into *The Art of Great Care*.[112] This document, and these stories, are being used to promote a focus on quality in New Zealand by describing the type of care that people want to experience.

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 in the US has developed an online toolkit to help organisations initiate patient safety rounds.[113] In addition, the UK Department of Health publication, *Understanding What Matters — A Guide to Using Patient Feedback to Transform Services*,[110] sets out best practice in terms of collecting, analysing and using patient feedback. In Australia, WA Health has developed a toolkit for collecting and using patient stories for service improvement.[114]

Improved complaints processes

Complaints about health services are a rich source of feedback, and should be seen as an opportunity to improve health care. In England, the Healthcare Commission and the Parliamentary and Health Services Ombudsman have both encouraged the use of complaints feedback as a tool 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*.[115]

The aim of the reforms is to improve the way healthcare organisations 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. England's Department of Health has published a guide and advice sheets on their new approach to complaints.[110]

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 and care of patients.

Australia also follows the model of locally managed organisation or service-level complaints processes and systems. Each state and territory also has a healthcare complaints commissioner, who is responsible for responding to complaints escalated from local level mediation processes as well as directly from the public.

Engaging patients in safety improvement

Patient-centred care involves more than ensuring a positive experience of care. It is also about engaging patients as partners to identify safety issues and develop ideas about improvement and risk reduction. To date, strategies to improve safety and manage incidents have mainly focused on systems of care and professional behaviour, but there is a growing interest in engaging patients in safety initiatives, including identifying and preventing safety incidents, and incident management.[116–117]

Patients can identify adverse events and incidents that occur in hospitals.[118–119] They have a unique perspective regarding the care they receive, and can provide information and insights that healthcare professionals might not otherwise have known.[120] When adverse events occur, it is often the patient, their family or carer who has the most complete, first-hand knowledge of the events that happened—in contrast with the healthcare team, whose membership may change often. In addition, patient involvement in incident investigation meetings following an adverse event improves the dynamics of these meetings, and anchors people's sense of what went wrong to appropriate recommendations for change.[117]

Active patient participation in decision-making processes and the care of chronic illness has the potential to decrease medical errors and adverse events.[121] One study found an inverse relationship between patient's participation in their care and adverse events.[48] The results indicated that even passive

participation contributed to a reduction in risk. This suggests that patients who participate in their own care are more likely to observe, identify and communicate potential issues, thereby mitigating risk and increasing the safety and quality of care.[48]

While it is clear that patient participation in care improves safety and quality, research also suggests that patients are often discouraged from communicating their concerns to health professionals. Other obstacles to participation in care include health literacy levels, age and sociodemographic factors.[121]

To promote patient engagement in safety initiatives, healthcare professionals need to be receptive and open to patient concerns and questions, and facilitate patients' attempts to be involved in their care. Brusque, dismissive or disinterested attitudes in the healthcare professional can inhibit patients from carrying out many of the roles proposed as means by which they might improve their safety.[116] Encouragement by doctors and nurses is crucial to engaging patient participation in promoting safe care. For example, patient willingness to ask challenging questions is increased when clinicians encourage active patient participation in care.[122]

Opportunities that encourage patients to communicate their knowledge are increased if patients are provided with clear information about how to participate in their care, and if they are partnered in structured activities such as team handovers, ward rounds, team practice review meetings and near-miss discussions. For example, the US Joint Commission's Speak Up program encourages patients to take an active role in preventing healthcare errors by seeking to be a participant in the healthcare team. The Joint Commission has developed a range of educational brochures, posters and videos for patients on a variety of safety topics such as preventing error in your care, preventing infection, planning follow-up care and knowing your rights as a patient.[123] The Australian brochure *10 Tips for Safer Care* has a similar role.[124] To this end, the NSW Clinical Excellence Commission has established a Partnering with Patients program, which aims to foster the inclusion of patients and families as care team members to promote safety and quality.

There is also a growing recognition of the need to openly disclose adverse events to patients. Open disclosure is the 'open discussion of incidents that result in harm to a patient while receiving health care'. Open disclosure and incident management are important tools for learning organisations to assess and review processes, with a view to understanding patients' and carers' perceptions of their care when things go wrong. The *Australian Open Disclosure Standard*,[125] published in 2003, aims to facilitate more consistent and effective communication after an adverse event. Open disclosure policies are also in place in Canada,[126] England[127] and the US.[128]

Using information and education to facilitate partnerships

The provision of information and education improves patient, family and carer capacity for involvement, understanding, participation and partnership in an individual's health care. It can also build an individual's capacity for meaningful engagement with healthcare organisations at the governance level.

Patient-centred approaches to engaging patients and families in their own care through the provision of information can include printed and electronic information, educational programs, telephone support and reminders, personalised information packages and sharing medical records.

The Picker review found that printed and electronic information and educational programs can benefit patients' knowledge and understanding of their condition, increase patients' sense of empowerment, satisfaction and ability to cope, and may help reduce anxiety. Among cancer patients, question prompt sheets and audiotapes of consultations improve the recall of medical information given in clinical consultations. Studies of stroke patients show that information strategies that actively involve patients and their care givers are more effective in reducing anxiety and depression.[101]

Telephone helplines, telecounselling and telemonitoring can also reduce social isolation, increase decision-making confidence and self-efficacy, and improve satisfaction. Telephone reminders can help to increase attendance rates and improve medication adherence, and reminder packaging may improve adherence to self-administered long-term medication.[101]

Personalised information packets given to patients on discharge are also useful.[13] 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.[13]

A certain level of health literacy is required for patients, families and carers to take full advantage of this type of information. Health literacy is an important driver of health behaviour, and lower health literacy is associated with poorer health outcomes.[129] In 2006, the Australian Bureau of Statistics found that approximately 59 per cent of Australians aged 15–74 had a health literacy level below minimum standard.[130] While efforts to improve health literacy have been discussed at an educational and societal level, health professionals and healthcare organisations can take actions to reduce literacy-related barriers. These actions relate to the content and design of information and material, the physical and social environment of healthcare organisations, and the processes used to communicate with patients, consumers, families and carers.[131–132]

Traditionally, medical records have remained the property of the health service providers, but some providers now use medical records as a teaching tool and 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 on the best course of treatment together.[13] 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.[13]

Encouraging greater access to records

The Open Notes project is being conducted at the Beth Israel Deaconess Medical Center, the Geisinger Health System and the Harborview Medical Center in the US. More than 100 doctors and 25 000 patients are participating in the project, which aims to explore what happens when a patient's medical record is made more accessible and transparent for the patient.

As part of the project, primary care doctors invite their patients to access their medical notes via a secure website hosted by their healthcare organisation. The patients can then use email correspondence and phone conversations to follow up on any questions they have regarding the content of the notes.

The project will be evaluated using pre- and post-design doctor and patient surveys to explore the feasibility and impact of providing patients with ready access to doctors' notes in an electronic form.[133]

Open Notes Project
www.myopennotes.org

In 2010, the Australian Government committed to the development of a Personally Controlled Electronic Health Record for every Australian who wants one. This secure, electronic medical history record will be a subset of the patient's complete medical history and will be accessible to both the patient and any authorised medical provider. This will provide greater transparency of, and access to, health records for patients, and will contribute to improvements in information transfer between healthcare organisations.

Patient and carer engagement in personal care

Health services and health professionals are adopting strategies to empower and facilitate patients, families and carers to be actively engaged in their own care.[134] A strong driver for this work has been the focus on shared decision making and self-management approaches, particularly for people with chronic and complex conditions.[135–137] Key interventions for increasing patient engagement in their own care that have been examined include:[138]

» providing health information through printed and online channels
» use of patient decision aids
» coaching and question prompts for patients
» self-management education
» self-help groups and peer support
» encouraging adherence to treatment regimens
» checking records and care processes.

Using carer knowledge

Carer knowledge can provide valuable information about patients that can aid healthcare professionals. The Top 5 program, developed and implemented in the Central Coast Sector of North Sydney and Central Coast Area Health Service in NSW, acknowledges the value of this information. It formalises the recording of tips for effective communication and supportive care, which promotes personalised care.

The Top 5 program was initially designed to support patients with cognitive impairment. It involves staff engaging with carers to elicit their five most important tips and management strategies for patients. The Top 5 tips are recorded and placed on the patient's bedside chart for ease of access by clinical staff.

Following a pilot in five wards in three Central Coast hospitals, nurses reported being more confident and comfortable in caring for patients, and carers perceived the hospital as providing a better health service. Patients were reported as being more compliant with treatment, receiving more effective treatment, being less distressed, and having quicker recoveries and shorter lengths of stay. Nurses also reported greater work satisfaction, better time management, feeling safer in the work environment and receiving fewer complaints from families.

Central Coast Area Health Service
Personal communication

Healthcare organisations can also look at how they put in place systems to encourage active involvement of family members and carers in the care process. 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 can include patient-directed visitation, which removes restrictions on visiting times, allowing the patient to decide on the visiting times that best suit them. This strategy benefits overall patient experience and decreases anxiety by 65 per cent.[13] A related strategy is the capacity for patients and families to trigger an escalation of care, calling a medical emergency or rapid-response team when they are concerned about changes in a patient's condition.[139] Other examples include 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.[13]

Patient and carer engagement at the governance level

There is a strong tradition of consumer engagement in health service policy and planning internationally and in Australia. In addition to the input provided by consumers and citizens, patients, families and carers who have recently received health care in a particular service can have their own unique perspectives, and they also have roles in governance and planning processes. This can occur through their appointment to new advisory councils and committees, or through integration of consumer advisers into existing councils and committees.

Patient and family advisory councils can serve as the 'patient voice'. Such councils provide the institutional infrastructure for including patient and family members' perspectives 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,[13] 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, carers and staff.

In England, and more recently in Australia, the establishment of patient improvement advisory groups ('Critical Friends Groups') in general practices has proven a successful method of using patients' perspectives to improve quality in the primary healthcare sector.[140] The method involves a group of patients and practitioners working in partnership to identify and address issues of concern within the practice. Some practices have established groups to improve organisational issues such as telephone systems, information and dissemination practices, appointment structure, waiting room facilities, the role of the practice nurse and procedures for repeat prescriptions. Other practices use these groups to help practices interpret results of systematic patient feedback.

The *Massachusetts Health Care Quality Act 2010*[141] requires all acute, chronic and long-term care hospitals in the US state of Massachusetts to establish a patient and family advisory council. These councils allow patients 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.

Training consumers in engagement

The Health Issues Centre received funding from the Victorian Quality Council to develop two accredited training courses for consumers and health professionals to support effective partnerships. The program was based on research that identifies 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.[142]

The training courses target consumers, carers, community representatives and health professionals, and provide nationally recognised qualifications and nationally consistent competencies in consumer engagement.

To date, a Consumer Leadership course and a Vocational Graduate Certificate in Consumer Engagement have been piloted and evaluated. The training materials can be adapted and used by different organisations.

Health Issues Centre
www.healthissuescentre.org.au

User-centred design and redesign

In both the US and England, 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. This is based on environmental psychology principles, in which spatial design is seen as an important part of patient experience and wellbeing.[143] 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, and then identifies core patterns and areas for improving the environment to better meet patients' emotional experience of care.

The leading case study for user-centred design is Kaiser Permanente's work in the US. This work improved staff efficiency, and interaction and information flow both among staff, and between staff and patients. It also provided examination rooms that could accommodate carers and families, increased attention to privacy and comfort in patient rooms, and provided more comfortable waiting areas, easier check-in procedures and improved signage to help patients orient themselves more intuitively.[143]

In England, several NHS services have been redesigned. 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 the patient and all key staff involved in the patient's journey to identify the problems throughout the journey.[144] 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 design and co-design

Experience-based design (EBD) is a methodology developed by Bate and Robert[145] for working with groups of patients and staff to improve services. It draws on knowledge and ideas from design sciences and professions in which products or buildings are improved by making the user integral to the design process.

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. EBD works with patients to identify developments that could improve their care experience. It can also involve co-designing solutions with patients to address identified problems and improve patients' experience of using the service.

Involving patients and staff on an equal footing is more integral to EBD than to 'patient involvement' projects, in which patients are often treated as objects for study, rather than partners. How the service 'feels'

or is experienced is seen as equally important to how functional and safe the service is. Bate and Robert provide a step-by-step guide to the EBD 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. Their method has also been used in other clinical specialties and hospitals in England and Australia.[94]

> ### Patient feedback influencing design
>
> Design and construction of the new Queensland Children's Hospital has been informed by a Youth Advisory Group. The group, established in 1997, comprises young people aged 12–18 who have experienced a range of inpatient and outpatient clinical treatments.
>
> The group meets every one to two months and discusses issues related to the development of the Children's Hospital from a consumer and patient's perspective, including architecture, service delivery and experiential qualities of the building. The group has conducted site visits and participated in planning processes throughout the hospital, including working with architects, designers and policy officers to contribute to the design of wards, retail areas, adolescent relaxation and family-focused spaces.[146]
>
> *Queensland Children's Hospital Youth Advisory Council*
> **www.health.qld.gov.au/childrenshospital/ content/establish_yaf.asp**

Consultation styles and communication training

Regulators and professionals in England, the US and Canada are investigating the effects of patient-centred consultation styles on continuity of care, length of consultation and increased support for patients related to nonclinical issues and concerns.[101] 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.[147] Research in England and US also demonstrates that overall patient satisfaction strongly correlates with patients' assessment of clinicians' interpersonal skills.[148–149]

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.[13] Strategies include developing and using verbal communication guidelines for staff, and scripting tools and cues for effectively communicating with patients. *The Patient-Centered Care Improvement Guide*[13] 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 scheduled date and time for specific procedures.

A carer's experience of communication

'We arrived in the ward—a very frightened, confused and depressed woman and her worried husband—and were kept waiting for a long time without explanation.

In due course the psychiatrist appeared. He addressed my wife directly. I was ignored, but I tagged along. The family unit of a man and his wife had become a patient and an appendage. We entered the room. Then ominous silence for a while. No introductions; the doctor without a name. No introductions or explanation [as to] who might have been the unknown young observer sitting in on the consultation. The patient had become an item on a conveyor belt. The doctor faced the desk and had his back to us. At no time did he turn round to face us. I entered the discussion only when I felt that my comments were needed since my wife, because of her mental state, could not answer all the questions. I felt that my presence was not welcome.'

