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Disclaimer

Inherent Limitations
This discussion paper has been prepared as outlined in the introduction. The services provided in connection with this engagement comprise an advisory engagement, which is not subject to assurance or other standards issued by the Australian Auditing and Assurance Standards Board and, consequently no opinions or conclusions intended to convey assurance have been expressed.

No warranty of completeness, accuracy or reliability is given in relation to the statements and representations made by, and the information and documentation provided by, stakeholders consulted as part of the process.

KPMG have indicated within this report the sources of the information provided. We have not sought to independently verify those sources unless otherwise noted within the report.

KPMG is under no obligation in any circumstance to update this report, in either oral or written form, for events occurring after the report has been issued in final form.

Third Party Reliance
This report has been prepared at the request of the Department of Health in accordance with the terms of KPMG’s engagement contract dated 22 October 2013 and for the sole purpose set out in the introduction of the report. Other than our responsibility to the Department of Health, neither KPMG nor any member or employee of KPMG undertakes responsibility arising in any way from reliance placed by a third party on this report. Any reliance placed is that party’s sole responsibility.
Overview

This document is a report on the current state of consumer participation policy and practice in Australia and selected international jurisdictions.

The current state report is the first component of the evaluation of the Victorian Department of Health’s (the ‘Department’) *Doing it with us not for us* policy. Its purpose is to inform the development of the policy logic and evaluation strategy.

*Figure 1: Summative evaluation of Doing it with us not for us*

The current state analysis will also – in conjunction with all other evaluation components – be drawn on throughout the evaluation to inform the final discussion paper. The discussion paper will be used by the Department to hold a public consultation on the development of a new Victorian public policy on consumer participation.

The document structure is outlined in Table 1.

*Table 1: Structure of the Summative Evaluation of Doing it with us not for us*

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<tr>
<th>Chapter</th>
<th>Outline</th>
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<tbody>
<tr>
<td>Executive summary</td>
<td></td>
</tr>
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</table>
| Chapter 1: Introduction | • Sets out the context for the evaluation of *Doing it with us not for us*.  
• Outlines the purpose, scope and methodology of this report. |
| Chapter 2: Conceptualising participation | • Provides an overview of the evolution of the concept of consumer participation in healthcare. It highlights key influences, drivers and current trends.  
• Introduces a selection of the most frequently cited frameworks used to conceptualise various methods of consumer participation. |
<p>| Chapter 3: Consumer participation policy in Australia | • Provides an overview of national and state-based consumer participation policy in Australia. |
| Chapter 4: Consumer participation policy overseas | • Provides an overview of national and state-based consumer participation policy in selected international jurisdictions (New Zealand (NZ), United Kingdom (UK), United States (US), Canada and the Netherlands). |</p>
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<th>Chapter 5: Maximising consumer</th>
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</tr>
<tr>
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</tr>
</tbody>
</table>
Executive Summary

This report on the Current State Analysis is the first component of the evaluation of the Doing it with us not for us policy and an important resource in progressing the evaluation, specifically the development of the policy logic and evaluation strategy.

The report is structured to provide a high level review of the current state of consumer participation policy and practices in Australia and selected international jurisdictions. The report identifies evidence based approaches to maximising consumer participation, person and family centred care and patient experience.

Policy background to consumer participation in health care

The development of consumer participation in health care has been evolutionary in nature and influenced by a range of factors both within and external to the health system, including:

- social movements, human rights frameworks, increased consumer access to health information and democratic approaches to health care that have led to greater advocacy, involvement, transparency and accountability for preventative health and clinical services
- community development and primary health leading to a reorientation of medical driven models to a greater emphasis on person-centred approaches
- inquiries into medical failure demonstrating, amongst other things, the need for stronger accountability arrangements, and opportunities for listening to and involving patients in governance
- market approaches to health care, growing healthcare costs and evidence-based healthcare have encouraged both funders and providers of health services to create alignment between consumer experience, choice and quality outcomes
- patient-centred care approaches, principally led by the Picker Institute, to identify what matters to patients so that appropriate policies and approaches to healthcare can be developed. More recently – and particularly in the aged care and disability sectors – Consumer Directed Care (CDC) approaches have developed to enable consumers, care recipients and their carers to choose and control the services they receive to the level and extent that they are capable and wish to do so.

Frameworks for participation

Consumer participation may encompass a range of different activities across any level of the health system and at different levels of intensity, from passive involvement to direct roles for consumers in decision-making. The development of the types of approaches, the levels of the health system at which they should apply and the intensity with which they should be delivered, is dependent on characteristics unique to health systems, service providers and consumers. As such, these considerations are typically useful for identifying approaches rather than prescriptive methods for developing frameworks for consumer participation and engagement.

Consumer participation policy in Victoria

Victoria has led the way in the development of consumer participation policy.
Doing it with us not for us\(^1\) was launched in 2006, and sets out the guiding principles for public mental health services, community health services, hospitals and residential aged care facilities.

This policy was subsequently updated in 2009 and 2011 resulting in the current Doing it with us not for us: Strategic Direction 2010-2013\(^2\) (the ‘Strategic Direction’). Following a review of cultural and linguistic diversity (CALD) and cultural competence reporting requirements, minimum standards and benchmarks for Victorian health services, a cultural responsiveness framework was also developed in 2009.