Submission received in the consultation on the draft patient-centred care discussion paper

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A successful communication strategy that has facilitated patient-centred care is the 'Just Ask Campaign' run by 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, providing clothing that clearly distinguishes staff members and follow-up discharge phone calls are further examples of communication strategies to support patient-centred care.[13]

Some health professionals think there is tension between providing the best practice evidence-based clinical care and providing patient-centred care. It is important to acknowledge that adopting a patient-centred approach to health care does not negate the need to adhere to best practice clinical standards and guidelines. To achieve patient-centred care, health professionals need to negotiate a balance between care that aligns with the best clinical evidence available and care that is acceptable to the patient.[150] Healthcare professionals must be good communicators who effectively involve their patients in decisions about their care.[75, 151]

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.[13] At Sharp Coronado Hospital outside San Diego, California, every employee has completed the sentence 'I come to work to make a difference by...'; the laminated statement is adhered to their name badge as a constant reminder that what they do is meaningful and makes a difference to people's lives. Directly involving staff in determining organisational values and defining the behaviours that embody those values fosters a culture of patient-centred care. Making the organisation's values visible can remind staff of the patient-centred behaviours expected of them.[13]

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 chairside chats, and clinician, employee and board engagement, are successful ways to strengthen the foundation of patient-centred care.[13] Staff rounding involves service-provider leaders moving through their organisation and hearing what is happening first hand from patients and staff. Patients and staff can express their views in a personalised, dialogue-based way that enables managers to understand the hospital experience. Similarly, staff may be invited to meet with managers to share ideas or express concerns in fireside or chairside chats. The strength of these communication methods is the direct interaction they afford between management, frontline staff and patients.[13]

Further strategies to establish and sustain patient-centred care include engaging staff and clinicians by involving them in patient-centred advisory councils, and identifying and recognising role models and champions of other patient-centred practices.[13]

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, having a board member on a patient advisory council, and including patient-centredness as a defined and measurable organisational aim.[13]

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.[13] 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 an employee-of-the-month program, or public acknowledgment in a newsletter of a staff member's impact on a patient, family member or another employee. 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. Some providers have successfully adopted a strategy in which a senior manager writes an inspirational weekly message that is recorded on a dedicated phone line and can be accessed by any employee. Scrolling screensaver messages and staff rounding are further tools to help employees engage in creating a patient-centred culture.[13]

Developing understanding and awareness of person-centred care

The Enhancing Practice Program was developed by Northern Health, Victoria, in collaboration with the Council on the Ageing to improve the way health services work with older people and their carers.

The program comprises a series of workshops, co-hosted by health professionals and consumers, that provide participants with an opportunity to reflect on current practice, and look at opportunities for adopting a more person-centred approach to care. The program aims to challenge attitudes and behaviours to encourage practice change.

The program's target audience includes all health professionals who work with older people. By late 2010, more than 1500 staff and 500 managers from 23 Victorian agencies had participated in the program.

The program was reviewed by the National Ageing Research Institute as part of the Best Practice in Person-centred Health Care for Older Victorians project, and in 2010 was the recipient of a silver award at the Victorian Public Healthcare Awards.

National Ageing Research Institute website
www.mednwh.unimelb.edu.au/pchc/
Resources/Training/Staff%20training/
Enhancing%20Practice%20Program.pdf

Staff satisfaction strategies

According to Shaller,[15] 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.

Improving patient and staff experience

In 2011, NSW Health commenced the Improving Patient and Staff Experience Program. This program is part of the patient and carer experience strategy and has been specifically designed to improve the health experience for both staff and patients. The program will be delivered over 12 months to more than 80 clinical areas across 20 hospitals.

Each partner hospital will receive:
» dedicated and facilitated on-site coaching
» executive coaching of leaders to support the implementation of the program
» access to online resources and staff education program
» near real-time measurement of patient experience using the Patient Experience Tracker.

The program will be externally evaluated to determine its impact and will contribute to the evidence base of patient-centred approaches to care in Australia.

NSW Health
Personal communication

Accountability strategies

To become patient-centred, organisations need to encourage and promote staff ownership of the cultural change required. The organisation should therefore 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 management and nonsupervisory staff.[13] Specific commitments and expectations can be outlined in professional codes of conduct to define the way patient-centred care is provided. Some patient-centred

organisations in the US have incorporated performance measures to support the behaviours defined in codes of conduct[13] and performance incentives based on improving quality metrics, including patient experience.[152]

Case study 2: Medical College of Georgia Health Inc., Georgia, United States

Located in Augusta, Georgia, Medical College of Georgia Health Inc. is a non-profit health service affiliated with the Medical College of Georgia (MCG). The medical district, including the university hospital, is the largest employer in Augusta and has 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 in 1998, when they built a new paediatric medical centre. 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 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 fit-outs

» introducing executives' 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 the 74th percentile, rated using surveys administered by an independent vendor, Press Ganey. The neurology intensive care unit was also renovated with patients' input, introducing a 24/7 family access policy. Within five years, patient satisfaction ratings increased from the 10th to the 95th percentile and the length of stay of 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 a falling overall staff vacancy rate — from eight per cent to zero 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 INTERNATIONAL ORGANISATIONS

Several international private or not-for-profit organisations advocate specific patient-centred frameworks or approaches to health service improvement built around a combination of the strategies outlined in Section 2.4. Both public and private health service providers have used these frameworks. The leading organisations advocating patient-centred healthcare frameworks are described below. Websites and links to resources on strategies to promote patient-centred care are provided in Appendix C.

World Health Organization

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

WHO advocates for a 'responsive' healthcare system that meets people's expectations.[14] It also advocates for involving patients and carers as partners in initiatives to improve the safety and quality of care,[153] particularly through its Patients for Patient Safety program. This program 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 Patients for Patient Safety 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.

The program is designed to ensure that the perspective of patients and families is a central reference point in shaping the safe and high-quality delivery of health services, including health service decision making. It 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.[153]

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', which sets out the processes for improving patient-centred care in a variety of areas. These include 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 website provides a variety of publications, resources, tools and improvement stories to help organisations achieve patient-centred care. In 2011, the IHI published a white paper to assist hospitals in achieving exceptional patient and family experiences of inpatient care.[154]

Picker Institute

The Picker Institute was established in 1994 as an independent non-profit organisation based in Boston, Massachusetts. 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 validated, nation-wide 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). 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, England, 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*,[13] and a self-assessment tool written in conjunction with Planetree (see below). The institute has also established the Always Events program, which aims to establish a set of events

that patients can expect to occur at every healthcare experience, through demonstration projects and the establishment of a collaborative learning network.

A variety of resources on patient-centred care is provided on the website of the institute's sister organisation, Picker Institute Europe.

Institute for Patient- and Family-Centered Care

The Institute for Patient- and Family-Centered Care (IPFCC) 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 IPFCC website 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*[57]
» *Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System — Recommendations and Promising Practices*[155] (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.*[28]

Planetree

Planetree was founded in 1978 by Angelica Thierot, a patient 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.*[156]

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.

In 2008, Planetree partnered with the Picker Institute to produce *The Patient-Centered Care Improvement Guide*.[13] This and other Planetree publications are available on the Planetree website.

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. Other tools concentrate on improving patient experience by first improving staff satisfaction and experience, such as the '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.

Kenneth B Schwartz Center

The Kenneth B Schwartz Center is a non-profit organisation based at Massachusetts General Hospital in the US. 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 providers, including Schwartz Center Rounds,

the CarePages website and the Patient Voice for Compassionate Care program.

Schwartz Center Rounds are a multidisciplinary forum in which care givers discuss difficult emotional and social issues that arise in caring for patients. An evaluation of Schwartz Center Rounds[157] 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 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 providers 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 identifies specific changes necessary to improve communication, and reconvenes 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.

The King's Fund

The King's Fund is a charity that seeks to understand how the health system in England 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 staff, hospital boards, and patients and their families to research, test and share new approaches to improving patients' experiences.

Seeing the Person in the Patient: Point of Care Review Paper[16] considered current debates and dilemmas in relation to patients' experience of care in acute hospitals in England. 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).[16] These levels are similar to the Institute of Medicine's levels of patient-centred care described in Section 1.4.[2]

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

3

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.

Australia has a mixed healthcare system, in which 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.[158] Despite the complexity of the Australian healthcare system, many of the strategies and approaches to patient-centred care used internationally are highly applicable to Australia.

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.[158] 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, both general practitioners (GPs) and specialists, pharmacists, numerous private hospitals and day hospitals, a large diagnostic services industry and a number of private health insurance funds. Ownership of private hospitals is mostly centralised, with more than two-thirds of all private beds owned by large for-profit chains or the Catholic Church.[158] GPs and pharmacists are largely self-employed and funded by Medicare and the Pharmaceutical Benefits Scheme through fee-for-service, the Practice Incentive Program and the Fifth Community Pharmacy Agreement (including the Pharmacy Practice Incentive and Accreditation Program). These last two programs offer financial incentives for accredited GPs and pharmacists, respectively, to improve the quality and accountability of their services.

Both the public and private sectors are seeking to improve the overall quality of health care. 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.

The current reform of accreditation for health care facilities, led by the Commission, is another aspect of Australia's healthcare system that could further facilitate patient-centred care. To date, the requirement for healthcare organisations to be accredited has varied across public, private, acute, primary and aged care sectors. For example, in the acute sector, most public hospitals are required to seek accreditation and most large hospitals seek accreditation.[158] In addition, in some jurisdictions, private hospitals are also required to be accredited as part of their licensing arrangements. Many private hospitals will voluntarily seek to meet accreditation standards as private health insurers pay higher reimbursement rates to accredited facilities.[158] However, accreditation coverage is far from consistent or complete.

The Commission's work on accreditation reform and the development of the National Safety and Quality Health Service (NSQHS) Standards will create greater consistency of accreditation by introducing the NSQHS Standards to be used in accreditation processes for hospitals and day procedure services. The application of the NSQHS Standards will incorporate patient-centred principles into accreditation requirements, particularly through Standard 2, 'Partnering with Consumers'.

3.2
NATIONAL HEALTH REFORM

National policy reforms set out in the *National Health and Hospitals Network Agreement*[159] and the *Heads of Agreement—National Health Reform*[160] focus 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*, which consists of national performance indicators, new hospital and health service performance reports, and national clinical safety and quality standards to be developed by the Commission.

The *Performance and Accountability Framework* builds on the requirement for public reporting on objectives and outcomes of the National Healthcare Agreement.[161] This agreement 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'.[161]

Progress towards these objectives and outcomes will be measured by nationally comparative information that indicates patient satisfaction levels on key aspects of the care they receive. In the first National Healthcare Agreement report in 2010, agreement had not yet been reached on how to measure this progress, and no data were included. In the future, progress reports will be drawn from patient experience surveys in each jurisdiction, and a national population-based survey conducted by the Australian Bureau of Statistics on the healthcare experiences of individuals in private households (see Section 4.1).[161]

The draft 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 current draft 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.[159] The indicators also facilitate transparent monitoring across services and jurisdictions, and will set a minimum standard of healthcare quality to which each provider should adhere.

A new, independent National Health Performance Authority is expected to be established as part of the health reform governance framework. The National Health Performance Authority is anticipated to have responsibility for producing performance reports for Local Hospital Networks, hospitals (both public and private) and Medicare Locals.

Nationally consistent, activity-based funding is anticipated to be introduced for public hospital services. This is likely to be based on a nationally efficient price determined by a new Independent Hospital Pricing Authority (IHPA). When setting the nationally efficient price, the IHPA is expected to consider a range of issues, such as reasonable access, clinical safety, efficiency and fiscal considerations, as well as healthcare needs of people living in rural Australia, and Aboriginal and Torres Strait Islander peoples.[159] By linking this funding to performance, the nationally efficient price is expected to consider clinical indicators and outcomes, as well as patient experience.[159] Improving the patient experience through patient-centred care, therefore, has important implications for both patients and providers.

The Commission will also play a role in the implementation of health reform. In 2011, the Commission was established as an independent permanent body with an expanded remit to develop, monitor and implement national standards for improving clinical safety and quality in hospitals and healthcare settings. These standards will complement the NSQHS Standards.

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 *Australian Safety and Quality Framework for Health Care*. National strategies, such as the *National Primary Health Care Strategy*, the *National Chronic Disease 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.[162] From 1993, each Australian state was required to develop public hospital patient charters to inform patients of their rights under the *Australian Health Care Agreements*.[163] 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.[162] A copy of the *Australian Charter of Healthcare Rights* can be found in Appendix D.

Australian Safety and Quality Framework for Health Care

In 2010, Australian Health Ministers endorsed the *Australian Safety and Quality Framework for Health Care*. The overall aim of the framework is to provide direction for improving the healthcare system. In developing the framework, the Commission recognised that consumer engagement is vital to safety and quality improvements, and should underpin the strategic plan for the system.[164]

The Commission has developed a series of guides for policy makers, managers, healthcare teams, executives and boards to support the use of the framework. A copy of the *Australian Safety and Quality Framework for Health Care* — including the actions proposed for health systems and providers to achieve patient-centred care — can be found in Appendix E.

National Safety and Quality Health Service Standards

The NSQHS Standards provide an explicit statement of the expected level of safe and good-quality care to be provided to patients. There are ten standards, nine of which have components relevant to patient-centred care. Two of the standards — Standard 1, 'Governance for safety and quality in health service organisations' and Standard 2, 'Partnering with consumers' — describe explicitly how healthcare organisations should engage with consumers at a governance and organisational level. These two standards form the foundation on which each of the other standards should be applied. In addition, seven of the remaining standards include criteria that describe different requirements for engaging with patients, through communication and the provision of information for each of the specific topic areas. Further detail on these standards can be found in Table 1.

In 2010, health ministers agreed that all health services that pose a high risk of harm to patients be accredited against the NSQHS Standards.[a] Under these arrangements, accrediting agencies will assess health services using the NSQHS Standards, with the transition period to commence from 1 July 2011 and full implementation by early 2013. In addition, all other health services may use the NSQHS Standards as part of their internal safety and quality assessment processes.

Table 1

Excerpt from the National Safety and Quality Health Services Standards: standards and criteria relevant to patient-centred care

STANDARD	CRITERIA RELEVANT TO PATIENT-CENTRED CARE
Standard 1: Governance for safety and quality in health service organisations	*Patient engagement and rights:* Patients' rights are respected and their engagement in their care is supported.
Standard 2: Partnering with consumers	*Consumer partnership in service planning:* Governance structures are in place to form partnerships with consumers and/or carers. *Consumer partnership in designing care:* Consumers and/or carers are supported by the health service organisation to actively participate in the improvement of the patient experience and patient health outcomes. *Consumer partnership in service measurement and evaluation:* Consumers and/or carers receive information on the health service organisation's performance and contribute to the ongoing monitoring, measurement and evaluation of performance for continuous quality improvement.
Standard 3: Preventing and controlling healthcare associated infection	*Communicating with patients and consumers:* Information on healthcare associated infection is provided to patients, carers, consumers and other service providers.
Standard 4: Medication safety	*Communicating with patients and carers:* The clinical workforce informs patients about their options, risks and responsibilities for an agreed medicines management plan.
Standard 6: Clinical handover	*Patient and carer involvement in clinical handover:* Health service organisations establish mechanisms to include patients and carers in clinical handover processes.

a High-risk services are defined as those that undertake invasive procedures into a body cavity or dissecting skin while using anaesthesia or sedation.

STANDARD	CRITERIA RELEVANT TO PATIENT-CENTRED CARE
Standard 7: Blood and blood products	*Communicating with patients and carers:* Patients and carers are informed about the risks and benefits of using blood and blood products, and available alternatives when a treatment plan is developed.
Standard 8: Preventing and managing pressure injuries	*Communicating with patients and carers:* Patients and carers are informed of the risks, prevention strategies and management of pressure injuries.
Standard 9: Recognising and responding to clinical deterioration in acute care	*Communicating with patients and carers:* Patients, families and carers are informed of recognition and response systems, and can contribute to the processes of escalating care.
Standard 10: Preventing falls and harm from falls	*Communicating with patients and carers:* Patients and carers are informed of the identified risks from falls and are engaged in the development of a falls prevention plan.

Source: Australian Commission on Safety and Quality in Health Care 2011[165]

National Primary Health Care Strategy

The *National Primary Health Care Strategy*[166] is a high-level action plan consisting of ten elements aimed at improving primary health care through patient-centred approaches. 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.[166]

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.[166] The *National Primary Health Care Strategy* recognises that an inclusive and patient-centred focus is a key element of all future reforms in primary health care.

National Chronic Disease Strategy and National Service Improvement Framework

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 Framework* (NSIF) for asthma, cancer, diabetes, heart disease, stroke and vascular disease.[167] 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.[167]

National Mental Health Plan

The *Fourth National Mental Health Plan—An Agenda for Collaborative Government Action 2009–2014*[168] 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 this 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, and 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.[168]

Fifth Community Pharmacy Agreement

The *Fifth Community Pharmacy Agreement*[169] 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 policies

In addition to the *National Primary Health Care Strategy*, Aboriginal and Torres Strait Islander primary healthcare policies reflect patient-centred principles and aim to be community- and family-centred. Patient-centred care in this context requires a critical focus on the cultural safety of, and cultural respect for, the patient, their family and community, and may involve considerations that are not normally associated with health care in mainstream services.

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 primary healthcare services are initiated and operated by local Aboriginal communities. They deliver holistic, comprehensive and culturally appropriate health care to the community that controls it, through locally elected boards of management.

The National Aboriginal Community Controlled Health Organisation is the peak national Aboriginal health body representing Aboriginal community-controlled health services throughout Australia. According to the organisation, 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.*[170]

In a review on the link between primary health care and health outcomes for Aboriginal and Torres Strait Islander people, Griew[171] identified 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 activity in relation to Aboriginal and Torres Strait Islander primary health care emphasises 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.[172]

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.[172] 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.[172]

Home visiting, health and wellbeing

The Australian Nurse Family Partnership Program is a national government-funded program based on the successful Nurse Family Partnership home visiting model, which was developed and refined over the last 30 years by Professor David Olds in the US.

The program is an intensive home visiting program for women pregnant with an Aboriginal and/or Torres Strait Islander child and their families. The aim of the program is to achieve the best physical, social and emotional health outcomes during pregnancy and the early years for the whole family.

The program provides a structured, sustained service delivered by skilled health professionals. Nurses visit mothers and their families in their own homes, commencing during pregnancy and continuing until the child is two years old, with the frequency of visits tailored to each family's needs.

The program aims to improve pregnancy outcomes by helping women improve their own health while they are pregnant, and then improve child health and development in the early years, through good preventative health practices and early identification and treatment of potential health issues.

Australian Nurse Family Partnership Program
www.anfpp.com.au

Current jurisdictional and other activity in Australia

4

This section highlights some of the patient-centred care initiatives being undertaken in Australia, ranging from the adoption of patient experience measurement strategies at a state level to the implementation of co-design and peer support projects at a local level.

The need to improve the safety and quality of health care has led public and private healthcare organisations to adopt a variety of approaches to deliver more patient-centred care.

Many of the initiatives described in this section evolved from the need to address the safety and quality of health service delivery, revealed by several high-profile, state-based inquiries. These inquiries involved patient care and adverse clinical incidents at the King Edward Memorial Hospital in Perth,[173] Canberra Hospital,[174] Royal Melbourne Hospital,[175] Campbelltown and Camden hospitals,[176] Bundaberg Hospital and Queensland Health,[177–178] Royal North Shore Hospital,[179–180] and, more generally, acute care services provided by NSW Health.[181–182]

Hindle and colleagues[183] reviewed the common features of the King Edward, Royal Melbourne, and Campbelltown and Camden inquiries. They found that quality monitoring processes were deficient, and that 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 also unsure of their rights and were frequently afraid of exercising them, sometimes treated in inconsiderate ways, and seldom received sympathetic or helpful support when they made complaints.

The inquiries concerned allegations of poor clinical practice and poor communication between healthcare organisations and patients, their families or other carers, which led to a loss of trust in the health system by patients and the community.[85]

The response to each of these inquiries was an increased focus on patient-centred care. Several strategies to achieve this are in place within jurisdictions, 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.[184–185] These and other approaches are discussed in this section. Links to many of the organisations, programs and projects discussed in this section are included in Appendix C.

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.[186] Other state 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 as part of its overall framework for patient-centred care.[187]

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.[188] Patients and consumers can be part of the process of interpreting the results of surveys, and can provide direction about priority areas for change.[189]

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, dentistry, and pathology and imaging. 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 about 6500 people, has the advantage of

capturing information about people who could not access services and exploring the 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,[190] 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 general practitioners (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 fourth edition of the *Royal Australian College of General Practitioners Standards*[191] requires GPs to obtain feedback from patients. More specifically, the standards require that general practices actively seek feedback about patients' experiences of the practice at least once every three years, demonstrate improvements they have made in response to analysis of patient feedback, and provide information to patients about practice improvements made as a result of their input.

Another source of feedback is complaints from patients and consumers. Complaints received at a local level provide an important source of information about the experience of patients receiving care. In addition, all states and territories have a healthcare complaints commission, or similar body, which works with patients and providers to manage complaints.

4.2
THE AUSTRALIAN INSTITUTE FOR PATIENT AND FAMILY CENTRED CARE

The Australian Institute for Patient and Family Centred Care was founded in 2009 by a diverse group of healthcare professionals, patients and families. The institute's aim is to bring patients, families and healthcare professionals to the same table to transform the experience and improve the outcomes of health care.

The institute's three key pillars of work are:
» Partnership: Building strong healthcare partnerships between patients, families and healthcare workers.
» Culture: Promoting a supportive and transparent workplace culture within healthcare environments across Australia.
» Environment: Encouraging the development of improved healing environments through meaningful art, architecture and design.

The activities of the institute include:
» advancing the understanding and practice of patient- and family-centred care through training and consultancy
» partnering with universities, hospitals and insurers to support research into patient- and family-centred practice
» advising healthcare program planners and decision-makers on policy that supports patient- and family-centred practice
» maintaining a library of information on patient- and family-centred practice accessible via a website portal.

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. In some states and territories, these initiatives form part of broader consumer engagement frameworks designed to involve a variety of people at all levels of health care. In other states and territories, patient engagement is implemented separately to citizen engagement. Some examples of state and territory-based frameworks and patient-centred initiatives are described below.

ACT Health

In 2003, ACT Health established the Consumer Feedback Project. This involved comprehensive consultation with the community and resulted in the report *Listening and Learning, ACT Health's Consumer Feedback Standards*.[192] 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*[193] in 2008. The policy outlines the general principles and approach of all ACT Health staff to manage consumer feedback.

Patient experience and redesign programs are currently underway in the Australian Capital Territory. More than 200 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. ACT Health also 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 in preparation 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 and other groups to increase community awareness of advance care planning.

In early 2011, ACT Health released the discussion paper *Towards a Patient and Family-Centred Model of Care in the ACT*[94] for consultation, and is also exploring options for piloting this work.

NSW Health

The NSW Health *Caring Together: Health Action Plan*[184] was developed in response to the New South Wales inquiries, and focuses on ensuring the patient is the centre of the healthcare system.

The action plan 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. New emergency department nurse positions that focus on the needs of the patients in the waiting room have been established. These nurses are providing better communication on waiting times, initiating basic treatments and completing required admissions documentation.[184]

The action plan also led to the establishment of a range of programs that support patient-centred approaches to care. 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 New South Wales have also implemented Studer Group training and programs. The Essentials of Care Program also has a patient-centred focus, and aims to encourage patient participation in decisions about their care, focusing on patients' needs and their experiences of care provided, and encouraging the appreciation of the value of contributions from all involved in care.

NSW Health has implemented a variety of other patient-centred initiatives, including two experience-based co-design programs in hospital emergency departments and departments that receive patients from the emergency departments.[94, 195–196] 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

» 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.[94, 195–196]

NT Department of Health and Families

The Northern Territory has implemented a range of strategies that facilitate patient-centred approaches to care, including conducting patient surveys and engaging patients in the evaluation of services. In addition, families and carers are involved in the development of patient pathways and service models.

All Northern Territory hospitals have boards with consumer representation, and consumers are included in reference and advisory groups. In addition, the Northern Territory has commenced implementation of shared electronic records enabling health information to follow patients as they move between healthcare providers, improve the quality of care in emergency presentations, reduce duplication of diagnostic tests and improve medication management.

Specific projects to improve patient-centred care with Aboriginal and Torres Strait Islander patients have included:

» placing Aboriginal Community Workers in remote Northern Territory communities, helping to make communication between health professionals and patients easier.

» expanding mobile dental services through the establishment of a new vehicle based in Alice Springs, which will provide dental services to approximately 8000 people in surrounding communities.

» developing the Indigenous Renal Palliative Care Pathways, in conjunction with consumers and their families, to facilitate use of and engagement with renal palliative care processes for Aboriginal and Torres Strait Islander patients, particularly those living within remote communities.

In addition, a range of resources tailored to the needs and preferences of Aboriginal and Torres Strait Islander peoples have been developed, including:

» *Talking Posters* which, through embedded microchips, enable the provision of health and related information in local Aboriginal dialect.

» *Looking from a new perspective to create a brighter future.* A DVD developed and designed to help health services staff understand Aboriginal and Torres Strait Islander peoples' culture and needs, and improve methods of communication and service delivery.

» *Waiting. Going to hospital. Coming home strong.* A DVD and flip chart designed to help health professionals communicate better with Aboriginal and Torres Strait Islander patients, and to reduce misconceptions that Aboriginal and Torres Strait Islander peoples have about hospitals, and to help break down communication barriers between patients and medical staff. The DVD aims to help inform patients about what to expect, their rights and responsibilities, and the services that they are entitled to during their stay in hospital.

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 statewide 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). The programs also 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, malnutrition, patient identification, recognition and management of the deteriorating patient, and falls and pressure ulcer prevention. Both programs have developed patient satisfaction and patient experience assessments to measure improvement in these initiatives. 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.

It provides the Minister for Health with information and advice from a consumer perspective, and supports and promotes consumer engagement and advocacy.

SA Health

In 2009, SA Health released its *Consumer and Community Participation Policy Directive*[197] and *Consumer and Community Participation Guideline*.[198] These aim to ensure consumers and the community have the ability to participate in healthcare decisions, and to support managers and staff to develop a culturally appropriate organisation that is responsive to the perspectives and needs of a diverse range of consumers and community members. SA Health is reviewing these documents in collaboration with the Health Consumers Alliance of South Australia, and will relocate them under a broader, patient-centred care framework along with other relevant policies and strategies.

SA Health's policies, plans and strategies have benefited from consumer input through the many consumer advisory boards and committees, and consumer representatives on clinical networks and advisory structures.

In South Australia, efforts to improve the experience of patients are also informed by patient surveys and computer-based information systems. The Patient Evaluation of Hospital Services survey collects information on patient satisfaction. The new South Australian Consumer Experience Surveillance System is focused on measuring the patient experience as part of a more deliberate strategy to focus on patient-centred care. The Safety Learning System is a new computer-based information and reporting program that enables clinicians and staff to more systematically and accurately collect information (including consumer feedback and complaints), and report on adverse events to target areas for change and to provide data for measuring improvements in health practice.

Tasmanian Department of Health and Human Services

In 2010, the Tasmanian Department of Health and Human Services developed the consumer, carer and community engagement framework *Your Care, Your Say*, which encourages consumers, carers and the community to take part in decision making. The framework establishes four key objectives for the department:
» No wrong door: Making sure you can access the services you need.
» Listening and responding: Involving you in developing responsive, accessible and sustainable health care services.
» Capacity building: Making sure service providers have the skills, knowledge and know-how to practise engagement meaningfully.

» Relationship building: Developing trust and understanding to develop healthier communities.

Implementation of the action plan is currently being progressed.

One of the initiatives currently being undertaken focuses on improving health literacy in the effort to help patients understand their condition, which facilitates better decision making through informed consent. The project has two objectives:
» improving the capability of the department in providing health information to clients in the most efficient and easily understandable way possible
» developing strategies to improve the health literacy among the wider community to assist the broader effort of improving the health outcomes for Tasmanians.

In April 2011, the department held a patient-centred care statewide video conference with the aim of improving the understanding of the patient's perspective and facilitating cross-professional learning and information sharing. The conference focused on concepts of patient-centred care, making progress on patient-centred care in Australia, and examples of state and territory initiatives.

Consumers have been recruited to all clinical networks. The networks encourage the exchange of information and collaboration between clinicians and consumers in order to coordinate and plan for the efficient use of resources. There are four clinical networks in existence, with another three under development and a further three identified for development in the future.

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*.[199] The policy encompasses consumer engagement at the individual service, program, organisational and system levels. For the period 2010–13, a new strategic direction for this policy has been developed.[200] New standards, indicators and targets to facilitate engagement at all levels of health care have been developed in collaboration with health services, consumers, carers and community members, and will be applicable to all public health sectors in Victoria.

The Victorian Mental Health Reform Strategy 2009–19 and accompanying action plan and quality framework, developed in partnership with patients and carers,[201] promotes 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 UK NHS are currently being piloted. The projects aim to increase safety, patient complaints, length of stay,

staff morale and retention, and the time staff spend caring for patients.
» In 2008, a stroke project aimed at improving the care pathway for stroke patients 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 the broader Improving the Patient Experience Program. Under this program, emergency departments in Victoria upgraded their physical amenities and reviewed 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.

As part of the Victorian Department of Health's Consumer Participation and Information Program, the Health Issues Centre is funded to support and promote consumer participation. Similarly, the Centre for Health Communication and Participation is funded to identify evidence-based improvements to clinical practice, focusing on consumer interactions with healthcare professionals, services and researchers. Links to these organisations can be found in Appendix C.

The Victorian Quality Council has also introduced an initiative to improve the patient journey. This initiative aims 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 noncritical patients.

WA Health

In 2007, Western Australia adopted a *Consumer, Carer and Community Engagement Framework*[202] to support area health services and WA Health staff and managers to effectively engage with health consumers across the state. The intent of the framework is to support staff to develop and evaluate productive consumer engagement strategies that promote quality and safety in health care.

The accountability and reporting of consumer, carer and community engagement activity is incorporated in the *WA Strategic Plan for Safety and Quality in Health Care 2008 – 2013 Placing Patients First*.[203] Specific strategies incorporated in the strategic plan to enhance patient-centred health care include ensuring consumers, carers

and the community are well informed, improving communication between patients and healthcare providers, and facilitating the involvement of consumers and community members in the planning and delivery of health care.

Examples of WA Health programs underpinned by a patient-centred focus include the Patient First Program, described in case study 6, and the Four Hour Rule Program. The Four Hour Rule Program commenced in 2009 and is an extensive redesign program aimed at improving the patient experience across the hospital journey from emergency admission to ward discharge. As part of the implementation of this program, patient experiences were gathered through 'Voice of the Patient' interviews to ensure that patient feedback about their care experiences was incorporated in the program.

In addition to patient-centred programs, all WA Health hospitals have procedures in place for managing both complaints and feedback provided by healthcare consumers. These procedures are underpinned by the *Western Australian Health Complaint Management Policy 2009*,[204] which recognises the role of complaints and feedback in highlighting areas of improvement to promote safe quality health care.

WA Health has also measured patient satisfaction since 1997. The annual Patient Evaluation of Health Services involves interviews with over 7000 health consumers and measures their satisfaction across a range of domains including information and communication, and the right to be involved in care and treatment. Results gleaned from the evaluation are used to fulfil quality assurance commitments and inform service improvement initiatives.

In 2009, the inaugural Australian Patients for Patient Safety Workshop was held in Perth. The workshop was a collaboration between the WHO Alliance for Patient Safety, the London, Chicago and Australian networks for Patients for Patient Safety, 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 — and healthcare providers and health policy makers from around Australia. The workshop resulted in *The Perth Declaration for Patient Safety*, which 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, forming an Australian community of committed people who seek to ensure that future health users are not harmed. A copy of *The Perth Declaration for Patient Safety* is in Appendix F.

4.4 CASE STUDIES OF CURRENT PATIENT-CENTRED CARE ACTIVITIES IN AUSTRALIA

The following case studies demonstrate examples of patient-centred programs and activities currently being undertaken in Australia.

CASE STUDY 3: CALVARY HEALTH CARE SIMPLY BETTER PROGRAM

In 2006, staff at Calvary Health Care — a mixed public and private service in the Australian Capital Territory — 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. The program used 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, values and service accreditation processes. The program:

» obtained commitment from the executive team and departmental managers
» developed measurable goals and performance indicators (e.g. preventable harm of patients and unplanned employee leave)
» built a service culture by training and coaching staff, and regularly providing staff with patient feedback
» provided managers with executive leadership training
» focused on staff satisfaction, including staff rounding, to engage staff in the improvement processes
» built accountability by reviewing measurable goals and meetings with line managers to identify 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 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 the 69th to the 99th percentile), public day surgery (from the 56th to the 74th percentile) and private day surgery (from the 47th to the 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).[205]

Case study 4: 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.

Redesigning Care aimed to redesign patient flow and eliminate duplication and delays to ensure that each step in the process added value and improved outcomes for patients and staff.[195] 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.[145]

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 centre's emergency department and to trial the EBD methodology as a sustainable approach to patient and carer participation within the centre's management system.[195] In 2007–08, data were generated through observations of 29 staff interviews, 22 patient and carer real-time experiences, and 14 patient and carer reflective interviews.

Some of the solutions for action related to recommendations for physical changes, and resulted in a capital works redevelopment of the centre's emergency department to increase patients' comfort and improve their environment. For example, a physical redevelopment reduced noise levels and improved visual management by staff. The main solutions outside the redevelopment involved communication processes and teamwork. The program was considered successful in improving teamwork and communication between staff and patients.[94]

Case study 5: Quality Framework for Australian General Practice

To support their work to improve quality, the Royal Australian College of General Practitioners has developed a quality framework for general practice.[206] The framework can be used to plan or evaluate quality initiatives, map the current activities, clarify roles and responsibilities and stimulate broader thinking about quality.[206] It includes six domains (professionalism, knowledge and information management, competence, capacity, financing and patient focus) and four levels of analysis and action (national, regional, setting of care and consultation) within each domain.

The patient focus domain is based on the wishes of patients and consumers to fully participate in improving quality at all levels[207], in particular as:[207]
» active partners in the consultation
» customers in the setting of care
» the population of a region whose collective health is dependent on the region's services
» consumers, community members and taxpayers who have a legitimate stake in the health systems of the country.

Examples of activities included in the patient focus domain of the quality framework include:[206–207]
» ensuring a practice is accessible
» using a patient-centred approach during consultations
» collecting feedback from patients
» involving carers and consumers in regional and jurisdictional projects, programs and policy development
» ensuring that health inequalities are addressed by activities at all levels of action
» encouraging national advocacy by and for carers and consumers.

Case study 6: Patient First Program

WA Health has developed the Patient First Program,[208] which places patients and their carers at the forefront of clinical processes by increasing patients' understanding of their condition. This 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 as a way to mitigate those risks, while also giving patients 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, and information and privacy.[209]

Using a Patient First Ambassador to distribute the booklets improved communication with patients; 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 nonthreatening way.[208]

Case study 7: Respecting Patient Choices Program

The Respecting Patient Choices Program is an advanced care planning program that encourages patients to have input in their current and future health care. The program was originally developed in the US, in the context of advances in medical technology that gave medicine the ability to prolong life through artificial or mechanical means. In this environment, healthcare professionals and families can often find themselves having to decide when to withhold or withdraw life-sustaining treatments, because the patient can no longer communicate their own decisions.

The program has developed a systematic approach to advanced care planning. This approach supports the integration of the program into routine health care, and ensures that patient preferences are known and respected. The quality-assured system of discussing and documenting a patient's preferences for their future health care prepares for a time when patients might not be able to make decisions about their end-of-life care. This can be done in consultation with health providers, family members and other important people in patients' lives, helping to ensure that future medical care is in line with the patient's wishes and views.

The Respecting Patient Choices Program was adapted by Melbourne's Austin Hospital in 2002–03, and has now been taken up by many other healthcare organisations within Australia. It was trialled as a community extension program in a number of residential and community aged and palliative care facilities in 2004–05. An evaluation of this community extension program found that advanced care planning had significant impact on the level to which consumers were involved in choices regarding their future care, and on the skill and confidence of health service providers in attending to patients' wishes.[210]

Case study 8: Peer service in mental health project

The Southern Mental Health Peer Service was established in southern Adelaide as a three-month pilot project in peer support, and operated from 2006 to 2008.[211] The consumer-driven and operated project was funded and supported by Southern Mental Health, Flinders University and SA Health's Mental Health Unit. Metro Home Link, a state government funded service, was also involved in the project.

Initially, a group of consumers of mental health services, mental health managers, nongovernment representatives and general practice staff came together to discuss consumer needs and priorities, and how these might be better met. Consumers identified the first days after leaving hospital as significant. They reported feeling that limited support was available at a time when they were vulnerable to relapse. Consequently, Southern Mental Health Peer Service was established with the goal of early discharge and future hospital avoidance.

Peer support workers who had experience and training in support work, and had experienced a mental health condition that required hospitalisation, were employed by the service. Workers were paid, supported by a coordinator and participated in a six-week specific peer worker course. Over the course of the project, they partnered with peer volunteers interested in becoming peer support workers.

Following consumer consent, referrals were made through a statewide call centre by GPs, consumers, carers, staff from inpatient wards and emergency departments, short stay units and hospital in the home services.

Over the first 12 months, the project provided support to more than 300 people, with referrals from the full range of service providers across the southern half of Adelaide as well as from some country regions.

It was concluded that using peers to provide support to consumers at this stage of their recovery seemed highly effective, had personal benefit to consumers and peers, provided savings to the system in terms of bed-days, and had the potential for encouraging mental health service culture and practice towards a greater recovery focus.

It was further concluded that with adequate support, training and supervision, people with mental illness who are living well can provide meaningful emotional and practical support to other consumers.

The program and its impact has informed other government initiatives, such as the Personal Helpers and Mentors initiative, managed through the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.

Making progress on patient-centred care in Australia

5

This section describes a range of recommendations and linked strategies that healthcare organisations could consider in their approaches to implementing patient-centred care.

Many healthcare professionals and organisations are seeking to provide care that reflects patient-centred principles; however, there is little Australian guidance on how to achieve this. Like any activity that seeks to improve quality, patient-centred care needs to be integrated into existing systems and processes at the policy, organisational and service delivery level.

Current and emerging policy points to the need for healthcare services to be patient-centred, but the 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 may struggle to engage patients and learn from their experience.[1] A range of Australian organisations are currently implementing projects that focus on different aspects of patient-centred care and are achieving positive outcomes. However, there is little guidance on how to implement patient-centred care in health services in Australia in a systematic way.

This section highlights strategies and makes recommendations that practitioners, managers and policy makers can consider using to build partnerships with patients, families, carers and consumers. Sections 5.1, 5.2 and 5.3 consider the key issues of redefining quality in health care, performance monitoring, education and research, and provide system-oriented recommendations. Section 5.4 includes service-oriented recommendations that healthcare organisations should consider when looking to design systems that are patient-centred. Organisations need to consider how these recommendations might be applied within their own context, as each organisation is unique and will have its own set of challenges and variables. 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 requires 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.[10] In contrast, patient-centred care takes a broader view. For example, the *Next Stage Review*[59] defines quality as consisting of patient safety, clinical effectiveness and patients' experience.

In the US, the Institute of Medicine report identified patient-centred care as one of six quality aims for improving care.[2] Berwick[150] 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.[150]

In Australia, it is recognised that 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.[212] Patient-centred care is now considered to be an integral dimension of quality health care in Australia; the *Australian Safety and Quality Framework for Health Care* positions patient-centred care as one of three dimensions of safety and quality (see Section 3.3).[164] 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.

5.2
PERFORMANCE MONITORING AND MEASUREMENT

All Australian states and territories 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.

Patient surveys are a commonly used method of collecting patient care experience data. Survey data is useful for monitoring care because it identifies trends and provides an overall snapshot of patient experience across the system. However, it should not be viewed as the only method; a variety of other methods for collecting patient experience data can provide a deeper level of understanding at the individual care and service levels.

Most state and territory regulators have performance improvement divisions in place that seek to facilitate the implementation of patient-centred care strategies. For example, the collection of patient experience data via patient interviews, and redesign and co-design projects has seen the implementation of significant changes to service delivery that have been driven by both patients and staff.[213]

Regulators and policy makers should continue to facilitate the implementation of a wide variety of patient experience methodologies to augment patient survey data. Information on additional ways to source patient care experience data can be found at Section 2.4.

In the US, the Institute for Patient- and Family-Centered Care (IPFCC)[155] states that processes and outcomes associated with quality, safety and experience of care should be measured 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.[155]

According to the International Alliance of Patients' Organizations,[10] 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 to achieve.

In Australia, approaches to the measurement of safety and quality in health care are increasingly being standardised across the country. Patient care experience is an essential part of safety and quality measurement,[214] and there is a need, over the medium to short term, to move towards standardised measures of patient care experience and indicators that can be used at service and policy levels nationally, across states and territories, and within health regions.

Currently, different organisations, jurisdictions and healthcare sectors use different survey tools, preventing the analysis of national-level data. To standardise patient experience data collection, the data collection tools should address the principles of patient- and family-centred care, including responsiveness, respect, information sharing and collaboration. Working towards national agreement on a set of core items that could be included in patient experience surveys would facilitate analysis of national-level data.

Steps are being made in this direction. The proposed new national-level *Performance and Accountability Framework* indicators are likely to measure traditional operational and clinical performance indicators, as well as patient-reported quality based on the patient experience.[159] These performance indicators are expected to facilitate transparent monitoring across services and jurisdictions, setting a minimum standard of healthcare quality to which each provider should adhere.[159]

Australia is also improving transparency. State and territory health departments are increasingly reporting patient survey and experience data, with survey results publicly available on departmental websites. In 2010, the New South Wales Bureau of Health Information[186] 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 to improve transparent data reporting in Australia. For example, in England, 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 (e.g. infection prevention), and outcomes of medical conditions and surgical conditions (e.g. mortality, surgical readmission rates) through the Hospital Compare website.

5.3
EDUCATION AND RESEARCH

As was noted in Part 1.5, the focus of patient-centred care is being able to take account of patients' desire for information and involvement in decision making by providing a supportive and collaborative environment.

Changes in the expectations of patients and consumers, and the dynamics of relationships between health professionals, patients, families and carers can have significant implications for the education and professional development needs of healthcare professionals.[215] To promote an approach to health care delivery in which power and decision making are shared

and face-to-face relationships are more equal, healthcare professionals need to be equipped with new skills. This may require further education and training.

Efforts to break down professional boundaries through education and training provide opportunities for the re-engineering of professional roles in ways that offer the chance to draw on interdisciplinary models of care.[215]

This approach is beginning to be adopted internationally. In Canada, the Patient-Centered Care: Better Training for Better Collaboration program, funded by Health Canada, developed the theoretical and practical basis required for healthcare professionals to work more collaboratively to ensure effective patient-centred practice. An evaluation of the program found that although the implementation of an interfaculty training curriculum on interprofessional collaborative practice is challenging in many ways, it offers a true opportunity to prepare future health professionals for contemporary patient-centred practice.[216]

If patient-centred care is to be integrated into the way the health system does business, then there is a need to ensure that healthcare professionals receive training in both the principles and application of patient-centred care in parallel to their clinical training.

A English study[217] exploring the extent to which doctors are being trained to work in partnership with patients found that patient partnership is becoming more prominent on the agenda in medical education.

Patient partnership appears in codes, statements of principle and some of the new curricula, and methods of assessing the relevant competencies are being developed. Despite promising developments in some medical schools and certain postgraduate training programs, the study found skill gaps, a general lack of awareness of needs, and few examples of good practice.[217]

The study identified a range of barriers to change, including knowledge of how best to teach skills for partnering with patients. Hasman and Coulter[217] suggest that to address this, and other challenges to partnering with patients, greater use should be made of patients as teachers. Both real and simulated patients have a potentially useful part to play in clinical education, and there is considerable scope for extending and developing their role.

> **Recommendation 7:**
> Education programs should engage patients and families as teachers and collaborators, rather than solely as cases to be studied.

Much of the research and literature on patient-centred care originates from the US or Europe. Australian research has been undertaken on different components of patient-centred care, such as communication, care coordination and methods of consumer and citizen engagement. However, not a great deal is known about the implementation of patient-centred care practices within the Australian healthcare system, including the extent to which patient-centred approaches are practiced and the effectiveness of these approaches. To advance patient-centred care in Australia, further research is needed in this area.[215]

In addition, more general emerging principles and practices for patient-centred care in the Australian context require further research and evaluation to determine best practice. This type of research can provide a basis for the development of tools, models and educational strategies to promote consistent and evidence-based patient-centred practices.

> **Recommendation 8:**
> Research funding bodies should acknowledge the importance of patient-centred care to the health system, and this should be reflected in the distribution of funding.

5.4
ORGANISATIONAL STRATEGIES

In order to successfully implement patient-centred care at the organisational level of health care, it is important that it becomes part of the way an organisation does business. Therefore, a systematic approach to integrating the principles of patient-centred care needs to be adopted across an organisation as a whole.

This section considers practical strategies that healthcare service providers can introduce to integrate patient-centred care into their governance framework. It also considers tools for assessing current care delivery. Key characteristics[15, 152] of organisations that have

successfully transformed care delivery to patient-centred care include:
» having committed senior leadership
» engaging patients, family and carers as partners
» using data to drive change, including regular collection and feedback of patient care experience
» supporting 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.

Each organisation needs to reflect on its current care provision and feedback from patients before deciding how to implement strategies to improve patient-centred care. In addition, efforts should be made to ensure that any strategies or programs that are put in place are evaluated to allow the Australian healthcare community to benefit from the experience of individual healthcare organisations.

> **Recommendation 9:**
> Healthcare service executives and managers should ensure that organisational systems and processes are designed to be patient-centred.

The importance of committed senior leadership

Schall and colleagues[218] state that one of the most important lessons learned when implementing patient-centred care at their facility 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, it is hard to deliver high-quality services.

Key characteristics of a successful patient-centred care organisation are a strategic vision and mission that clearly articulate the organisation's focus on patients, and leaders who continuously convey this message to all levels of the service.[15, 152]

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:[219] incorporating creating a vision for change, communicating the vision, removing barriers, creating short-term wins, and anchoring the change in organisational culture. Programs by organisations

such as the Studer Group (see 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, sends a clear message to an organisation about the importance of this approach.

In their own behaviours and values, leaders set the tone for implementation of patient-centred care. Building credibility as a champion of patient-centred care requires a leader to understand the hospital experience from both patient and staff perspectives. It means communicating openly, and soliciting and responding to input from staff, patients, families and others. Many leaders at patient-centred hospitals accomplish this by spending considerable time in the field, including scheduling frequent rounding on all shifts, to listen to the experiences of patients and staff first-hand.[13]

> **Recommendation 10:**
>
> 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 as well as individual care. For example, a service aiming to improve safety by partnering with individual patients may actively engage patients in handovers, ward rounds, medication and incident reviews and team practice review meetings, as well as planning and managing their own care.

Strategies for partnering with patients, families and carers at the service level include:

» partnering in service redesign and co-design projects
» engaging patients, families and carers in incident investigation systems and processes
» establishing and involving patients, families and carers in open disclosure processes following adverse events
» involving patients, families and carers in educational programs for healthcare professionals and administrative leaders
» establishing an escalation of care for deteriorating patients
» 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.

In addition, engaging patients in open disclosure processes following adverse events may not only improve the individual patient experience, but can enable overall system improvement by providing an opportunity for services to assess and review how processes and services may be improved.

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, experience-based co-design in England facilitated provision of patient feedback to the board of governors through patients telling their stories at board meetings.[220] In Canada, Patients For Patient Safety champions are appointed to consumer advisory committees of safety and quality structures,[221] and at the provincial level, patients and families are invited onto patient safety advisory committees at hospitals. In England, the *Local Government and Public Involvement in Health Act 2007*[89] 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.[152] In this regard, the Commission has developed service-level standards for healthcare providers that outline principles for partnering with patients, families and carers to improve quality of care within services. Ten NSQHS Standards have been developed as part of a model national accreditation scheme that was approved by the Australian Health Ministers' Conference in November 2010. Of these, the 'Partnering with Consumers' Standard requires the effective and meaningful engagement of consumers in organisational planning. The NSQHS Standards provide a framework for a patient-centred service culture by involving consumers in the review, design and implementation of services.

It is important to note that ensuring that individuals have the necessary skills and capacity to engage with health service providers as equal partners is critical to effective engagement. Facilitating access to relevant orientation and training for patients, families, carers

and consumers engaging in partnership with an organisation is an important step in the engagement process. All the standards developed as part of the set of NSQHS Standards need to be considered in the context of partnering with patients.

As with any new strategies to foster patient-centred care, healthcare services should be encouraged to evaluate the effect of these partnerships to help build the evidence base for partnering with patients, families and carers to improve quality of care.

Recommendation 11:
Healthcare service executives and managers should develop and implement policies and procedures for engaging patients, families and carers in their own care.

Recommendation 12:
Healthcare service executives and managers should develop and implement policies and procedures for involving patients, families, carers and consumers at a service level, in policy and program development, quality improvement, patient safety initiatives and healthcare design.

Recommendation 13:
Healthcare service executives and managers should provide support for patients, families and carers involved in governance to develop the necessary skills and capacity required for effective partnerships with their healthcare organisation.

Recommendation 14:
Healthcare service executives and managers should ensure that the service meets the National Safety and Quality Health Service 'Partnering with Consumers' Standard.

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.[24] 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[24] 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.[152]

These measures need to be complemented with patients' personal stories, which can have a direct impact on those responsible for care.[94] 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.[16, 94] Other methods for collecting care experience information include conducting focus groups, providing patient journals, having patient adviser rounds on wards, using 'mystery shoppers' who report to governance committees, and asking patients to tell their stories at executive meetings.

It is also important to ensure that surveys and other methods of collecting data on patient experience are accessible for, and applicable to, people from diverse and vulnerable populations. This includes the young, the elderly, people with a disability, Aboriginal and Torres Strait Islander peoples, and those from culturally and linguistically diverse backgrounds.

Recommendation 15:

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 16:

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 17:

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.

Recommendation 18:

Healthcare service executives and managers should provide organisational support to enable staff to partner with patients and consumers and to implement necessary changes based on that partnership.

Supporting 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,[152] 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.[152] Patient advisers in a number of US services are viewed as the force for making health care more affordable.

Examples of responsive changes[152] made by hospitals to improve patient-centred care include:
» hourly rounding by nurses 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.

Although these examples demonstrate the types of responsive changes that organisations can make, it is not an exhaustive list. Other strategies are presented in Sections 2 and 4, along with resources to help foster a patient-centred approach. Further resources, including checklists, are summarised in the appendices.

Resourcing the improvement of the quality of the physical care environment strongly correlates with improved patient care experience and other health and business outcomes.[222] The Planetree approach in the US links architecture and physical space with healing, and outlines principles for healthcare service design (see Appendix C). 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 2.4).

Building staff capacity and a supportive work environment

The strategies to support staff highlighted in Section 2, 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 some jurisdictions. For example, a Studer Group program to improve communication between staff and patients is underway in New South Wales.

According to Coulter,[223] 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 health care

» 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's skills to support patient-centred care delivery.[152] Strategies to achieve this include:
» training staff in communication skills, including skills for communicating with patients with specific communication needs
» adopting communication techniques such as AIDET (Acknowledge, Introduce, Duration, Explanation, Thank you)
» training all staff in patient-centred values and customer service techniques
» tailoring the workforce through selection of staff committed to the mission of the organisation
» integrating discussion of patient-centred values into staff orientation sessions (e.g. 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 in which 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 work environment for staff 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.[152] This approach recognises that the workforce is the healthcare service's most important asset, and aligns with the move towards 'person-centred' organisations in which both patients and staff are valued.[15] 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.[224]

> **Recommendation 19:**
> Healthcare service executives and managers should support staff through training and education activities tailored to building the capacity of all staff to deliver patient-centred care.

> **Recommendation 20:**
> 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 the 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 the patient care experience.[152] 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 patients' experience of care
» 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, such as '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 board or governance committee meetings includes a strong emphasis on reviewing quality issues and quality performance data, including patient care experience.[152, 225]

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 21:**
> 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 supporting change and improvement.[152] 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 improve the capabilities of those who work with it or for it, to achieve sustainable objectives.[226] 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 to organisational performance.

Learning organisations are also open to learning from past failures.[227] 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 or severe harm of a patient during care. Such tragic events can cause an organisation to examine its own values and 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 22:**
> 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.

Acronyms and abbreviations

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

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Appendix A
Assessing organisational readiness to implement patient-centred care

Appendix A contains two tools that may assist health services to analyse their own needs regarding patient-centred care practices.

» **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 from the Institute for Patient- and Family-Centered Care (IPFCC) entitled Where Do We Stand? An Assessment Tool for Hospital Trustees, Administrators, Providers and Patients and Family Leaders.

CHECK YOUR ORGANISATIONAL READINESS FOR IMPROVING PATIENT CARE EXPERIENCE:

Question 1. Are you collecting patient care experience data?   Y / N

Question 2. How are you collecting patient care experience data?

....

Question 3. Why are you collecting patient care experience data?

....

Question 4. How often are you collecting patient care experience data?

....

Question 5. How are you using the data/information collected?

....

Question 6. Is the data about patient care experience being reported?   Y / N

Question 7. To whom is it being reported?

....

Question 8. Is staff satisfaction monitored?   Y / N

Question 9. Is there a 'scorecard' of performance metrics monitored by the organisation?   Y / N

Question 10. Does the scorecard/set of metrics include patient care experience indicators?   Y / N

Question 11. What is the mission/vision of the organisation?

....

Question 12. What is the main message to staff from the leadership? CEO? Organisational governance?

....

Question 13. Is the culture of the organisation supportive of change? Open to learning?   Y / N

Question 14. Are successes by staff visibly celebrated?   Y / N

Question 15. What is the current area of focus for staff development?

....

Question 16. Have staff training activities included communication skills training   Y / N
or patient-centred values?

Question 17. Are patients and families considered 'partners' in care?   Y / N

Question 18. Are any patient or family/carer representatives involved in any organisational committees?   Y / N

Question 19. Are there any future plans for engaging patients at a service level within the organisation?   Y / N

Question 20. Have there been any tragic events within the service from which lessons have been learnt?   Y / N

Question 21. What did the organisation learn from these events?

....

Question 22. Are families/carers considered 'visitors' to the service (e.g. restricted 'visiting' hours)?   Y / N

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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
Select annotated bibliography

This annotated bibliography contains most of the citations from Section 1.3 regarding the evidence for patient-centred care.

The bibliography provides more information for individuals who may need to make a business case or support the development or implementation of patient-centred care strategies. The cited papers provide evidence about the relationship between patient-centred approaches and outcomes related to clinical quality, the experience of care, the business and operation of delivering health services, and the work environment. Citations from Section 1.3 that have not been published in peer-reviewed journals are not included in this bibliography.[42, 56–57]

Arbuthnott A, Sharpe D. The effect of physician–patient collaboration on patient adherence in non-psychiatric medicine. *Patient Education and Counselling* 2009;77:60–67.[47]

Type of study: Meta-analysis.

Aims and methods: To investigate the effect of physician–patient collaboration in non-psychiatric patient treatment adherence. An initial search of the Cochrane, Medline and PsycInfo databases using the keywords 'adherence', 'compliance', 'nonadherence' and 'noncompliance' was conducted. Studies eligible for inclusion were published in English between 1968 and 2007, and fulfilled the following three criteria: (i) measured some aspect of physician–patient collaboration (e.g. communication, satisfaction with degree of involvement); (ii) had patient adherence as an outcome variable; (iii) comprised a non-psychiatric sample.

Results and analysis: Data from 48 studies (n = 34 000 patients) were included in the meta-analysis. Patients had a range of illnesses, including asthma, bacterial infection, breast cancer, congestive health failure, diabetes, fibromyalgia, HIV, hypertension, inflammatory bowel disease, renal disease and tuberculosis. Patient–physician interaction was found to be associated with patient adherence (M_d = 0.145).

Limitations: The authors acknowledged the following limitations: (i) study designs and research questions varied; (ii) few studies were found measuring only a single aspect of collaboration; (iii) the inclusion of both observational and interventional studies was necessitated by the interdisciplinary nature of the question.

Conclusions: Strong patient–physician collaboration is associated with adherence to treatment.

Arnetz JE, Winblad U, Höglund AT, Lindahl B, Spångberg K, Wallentin L, et al. Is patient involvement during hospitalization for acute myocardial infarction associated with post-discharge treatment outcome? An exploratory study. *Health Expectations* 2010; 13(3):298–311.[37]

Type of study: Self-administered questionnaire.

Aims and methods: To investigate whether there is an association between patients' perceptions of their involvement during hospitalisation for acute myocardial infarction (AMI), and their health (e.g. shortness of breath) and behavioural (e.g. medication compliance) outcomes 6–10 weeks after hospital discharge. Cardiac patients attending their first follow-up visit were invited to complete a 53-item, forced-choice questionnaire rating their involvement on four-point Likert scales.

Results and analysis: Questionnaires were completed by 591 patients (age ≤75 years). Responses to questionnaire items were compared against ten medical and behavioural outcome variables from a national database of cardiac patients.

Limitations: Database follow-up information was missing for nearly one-quarter (n = 142) of questionnaire respondents, meaning their health outcomes were unknown. There was inconsistency in the timing of initial follow-up visits, so the time that patients received the questionnaire varied.

Conclusions: Higher ratings of patient involvement appear to be related to experiencing fewer cardiovascular symptoms (i.e. angina and shortness of breath). Patient ratings of involvement in care do not appear to be related to medication compliance.

Beach CM, Sugarman J, Johnson RL, Arbaleaz JJ, Duggan PS, Cooper LA. Do patients treated with dignity report higher satisfaction, adherence and receipt of preventive care? *Annals of Family Medicine* 2005;3(4):331–338.[52]

Type of study: Cross-sectional analysis using data from the Commonwealth Fund 2001 Health Care Quality Survey.

Aims and methods: To assess the association between two measures of respect (treating patients with dignity and involving them in decision making) and positive patient outcomes (satisfaction, adherence and optimal use of preventive health care).

Results and analysis: Data from 5514 respondents who reported a medical encounter in the previous two years were used in analyses. Separate logistic regression analyses were conducted to investigate the association of the two measures of respect with the three outcome variables, in adjusted and unadjusted models. Patients who were treated with dignity or involved in decision-making were more likely to report a higher level of satisfaction, but there were no significant differences between the groups in the probability of receiving optimal preventive care.

Limitations: As with all cross-sectional analyses, no conclusions regarding causality can be drawn. The modest response rate (54 per cent) means a response bias is possible. Recall bias may also have influenced findings, as patients were asked to think back over a two-year period.

Conclusions: Involvement in decisions and being treated with dignity are independently associated with positive outcomes, including patient satisfaction and adherence benefits.

Boulding W, Glickman S, Manary M, Schulman K, Staelin R. Relationship between patient satisfaction with inpatient care and hospital readmission within 30 days. *American Journal of Managed Care* **2011;17(1):41–48.**[41]

Type of study: Observational analysis comparing clinical performance, patient satisfaction and 30-day risk standardised readmission rates for three clinical outcomes (acute myocardial infarction, heart failure and pneumonia).

Aims and methods: To investigate whether patient satisfaction with inpatient care and discharge planning is associated with lower 30-day readmission rates for the three clinical outcomes. Data about readmission rates were sourced from Hospital Compare (for the period July 2005–June 2008). Data about patients' perceptions were sourced from the Hospital Care Quality Information from the Consumer Perspective database.

Results and analysis: Patients' overall satisfaction ratings and perceptions regarding the discharge process were negatively associated with 30-day readmission rates for acute myocardial infarction, heart failure and pneumonia. Satisfaction was strongly correlated with perceptions of quality of communication with nursing staff.

Limitations: The cross-sectional design means causality cannot be inferred. The authors acknowledge that it is possible that some patients were readmitted before completing the survey.

Conclusions: Patient experience data should be used to complement objective clinical measures in assessments of quality of health care.

Charmel P, Frampton S. Building the business case for patient-centered care. *Healthcare Financial Management* **2008;62(3):80–85.**[54]

Type of study: Discussion paper about patient-centred care.

Aims and methods: To present the argument that patient-centred care is fundamental to providing high-quality care. Patient-centred care encourages patients to be actively involved in their own care. Providing comfort through a sensitive organisational culture, a home-like physical environment, good nutrition and staff who are sensitive to patient's physical, emotional and spiritual needs is the essence of patient-centred care.

Content and scope: The authors describe the conception of Planetree 30 years ago. Planetree is a not-for-profit organisation dedicated to helping healthcare facilities achieve patient-centred care. The introduction of value-based purchasing in the US was anticipated to lead to healthcare facilities receiving reimbursement if they were able to demonstrate patient-centred care through providing excellent clinical outcomes and patient experiences.

Limitations: One of the authors is the president of Planetree, which may introduce bias.

Conclusions: Adopting a patient-centred care approach makes good business sense, as it is expected that consumers will be drawn to facilities that offer personalised care and value for money.

DiGioia AI, Greenhouse PK, Levison TJ. Patient and family-centered collaborative care: an orthopaedic model. *Clinical Orthopaedics and Related Research* **2007;463:13–19.**[229]

Type of study: Prospective data collection from patient-reported forms and the hospital's health management database; no exclusion criteria.

Aims and methods: To investigate patient- and family-centred collaborative care among orthopaedic patients in the Total Joint Replacement Program at the University of Pittsburgh Medical Center in the US. Participants were 618 consecutive patients undergoing hip or knee surgery. Patient satisfaction was measured by a national survey (Press Ganey Survey) and an internally developed survey.

Results and analysis: The authors describe the patient- and family-centred collaborative care process for total joint replacement in their program. Patient overall satisfaction ratings for the program were very high, with a mean rating of 91.4. Patient- and family-centred collaborative care was perceived as worthy by patients, with 99.7 per cent reporting that they would refer others to the program.

Limitations: There was no control group and most comparisons were made against national data. Baseline data from the hospital were not presented; therefore, it was unclear if improvements had been made.

Conclusions: Adopting a patient- and family-centred collaborative care approach can improve quality of health care, but requires reorganisation and restructuring of existing care delivery programs. However, this need not be complicated, expensive or highly technological. The authors also emphasise the importance of involving staff from all relevant departments, as well as the need for encouragement and support from hospital leadership.

Edgcumbe D. Patients' perceptions of hospital cleanliness are correlated with rates of methicillin-resistant *Staphylococcus aureus* bacteraemia. *Journal of Hospital Infection* 2009;71(1):99–101.[44]

Type of study: Letter to the editor briefly detailing an observational analysis.

Aims and methods: To investigate the association between patients' perceptions of hospital cleanliness and rates of methicillin-resistant *Staphylococcus aureus* (MRSA) bacteraemia, using two publicly available data sources. Data relating to patient's perceptions came from Question 19 of the Healthcare Commission patient survey, which asked, 'In your opinion, how clean was the ward that you were in?' Response options were 'very clean', 'fairly clean', 'not clean' or 'not at all clean'. Bacteria rates, expressed as the number of MRSA bacteraemia reported per 1000 bed-days, were obtained from the Health Protection Agency's mandatory reporting scheme.

Results and analysis: A statistically significant correlation (−0.384; P < 0.01) was found, suggesting that patients' perceptions of hospital cleanliness is related to MRSA rates.

Limitations: No limitations were identified by the author. Findings were in opposition to another study, which did not find that perceptions of cleanliness correlated with rates of MRSA bacteraemia; however, the author was unable to explain this discrepancy.

Conclusions: There is a paucity of research into the link between patients' perceptions of hospital cleanliness and clinical outcomes: in particular, hospital acquired infections. The author recommends that research be conducted to investigate this topic.

Epstein RM, Franks P, Shields CG, Meldrum SC, Miller KN, Campbell TL et al. Patient-centred communication and diagnostic testing. *Annals of Family Medicine* 2005;3(5):415–421.[49]

Type of study: Observational cross-sectional study using patient surveys and audio recordings of clinical visits.

Aims and methods: To investigate the relationship between patient–physician interaction style and diagnostic test expenditure. Physicians (n = 100) were covertly recorded on two separate occasions, by standardised patients wearing concealed audio recorders. Information about diagnostic testing costs for each physician and their real patients was extracted from a managed-care claims database.

Results and analysis: Audio recordings were scored using the Measure of Patient-Centred Communication. Higher (better) scores were associated with lower diagnostic testing expenditure and longer consultations.

Limitations: Measure of Patient-Centred Communication scores were restricted to only two patient visits, as this was the maximum number of standardised patients that physicians would consent to seeing.

Conclusions: The links between patient-centred communication, consultation length and diagnostic testing expenditures may affect the willingness of health systems to endorse such an approach. Confirmation of results in randomised trials is warranted.

Flach SD, McCoy KD, Vaughn TE, Ward MM, BootsMiller BJ, Doebbeling BN. Does patient-centered care improve provision of preventive services? *Journal of General Internal Medicine* 2004;19(10):1019–1026.[45]

Type of study: Observational data analysis.

Aims and methods: To investigate the relationship between patient-centred care and preventive service delivery using data from three national surveys. Eight domains of patient-centred care were measured, including access to care, inclusion of patient preferences, provision of patient education, coordination of visitors, coordination of care, courtesy, continuity of care and emotional support. Scores on the domains were compared against benchmarking scores on 12 preventive activities: (1–3) screening for hypertension, alcohol abuse and seat belt use; (4–6) counselling to quit smoking, increase physical activity and lose weight; (7–8) ordering tests for cholesterol and faecal occult blood; (9–12) ordering vaccinations against tetanus, influenza and pneumococcal infection, and undergoing flexible sigmoidoscopy.

Results and analysis: Patient-centred care data were sourced from the Veterans' Satisfaction Survey and data about receipt of preventive activities were sourced from the Veterans' Health Survey. Counselling about smoking cessation and ordering faecal occult blood tests were most strongly related to some of the patient-centred care components.

Limitations: The value that physicians place on preventive activities, and how this may affect initiation of the activity, is unknown. The accuracy of patients' self-reports of receiving preventive activities was not verified.

Conclusions: Some patient-centred care components are associated with hospital preventive activities.

Fremont AM, Cleary PD, Lee Hargraves J, Rowe RM, Jacobson NB, Ayanian JZ. Patient-centered processes of care and long-term outcomes of myocardial infarction. *Journal of General Internal Medicine* 2001;16(12):800–808.[38]

Type of study: Observational cohort study.

Aims and methods: To investigate the association between patients' experiences with nontechnical aspects of care, and health status and cardiac symptoms (overall health, physical health status, mental health status, presence of chest pain, shortness of breath) one year post-discharge. Participants (n = 2272) were inpatients with AMI recruited from 23 New Hampshire hospitals. Surveys posted at 1, 3 and 12 months after discharge were completed by 59.2 per cent (n = 1346), 46 per cent (n = 1046) and 42.4 per cent (n = 964) of participants, respectively. Primary analyses were conducted with data of the 762 patients who returned both the 1-month and the 12-month surveys.

Results and analysis: Patients returning surveys with lower ratings of experiences with care were more likely to report lower overall health and physical health; chest pain at 12 months was also more likely for these patients. However, this association may be offset by positive outpatient experiences.

Limitations: It is unclear if these findings can be generalised beyond AMI to other conditions. Data were incomplete for patients who died within the 12-month follow-up period, which reduced the number available to analyse.

Conclusions: Nontechnical processes of AMI hospital care are associated with long-term outcomes. Positive outpatient experiences may offset negative hospital experiences, for at least one outcome (chest pain at 12 months).

Glickman SW, Boulding W, Manary M, Staelin R, Roe MT, Wolosin RJ, et al. Patient satisfaction and its relationship with clinical quality and inpatient mortality in acute myocardial infarction. *Circulation: Cardiovascular Quality and Outcomes* 2010;3:188–195.[39]

Type of study: Observational analysis.

Aims and methods: To investigate the relationship between patient satisfaction, hospital clinical quality and mortality in patients with AMI. Patient satisfaction data came from surveys sent to patients within a week of discharge from hospital. Clinical process-of-care data were sourced from a registry (CRUSADE) comprising inpatient care and outcomes pertaining to specific cardiac conditions.

Results and analysis: Surveys from 3562 patients and clinical data from 6467 patients were used in analyses. Even when clinical performance was controlled for, higher hospital-level patient satisfaction was associated with lower inpatient mortality rates.

Limitations: Only data from hospitals contributing to CRUSADE were analysed, which may introduce bias. It is unclear if findings can be generalised beyond AMI to other conditions. Data were incomplete for patients who died during their hospitalisation, which reduced the number of satisfaction surveys.

Conclusions: Patients' levels of satisfaction should be considered a source of information on quality of care, as higher patient satisfaction is associated with improved guideline adherence and lower inpatient mortality.

Isaac T, Zaslavsky AM, Cleary PD, Landon BE. The relationship between patients' perception of care and measures of hospital quality and safety. *Health Services Research* 2010;45(4):1024–1040.[33]

Type of study: Secondary data analysis.

Aims and methods: To examine the relationship between patient experience and other measures of hospital safety and quality. Data from three sources were compared: patient experience data from Hospital Consumer Assessment of Healthcare Providers and Systems national database; and process of care measures from the Hospital Quality Alliance and Patient Safety Indicators to measure medical and surgical complication rates, sourced from Medicare claims data.

Results and analysis: The overall rating of the hospital and readiness to recommend the hospital, as rated by patients, were associated with technical quality of care for pneumonia, congestive heart failure, myocardial infarction and surgical care.

Limitations: The Hospital Quality Alliance measures, while widely used and accepted, are only a subset of medical and surgical care measures. The validity of patient safety indicators as safety measures has not been established.

Conclusions: Patient experience data are associated with some technical quality of care and hospital safety measures (as measured by patient safety indicators).

Jha AK, Orav EJ, Zheng J, Epstein AM. Patients' perception of hospital care in the United States. *New England Journal of Medicine* **2008;359(18):1921–1931.**[34]

Type of study: Secondary analysis of data from the Hospital Consumer Assessment of Healthcare Providers and Systems (H-CAHPS) survey.

Aims and methods: To investigate whether key hospital characteristics believed to improve patients' experiences (high ratio of nurses to patient days, being for-profit and not a teaching hospital) are associated with patient satisfaction. Data collected by the H-CAHPS survey about patients' experiences were linked with data about a range of key hospital characteristics collected annually by the American Hospital Association.

Results and analysis: Higher ratios of nurses to patient days predicted higher (better) patient experience scores. Hospitals that provided higher quality care also received higher patient satisfaction ratings. However, patients in for-profit hospitals gave lower satisfaction scores than patients in either private or public not-for-profit hospitals. Patients' ratings were not associated with whether they were in a teaching or non-teaching hospital.

Limitations: There is a possible nonresponse bias, as data were not provided by approximately 40 per cent of US hospitals.

Conclusions: High nurse to patient ratios appear to be associated with better patient experiences. Higher quality of care is also associated with greater patient satisfaction.

Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C et al. Observational study of effect of patient-centeredness and positive approach on outcomes of general practice consultations. *British Medical Journal* **2001;323:908–911.**[50]

Type of study: Observational study using pre-consultation and post-consultation questionnaires

Aims and methods: This study investigated patients' perceptions of patient-centredness and the relationship to, and ability to predict, three patient outcomes (enablement, satisfaction and burden of symptoms). Patients from three general practices were approached consecutively and invited to complete pre-consultation and post-consultation questionnaires. The questionnaires were designed to assess patients' expectations of what the doctor would do during the consultation, and tapped into five domains of patient-centredness: 'exploring the disease and illness experience, understanding the whole person, finding common ground, health promotion and enhancing the doctor–patient relationship'.

Results and analysis: A total of 865 patients consented and 661 (76 per cent) completed both questionnaires using seven-point Likert scales to rate how much they agreed or disagreed (very strongly agree to very strongly disagree) with each statement. The postconsultation questionnaire included items relating to the three outcome measures, reasons for consultation and demographic information.

Limitations: The study design precluded any conclusions regarding cause and effect, and the authors recommended the conduct of randomised trials or cohort studies with a homogenous sample. Patients wanted doctors to provide a patient-centred approach to care, and those who did not receive this were less satisfied, less enabled and may have had a greater symptom burden.

Conclusions: There are five components of patients' perceptions that can be reliably measured: communication and partnership; personal relationship; health promotion; positive approach to diagnosis and prognosis and interest in the effect on life. Measurement of these markers can indicate the quality of care.

Meterko M, Wright S, Lin H, Lowy E, Cleary PD. Mortality among patients with acute myocardial infarction: The influences of patient-centered care and evidence-based medicine. *Health Services Research* **2010;45(5p1):1188–1204.**[40]

Type of study: Secondary data analysis of the Veterans Affairs Survey of Healthcare Experiences of Patients.

Aims and methods: To examine the association between patient-centred care and technical care quality on one-year mortality among patients with AMI. Patient assessments of patient-centred care were from the national Veterans Affairs Survey of Healthcare Experiences of Patients, which was administered to veterans who had been hospitalised with AMI. Data on 14 measures of technical quality of care were obtained through a medical record review.

Results and analysis: Higher patient-centred care ratings were modestly associated with lower hazard of death one year after the AMI.

Limitations: As the sample was predominantly male and all participants were veterans, it is unclear if these findings can be generalised to other AMI patients. Only data from AMI patients with survey scores were analysed. This creates a response bias, as those missing survey data were an average of two years older. This has particular implications to the finding that increased age was significantly associated with higher risk of one-year mortality.

Conclusions: Providing patient-centred care may result in important clinical outcomes, such as a reduced risk of death one year post-hospitalisation for AMI among veterans.

Schneider EC, Zaslavsky AM, Landon BE, Lied TR, Sheingold S, Cleary PD. National quality monitoring of Medicare Health Plans. *Medical Care* 2001; 39:1313–1325.[36]

Type of study: Observational cohort study.

Aims and methods: To examine the relationships between reports on the quality of healthcare plans as measured by two publicly available measurement systems: the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey and the Health Plan–Employer Data and Information Set (HEDIS). CAHPS and HEDIS collect unique data. However, it would be expected that some data would be complementary; that is, ratings of experiences about a health plan (collected through CAHPS) may be related to some clinical measures (collected through HEDIS). Data from five composite measures and four ratings from CAHPS, and six measures of clinical quality from HEDIS, were compared.

Results and analysis: CAHPS items 'getting needed care' and 'health plan information and customer service' were positively and significantly associated with all HEDIS measures, except for the proportion of individuals who continued antidepressant medications after commencing treatment. In this group, health plan information and customer service was the most important factor.

Limitations: Not all HEDIS plans were complete, which could have implications for the power of the study.

Conclusions: Patient experience ratings relating to access to care and customer service provide markers for some measures of health plan quality.

Schneider J, Kaplan SH, Greenfield S, Li W, Wilson IB. Better physician–patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. *Journal of General Internal Medicine* 2004;19:1096–1103.[53]

Type of study: Cross-sectional analysis.

Aims and methods: To investigate the aspects of physician–patient interactions associated with high adherence to antiretroviral medication regimens in individuals with HIV infection. Patients with normal cognitive function who could read English were recruited from 22 outpatient HIV practices in metropolitan Boston. Patients completed six previously evaluated scales to assess the quality of interactions with their physician: (1) general communication;

(2) provision of HIV-specific information; (3) decision-making style; (4) global satisfaction with care; (5) readiness to recommend physician to others; and (6) trust. A seventh item was developed by the authors that assessed patients' perceptions of their physician's ability to help them adhere to their medication regimens. Adherence to medication was obtained through four items with Likert-type response options.

Results and analysis: Analyses were conducted on data from 552 patients who completed a patient–physician interaction questionnaire, were using antiretrovirals and had an adherence score. Of the seven measures of patient–physician interaction, six were independently associated with adherence score. Decision-making style was the only measure that was not significantly associated; however, a trend towards significance was reported.

Limitations: Adherence was assessed via self-reporting, and may therefore have been overestimated.

Conclusions: Multiple measures of interpersonal care show that better physician–patient relationships and physician–patient communication can produce better adherence with antiretroviral therapies.

Sequist TD, Schneider EC, Anastario M, Odigie EG, Marshall R, Rogers WH et al. Quality monitoring of physicians: linking patients' experiences of care to clinical quality and outcome. *Journal of General Internal Medicine* 2008;23(11):1784–1790.[35]

Type of study: Observational study.

Aims and methods: To examine the association between clinical performance (processes of care and outcomes of care) and patient experiences of care. Patient ratings of experience with physicians were obtained from the Ambulatory Care Experiences Survey instrument. Individual physician performance data were derived from an electronic medical record system containing clinician notes, laboratory reports, and diagnostic and procedure codes.

Results and analysis: Scores (0–100) for patient experience and clinical quality measures were calculated and correlations conducted. Clinical measures of care (cholesterol management, poor HbA1c control, LDL cholesterol control and control of high blood pressure) were not significantly associated with patient experiences of care.

Limitations: Data used were from five major health plans in Massachusetts; therefore, the ability to generalise the results may be limited.

Conclusions: Patient experiences data are not correlated with clinical outcomes and are only modestly correlated with clinical process measures.

Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston W et al. The impact of patient-centred care on outcomes. *Journal of Family Practice* 2000;49(9):796–804.[51]

Type of study: Observational cohort study.

Aims and methods: To investigate whether patients who experienced patient-centred communication at an initial consultation would, two months later, experience faster recovery, better self-reported health and less subsequent medical care. Participants included 39 family physicians and 315 patients. Adult patients with one or more recurring problems were approached in physician practices and invited to participate. Consultations were audio recorded and later scored for three components of patient-centred communication: (1) extent to which disease and illness experience was explored; (2) extent to which physician attempted to understand the whole person; (3) extent to which the physician attempted to find common ground. Participants were interviewed by a research assistant to investigate how patient-centred they perceived the consultation to be. Medical care during the two-month follow up was assessed by chart review and a telephone interview with the patient.

Results and analysis: Patient-centred communication scores (from audio recordings) were not significantly related to any of the health outcomes (recovery, health status) or medical care outcomes (total number of visits over two months, diagnostic tests ordered over two months, and number and type of referrals made over two months). Patient-centred communication scores (from audio recordings) were significantly correlated ($r = -0.16$) with patients' perceptions that they and the physician had found common ground. Patients who perceived their visit as patient-centred received fewer diagnostic tests and referrals in the following two months.

Limitations: Approximately 30 per cent of patients approached did not consent. Male patients were overrepresented; however, gender was not identified as a confounding factor.

Conclusions: Doctors should not underestimate the value of attempting to find common ground with a patient. The mechanism(s) by which patient-centred communication and efficiency of care (reduced diagnostic tests and referrals) are associated requires further study.

Stone S. A retrospective evaluation of the impact of the Planetree patient-centered model of care on inpatient quality outcomes. *Health Environments Research and Design Journal* 2008(summer):55–69.[46]

Type of study: Retrospective quasi-experimental study.

Aims and methods: To evaluate the Planetree patient-centred model of care, specifically the impact on patient satisfaction, clinical outcomes (length of stay and readmission) and care costs (per case and productive nursing hours per patient day). Adult patients (mean age 67.33, range 40–88 years) who had undergone primary elective surgical knee or primary hip total joint replacement between 2002 and 2006 were recruited from two hospitals. The treatment sample (n = 587) came from a 30-bed medical/surgical telemetry unit that had followed the Planetree model of patient-centred care since 2002. The control sample (n = 282) came from a 22-bed surgical telemetry unit, located within another hospital 15 miles away.

Results and analysis: Length of stay was significantly shorter at the Planetree facility (mean 3.26 vs 3.51 days), and cost per case was significantly lower (mean $5732.91 vs $7823.20) each year from 2002 to 2006. Patient satisfaction with their physician was significantly higher in the control unit. The authors noted that more Planetree patients than comparison patients were assigned to their physician, and this lack of choice may partially explain this difference.

Limitations: Sample sizes were uneven between groups (587 vs 282) because of the lower return of satisfaction groups in the control unit. Raw data regarding productive nursing hours were not available, limiting the analyses to summarisation and discussion of general differences only. No data for this variable were available for the year 2002 in the control unit. Health status was self-reported by patients and not independently verified.

Conclusions: A Planetree patient-centred model of care may positively influence patients' level of satisfaction, and reduce length of stay and cost per case.

Sweeney L, Halpert A, Waranoff J. Patient-centered management of complex conditions can reduce costs without shortening life. *American Journal of Managed Care* 2007;13:84–92.[55]

Type of study: Prospective cohort study.

Aims and methods: To examine the effect of intensive patient-centred management on patient access of key healthcare resources (i.e. admissions, inpatient days, emergency room visits, rehabilitation days, hospice days and home care days) and patient outcomes. Patients (n = 756) with a terminal diagnosis and multiple comorbidities (75% were oncology patients) were included in the patient-centred management intervention cohort (n = 358) or usual case management cohort (n = 398) based on their health plan membership. Each patient-centred management patient had a care team comprising a case manager, team leader and a physician. The care team met weekly to provide advice, ongoing assessment, anticipate medical problems, liaise with the patient's treating physician and suggest alternative treatment plans if appropriate. Goals were set with patients in an initial home visit, and patient-centred management ended when patients achieved their goals.

Results and analysis: Substantial reductions in hospital admissions (38 per cent), hospital days (36 per cent) and emergency visits (30 per cent) were noted among the patient-centred management group. Increase in use of hospices (62 per cent) and home care (22 per cent) were also noted. Cost analysis suggested an average saving of US$18 599 per patient when patient-centred management was used. Chemotherapy and radiation rates were higher among oncology patients in the usual care group than in the patient-centred management group. Membership of the patient-centred management group was also associated with lower inpatient symptoms, including nausea, anaemia, fluid disorder and fever.

Limitations: The authors minimised the possibility of allocation bias by conducting intent-to-treat analyses.

Conclusions: Patient-centred management was associated with reduced costs, lower rates of admissions, fewer days in hospital, and more home care and hospice days.

Weingart SN, Zhu J, Chiapetta L, Stuver S, Schneider E, Epstein AM, et al. Hospitalized patients' participation and its impact on quality of care and patient safety. *International Journal for Quality in Health Care* 2011; 13(3):269–267.

Type of study: Observational study using random sample telephone interview and medical chart review.

Aims and methods: To investigate the extent of hospitalised patients' participation in their own care, and associations between participation, quality of care and patient safety. Patients who had been hospitalised in the last 6–12 months underwent a telephone interview about their hospitalisation and any complications, and were asked seven questions about their level of participation while in hospital. Of the 2025 included respondents, 788 also had their medical charts reviewed to identify adverse events.

Results and analysis: Almost all patients (99.9%) reported at least one participatory activity. Patients who reported five or more of the seven forms of participation consistently gave higher ratings for quality of care and were less likely to experience an adverse event.

Limitations: The authors point out several study limitations, including that patients who died during hospitalisation or before the survey were not included, and sicker patients may be less likely to participate in their care. Nonresponse and recall biases are possible.

Conclusions: Most hospitalised patients participate in their care. Higher participation correlates with favourable ratings for quality of care and reduced adverse events.

Appendix C
Supportive resources

This appendix provides links to key organisations and resources relevant to patient-centred care approaches and strategies.

C1.
KEY ORGANISATIONS

Links to leading international organisations that focus on patient-centred approaches to care, as well as Australian organisations that are also beginning to focus on patient-centred care are listed below.

Leading international organisations

Dana-Farber Cancer Institute
www.dana-farber.org

Institute for Healthcare Improvement
www.ihi.org

Institute for Patient- and Family-Centered Care
www.ipfcc.org

Kenneth B Schwartz Center
www.theschwartzcenter.org

The King's Fund
www.kingsfund.org.uk

Picker Institute
www.pickerinstitute.org

Picker Institute Europe
www.pickereurope.org

Planetree
www.planetree.org

Studer Group
www.studergroup.com

World Health Organization — Patients for Patient Safety
www.who.int/patientsafety/patients_for_patient/statement/en

Key Australian organisations

Australian Institute for Patient and Family Centred Care
www.aipfcc.org.au

Australian organisations for health consumers

Carers Australia
www.carersaustralia.com.au

Centre for Health Communication and Participation
www.latrobe.edu.au/chcp

Cochrane Consumers and Communication Review Group
www.latrobe.edu.au/chcp/cochrane

Cochrane Consumer Network
www.cochrane.org/consumers

Consumers Health Forum of Australia
www.chf.org.au

Health Care Consumers' Association of the ACT
www.hcca.org.au

Health Consumers Alliance of South Australia Inc.
www.hcasa.asn.au

Health Consumers' Council (WA) Inc.
www.hconc.org.au

Health Consumers NSW
Email hcnsw@internode.on.net

Health Consumers Queensland
www.health.qld.gov.au/hcq

Health Consumers of Rural and Remote Australia Inc.
www.ruralhealth.org.au

Health Issues Centre Inc. (Victoria)
www.healthissuescentre.org.au

National, state and territory government organisations and programs

Department of Health and Ageing
www.health.gov.au

Department of Health and Ageing — National Primary Health Care Strategy
www.health.gov.au/primaryhealthstrategy

Department of Health and Ageing — National Chronic Disease Strategy and National Service Improvement Framework
www.health.gov.au/internet/main/publishing.nsf/content/7E7E9140A3D3A3BCCA257140007AB32B/$File/strata13.pdf

Department of Health and Ageing — Fourth National Mental Health Plan
www.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-f-plan09-toc

Department of Health and Ageing — Fifth Community Pharmacy Agreement
www.health.gov.au/internet/main/publishing.nsf/Content/fifth-community-pharmacy-agreement-copy

Australian Commission on Safety and Quality in Health Care
www.safetyandquality.org.au

New South Wales

Health Care Complaints Commission
www.hccc.nsw.gov.au

NSW Bureau of Health Information
www.bhi.nsw.gov.au

NSW Clinical Excellence Commission
www.cec.health.nsw.gov.au

NSW Health
www.health.nsw.gov.au

NSW Health Essentials of Care program
www.health.nsw.gov.au/nursing/projects/eoc.asp

NSW Health Patient and Carer Experience
www.health.nsw.gov.au/performance/pcexperience.asp

NSW Health Patient Survey
www.health.nsw.gov.au/hospitals/patient_survey

NSW Health 'Take the Lead' project
www.health.nsw.gov.au/nursing/projects/take_the_lead.asp

Australian Capital Territory

ACT Health Services Commissioner
www.hrc.act.gov.au/content.php/content.view/id/6

ACT Health
www.health.act.gov.au/c/health?a=da&did=11143891&pid=1288659671

ACT Health Healthcare Survey
www.health.act.gov.au/c/health?a=da&did=10101609&pid=1254789026

ACT Health Access Improvement Program
www.health.act.gov.au/c/health?a=&did=10109188

Queensland

Health Quality and Complaints Commission
www.hqcc.qld.gov.au

Queensland Health
www.health.qld.gov.au

Queensland Health Healthcare Experience Improvement Program
www.health.qld.gov.au/cpic/hlthcr_exp_improve/hlthcr_exp_improve.asp

Queensland Health Patient Satisfaction Survey
www.health.qld.gov.au/quality/pat_sat_survey/patsat.asp

Queensland Health Redesign Projects
www.health.qld.gov.au/cpic/service_improve/projects.asp

Victoria

Health Services Commissioner
www.health.vic.gov.au/hsc

Victorian Department of Health
www.health.vic.gov.au

Victorian Department of Health — Improving the Patient Experience Program
www.health.vic.gov.au/managementinnovation/resources

Victorian Department of Health — Victorian Patient Satisfaction Monitor
www.health.vic.gov.au/patsat

Victorian Quality Council
www.health.vic.gov.au/qualitycouncil/activities

Northern Territory

Health and Community Services Complaints Commission
www.hcscc.nt.gov.au

Northern Territory Department of Health and Families
www.health.nt.gov.au

South Australia

Health and Community Services Complaints Commissioner
www.hcscc.sa.gov.au

SA Health
www.sahealth.sa.gov.au

SA Health Patient Evaluation of Health Services Survey
www.health.sa.gov.au/pros/Default.aspx?PageContentMode=1&tabid=44

Tasmania

Health Complaints Commissioner Tasmania
www.healthcomplaints.tas.gov.au

Department of Health and Human Services Tasmania
www.dhhs.tas.gov.au

Western Australia

Western Australian Office of Health Review
www.healthreview.wa.gov.au

WA Health
www.health.wa.gov.au

WA Office of Safety and Quality in Healthcare & Patient First program
www.safetyandquality.health.wa.gov.au/involving_patient/patient_1st.cfm

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

C2.
KEY RESOURCES AND TOOLS

A variety of online international and Australian resources, including assessment tools and checklists for health service providers, are listed below.

General patient-centred care strategies and approaches

Partnering with Patients and Families to Design a Patient and Family-Centred Health Care System — Recommendations and Promising Practices (2008)
www.ihi.org/IHI/Topics/PatientCenteredCare/PatientCenteredCareGeneral/Literature/
PartneringwithPatientsandFamilies.htm

A comprehensive review of the worldwide evidence of what works to engage patients and the public in healthcare
www.investinengagement.info

Seeing the Person in the Patient: Point of Care Review Paper
www.kingsfund.org.uk/current_projects/the_point_of_care

The Patient-Centered Care Improvement Guide
www.planetree.org/publications.html

Patient-Centered Care Resource Compendium
www.planetree.nl/media/Ledengedeelte/Patient-Centered%2520Care%2520Improvement%2520Guide%2520Evidence%2520Base.pdf

Self-assessment tool
www.patient-centeredcare.org/inside/selfassessment.html

Advancing the Practice of Patient- and Family-Centred Care — How to Get Started
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
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
www.ipfcc.org/pdf/Roadmap.pdf

Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care
www.jointcommission.org/assets/1/6/ARoadmapforHospitalsfinalversion727.pdf

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

Schwartz Center Rounds
www.theschwartzcenter.org/programs/rounds.html

Carepages
www.carepages.com

Picker Institute Always Events Program
www.alwaysevents.pickerinstitute.org

Resources on collecting patient feedback

UK Care Quality Commission
www.cqc.org.uk/usingcareservices/healthcare/patientsurveys.cfm

UK Survey Coordination Centre
www.nhssurveys.org

UK General Practice Patient Survey results
www.results.gp-patient.co.uk/report/main.aspx

UK National Cancer Action Team Patient Experience
www.cancerinfo.nhs.uk

UK National Cancer Patient Experience Survey
www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_122520.pdf

UK National Institute for Health and Clinical Excellence patient experience standard
www.nice.org.uk/guidance/index.jsp?action=byID&o=13259

Understanding What Matters — A Guide to Using Patient Feedback to Transform Services, UK Department of Health

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099780

Agency for Healthcare Research and Quality (AHRQ) Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey

www.cahps.ahrq.gov/default.asp

AHRQ National CAHPS Benchmarking Database

www.cahps.ahrq.gov/content/ncbd/ncbd_Intro.asp?p=105&s=5

Royal Australian College of General Practitioners Patient Feedback Guide

www.racgp.org.au/Content/NavigationMenu/PracticeSupport/StandardsforGeneralPractices/Standards4thEdition/Patientfeedback/Standards4_PatientFeedbackGuide.pdf

Real-time patient feedback

UK websites offering patient reviews for healthcare services

www.iwantgreatcare.com and www.patientopinion.org.uk

Patient choice of provider

NHS Choices

www.nhs.uk

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

www.hospitalcompare.hhs.gov

US Department of Health and Human Services Physician Compare

www.medicare.gov/find-a-doctor/provider-search.aspx

Rights-based charters and codes

The NHS Constitution

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113613

American Hospital Association Communicating with patients

www.aha.org/aha/issues/Communicating-With-Patients/index.html

Centers for Medicare and Medicaid Services — Important Message From Medicare Notice

www.virginia.edu/uvaprint/HSC/pdf/CMS-R-193.pdf

Code of Health and Disability Services Consumers' Rights Regulation 1996 New Zealand

www.legislation.govt.nz/regulation/public/1996/0078/latest/DLM209080.html

Australian Charter of Healthcare Rights

www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/com-pubs_ACHR-pdf-01-con/$File/17537-charter.pdf

London Declaration for Patient Safety

www.who.int/patientsafety/patients_for_patient/London_Declaration_EN.pdf

Patient Rights (Scotland) Bill (SP Bill 42)

www.scottish.parliament.uk/s3/bills/42-PatientRights

ACT Human Rights Act
www.legislation.act.gov.au/a/2004-5/default.asp

Victorian Charter of Human Rights and Responsibilities
www.austlii.edu.au/au/legis/vic/consol_act/cohrara2006433/

SA Charter for Health and Community Services
www.hcscc.sa.gov.au/cgi-bin/wf.pl

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

Victorian Health Service Management Innovation Council — redesign website
www.health.vic.gov.au/managementinnovation/resources/what.htm

A Toolkit for Redesign in Health Care
www.ahrq.gov/qual/toolkit/index.html

Improving complaints processes

UK Department of Health guide and advice sheets
www.dh.gov.uk/en/Publicationsandstatistics/Publications

Listening, Responding, Improving: A Guide to Better Customer Care, UK Department of Health
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_095408

Consumer engagement and supporting consumer participation

Joint Commission Speak Up Program
www.jointcommission.org/speakup.aspx

Picker Institute Europe Invest in Engagement website
www.investinengagement.info/

QLD Health Community Engagement Handbook
www.healthissuescentre.org.au/documents/items/2008/04/204586-upload-00001.pdf

QLD Health Consumer and Community Participation Toolkit
www.healthissuescentre.org.au/documents/items/2008/08/226706-upload-00001.pdf

Improving Health Services through Consumer Participation: A Resource Guide
www.healthissuescentre.org.au/documents/detail.chtml?filename_num=226531

Consumer and Community Participation Self-Assessment Tool for Hospitals
www.healthissuescentre.org.au/documents/items/2008/04/204590-upload-00001.pdf

Standards

Australian Commission on Safety and Quality in Health Care — Draft National Safety and Quality Health Service Standards

www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/PriorityProgram-07

Royal Australian College of General Practitioners — Standards for General Practices (Fourth Edition)

www.racgp.org.au/Content/NavigationMenu/PracticeSupport/StandardsforGeneralPractices/
Standards4thEdition.pdf

National Institute for Health and Clinical Excellence — Quality Standard for Patient Experience

http://guidance.nice.org.uk/?action=byID&o=13259

Australian Commission on Safety and Quality in Health Care — Open Disclosure Standard

www.http://www.health.gov.au/internet/safety/publishing.nsf/Content/3D5F114646CEF93DCA2571D5000BFEB7/
$File/OpenDisclosure_web.pdf

Shared decision-making tools

Implementing Shared Decision-Making in the UK

www.health.org.uk/public/cms/75/76/313/595/Implementing%20shared%20decision%20making%20in%20the%20UK.
pdf?realName=vgvUMW.pdf

Shared Decision Aids website — Ottowa Hospital Research Institute

http://decisionaid.ohri.ca/

Sydney Health Decision Group

http://sydney.edu.au/medicine/public-health/shdg/about/aims.php

Interventions for Improving the Adoption of Shared Decision Making by Healthcare Professionals

www2.cochrane.org/reviews/en/ab006732.html

Health literacy

Invest in engagement — health literacy website

www.investinengagement.info/HealthLiteracytop

US Department of Health and Human Services — health literacy website
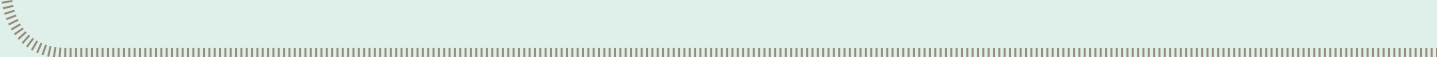
www.health.gov/communication/literacy/

AHRQ Health Literacy and Cultural Competency website

www.ahrq.gov/browse/hlitix.htm

Appendix D
Australian Charter of Healthcare Rights

AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS

The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. These rights are essential to make sure that, wherever and whenever care is provided, it is of high quality and is safe.

The Charter recognises that people receiving care and people providing care all have important parts to play in achieving healthcare rights. The Charter allows patients, consumers, families, carers and services providing health care to share an understanding of the rights of people receiving health care. This helps everyone to work together towards a safe and high quality health system. A genuine partnership between patients, consumers and providers is important so that everyone achieves the best possible outcomes.

Guiding Principles

These three principles describe how this Charter applies in the Australian health system.

1 Everyone has the right to be able to access health care and this right is essential for the Charter to be meaningful.

2 The Australian Government commits to international agreements about human rights which recognise everyone's right to have the highest possible standard of physical and mental health.

3 Australia is a society made up of people with different cultures and ways of life, and the Charter acknowledges and respects these differences.

For further information please visit
www.safetyandquality.gov.au

**AUSTRALIANCOMMISSIONON
SAFETYANDQUALITYINHEALTHCARE**

What can I expect from the Australian health system?

MY RIGHTS	WHAT THIS MEANS
Access	
I have a right to health care.	I can access services to address my healthcare needs.
Safety	
I have a right to receive safe and high quality care.	I receive safe and high quality health services, provided with professional care, skill and competence.
Respect	
I have a right to be shown respect, dignity and consideration.	The care provided shows respect to me and my culture, beliefs, values and personal characteristics.
Communication	
I have a right to be informed about services, treatment, options and costs in a clear and open way.	I receive open, timely and appropriate communication about my health care in a way I can understand.
Participation	
I have a right to be included in decisions and choices about my care.	I may join in making decisions and choices about my care and about health service planning.
Privacy	
I have a right to privacy and confidentiality of my personal information.	My personal privacy is maintained and proper handling of my personal health and other information is assured.
Comment	
I have a right to comment on my care and to have my concerns addressed.	I can comment on or complain about my care and have my concerns dealt with properly and promptly.

Appendix E
Australian Safety and Quality Framework for Health Care

Australian Safety and Quality Framework for Health Care

Consumer centred

Organised for safety

Driven by information

Safe and high quality health care for Australia

Australian Health Ministers endorsed the Australian Safety and Quality Framework for Health Care in 2010. The Framework describes a vision for safe and high-quality care for all Australians and sets out the actions needed to achieve this vision. The Framework specifies three core principles for safe and high-quality care. These are that care is **consumer centred, driven by information,** and **organised for safety.**

The Framework sets out twenty-one areas for action that all people in the health system can take to improve the safety and quality of care provided in all healthcare settings over the next decade.

The Framework should:

- be used as the basis of strategic and operational safety and quality plans

- provide a mechanism for refocusing current safety and quality improvement activities and designing goals for health service improvement

- be used as a guide for reviewing investments and research in safety and quality

- promote discussion with consumers, clinicians, managers, researchers and policy makers about how they might best form partnerships to improve safety and quality

Tools, resources, and examples to support local use of the Framework are available from the Australian Commission on Safety and Quality in Health Care at **www.safetyandquality.gov.au**

AUSTRALIANCOMMISSIONON SAFETYANDQUALITYINHEALTHCARE

December 2010

Australian Safety and Quality Framework for Health Care

Safe, high-quality health is always:	What it means for me as a consumer or patient:	Areas for action by people in the health system:
1 CONSUMER CENTRED This means: Providing care that is easy for patients to get when they need it. Making sure that healthcare staff respect and respond to patient choices, needs and values. Forming partnerships between patients, their family, carers and healthcare providers.	I can get high-quality care when I need it. I have information I can understand. It helps me to make decisions about my health care. I can help to make my care safe. My health care is well organised. The doctors, nurses and managers all work together. I feel safe and well cared for. I know my healthcare rights. If something goes wrong, my healthcare team look after me. I receive an apology and a full explanation of what happened.	**1.1** Develop methods and models to help patients get health services when they need them. **1.2** Increase health literacy. **1.3** Partner with consumers, patients, families and carers to share decision making about their care. **1.4** Provide care that respects and is sensitive to different cultures. **1.5** Involve consumers, patients and carers in planning for safety and quality. **1.6** Improve continuity of care. **1.7** Minimise risks at handover. **1.8** Promote healthcare rights. **1.9** If something goes wrong, openly inform and support the patient.
2 DRIVEN BY INFORMATION This means: Using up-to-date knowledge and evidence to guide decisions about care. Safety and quality data are collected, analysed and fed back for improvement. Taking action to improve patients' experiences.	My care is based on the best knowledge and evidence. The outcome of my treatment and my experiences are used to help improve care.	**2.1** Use agreed guidelines to reduce inappropriate variation in the delivery of care. **2.2** Collect and analyse safety and quality data to improve care. **2.3** Learn from patients' and carers' experiences. **2.4** Encourage and apply research that will improve safety and quality.
3 ORGANISED FOR SAFETY This means making safety a central feature of how healthcare facilities are run, how staff work and how funding is organised.	I know that the healthcare team, managers and governments all take my safety seriously. The health system is designed to provide safe, high-quality care for me, my family and my carers. When something goes wrong, actions are taken to prevent it happening to someone else.	**3.1** Health staff take action for safety. **3.2** Health professionals take action for safety. **3.3** Managers and clinical leaders take action for safety. **3.4** Governments take action for safety. **3.5** Ensure funding models are designed to support safety and quality. **3.6** Support, implement and evaluate e-health. **3.7** Design and operate facilities, equipment and work processes for safety. **3.8** Take action to prevent or minimise harm from healthcare errors.

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December 2010

Appendix F
Perth Declaration for Patient Safety

PERTH DECLARATION FOR PATIENT SAFETY

The Perth Declaration for Patient Safety and the Australian workshop information is available at www.hconc.org.au.

We, the participants of the inaugural Australian Patients for Patient Safety Workshop, convened in July 2009 to share profound health care experiences in our lives and to take forward our call for action to improve patient safety in Australia.

We are patients, family members, carers and health professionals — people from all walks of life. Each one of us is a testament to the personal experience of unintended harm in health care and its continuing. Much of that harm was preventable.

We declare

» Policies and protocols alone have not made us safer. This problem is systemic, widespread and deep-rooted. The fact that any person or family could one day experience needless devastating harm within the health care system is unacceptable.

» Action must be taken now across all aspects and all levels of health care to prevent more harm occurring to others.

» Our trusted health care workers and managers must recognise that we, your patients and our families, are an invaluable asset and resource for improving patient safety. We offer our stories and experiences. Seek to learn from our hard-won wisdom and partner with us to make lasting change.

» We are the owners and funders of our health care systems and have collective responsibility for them. We ask everyone in the community, including health care providers, administrators and the Government, to join us in making the right to safe health care a priority for all people, especially those who are currently disadvantaged.

» Care has no borders, neither does harm. The journey through all care settings must be better coordinated as too many lives have been lost or grievously harmed on this journey.

» We need to receive care that conforms to the best evidence and practice. Safe practice must be supported by the reporting of and learning from patient safety incidents, education, innovative solutions and information.

» Many barriers exist for Aboriginal and Torres Strait Islander people which limit access to safe health care. Interpreter services, effective transport, communication and accommodation are all integral elements of patient safety.

» Patients know their own bodies better than anybody else. It makes sense to include patients in decisions about their care and treatment. Patients must always be told the options available, the expected outcome of each option including risks and complications, and the likelihood of each outcome occurring.

» Patient safety is a basic human right. When harmed, people have the right to timely apology, explanation, redress and other remedies meaningful to them.

» In accepting that all humans err, we nevertheless dedicate ourselves to ensuring that effective systems are in place to
  – Track and learn from health care errors, adverse events and near misses.
  – Minimise the impact of errors on all involved, including the care provider.
  – Make changes to prevent the same errors happening again.

» Current reporting arrangements have failed to deliver safe health care for patients. We accept that everyone, including patients, their families and clinicians, needs to safely report patient safety issues and problems. We therefore demand the application of improved patient safety legislation, including sanctions, which enables good clinical practice and provides real safety.

» We cannot stay silent any longer, waiting and watching as more people are harmed in healthcare. As Australians, we own this problem and will work together with actions that go beyond words. To progress this call for action to improve patient safety, we expect partnership at all stages and at every level of the Australian health care system.

This Declaration is our kindling. We, the participants of the inaugural Australian Patients for Patient Safety Workshop, will use it to ignite the flame of change to advance patient safety for everyone.

This is our promise.

Perth, AUSTRALIA
5 August 2009

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