The development of the policy, strategic direction and cultural responsiveness framework occurred within an existing system of legislation, infrastructure and resources supporting consumer participation. This included funding and service agreements with peak consumer and carer non-government organisations, mental health consumer and carer consultants and programs, the requirement for health services to provide annual Quality of Care Reports, Statement of Priorities business rules, the Victorian Health Policy and Funding Guidelines, the Victorian Patient Satisfaction Monitor survey, and the specification of board Community Advisory Committees in the Victorian Health Services Act 1988.

In 2012, the Victorian Auditor-General’s Office (VAGO) performance audit report Consumer Participation in the Health System made a number of recommendations in relation to consumer participation, including that the Department:

- evaluate the impact of Doing it with us not for us: Strategic Direction 2010-2013
- update its consumer participation policy and guidelines in the context of the new National Safety and Quality Health Service Standards (NSQHS Standards) and the Victorian Health Priorities Framework.\(^3\)

**Consumer participation policy in Australia**

**National policies**

The recent release of the NSQHS Standards (the ‘Standards’) has significantly strengthened the accountability requirements for health services across Australia in relation to consumer participation. The first two standards – Standard 1: Governance for safety and quality in health service organisations and Standard 2: Partnering with Consumers - relate directly to consumer participation. They describe how healthcare organisations should engage with consumers at a governance and organisational level, providing a nationally consistent set of safety and quality measurements across health services.

The Standards build on a commitment at the national level to supporting consumer participation in health care. The two key policy documents underpinning this commitment are the:

\(^1\) Victorian Department of Health 2006, Doing it with us not for us – Participation in your health service system 2006-09: Victorian consumers, carers and the community working together with their health services and the Department of Human Services, Victorian Government, Melbourne.

\(^2\) Victorian Department of Health 2009, Doing it with us not for us: Strategic Direction 2010-13 – Participation in your health service system: Victorian consumers, carers and community working together with their health services and the Department of Health, Victorian Government, Melbourne.

\(^3\) Victorian Auditor-General’s Office 2012, Consumer Participation in the Victorian Health System, VAGO, Melbourne, p.xi
• **Australian Charter of Healthcare Rights** (2008)\(^4\), which supports a shared understanding of the rights of patients and consumers between those seeking health care and those providing healthcare

• **Australian Safety and Quality Framework for Health Care** (2010)\(^5\), which aims to guide quality improvement efforts across the health system and promote discussion with consumers, clinicians, managers, researcher and policy makers about how best to form partnership to improve safety and quality. Consumer centred care is one of the framework’s three core principles.

Commitment to consumer participation and consumer centred care is further reflected in a range of other national strategies, including the **National Primary Health Care Strategy** (2013), the **National Chronic Disease Strategy** (2006), the **Fourth National Mental Health Plan** (2009) and the **Roadmap for National Mental Health Reform 2012-2022**. A commitment to participation is also articulated in the **National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013**.

**State and territory policies**

A commitment to consumer participation and principles of patient-centred care is a feature of state based healthcare policy across Australia, although the pace at which states have progressed their policies and the extent to which performance and accountability frameworks are built in varies. Features of Australian jurisdiction’s commitment to consumer participation and principles of patient-centred care are summarised in Figure 2 (see overleaf). Many of the states and territories have drawn on the Victorian policy.

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Overall, all jurisdictions have demonstrated their commitment to diversity and have in place frameworks for Aboriginal and/or CALD community engagement. However, these frameworks generally lack specific direction for implementation.

**Consumer participation policy overseas**

A review of public policy in selected international jurisdictions, identified as leaders in approaches to consumer participation, patient and family-centred care and patient experience, provides a number of insights that may be applicable to Victoria.

All jurisdictions considered in this report have an overarching framework in place to guide consumer involvement in their respective healthcare systems. In the UK and the US, this has occurred within a framework of patient-centred care. Key drivers of patient-centred care in
these jurisdictions include mandatory requirements to collect and publish patient experience data; facilitating choice of service provider through the provision of publicly available performance information; and the incentivisation of patient-centred approaches by linking strong performance on measures of patient experience with payment systems. Recently the US has been leading investment in consumer, patient, led decision making about research in health care through the Patient Centred Outcomes Research Institute (PCORI).6

NZ has recently put in place a consumer engagement framework, Partners in Care7, which takes a project-based approach to capacity building and quality improvement through a four-year program of activities. Ongoing evaluation of all Partners in Care projects is a core component of the framework. The Framework states that the Health Quality and Safety Commission New Zealand (HQSCNZ) evaluation team will work alongside external evaluators to set indicators and measures for evaluation of all projects funded by the Commission, followed by a review of the overall achievements of the projects in year four.8 The focus on evaluation reflects an explicit desire to build the evidence base in NZ for effective and engagement and its contribution to health outcomes.

A program of Experience Based Design (EBD) projects is a core component of the framework. NZ is also undertaking a series of connected programs to improve the measurement and evaluation of quality and safety in the healthcare system, including the introduction in 2012 of the requirement for health care providers to report annually on service quality through Quality Accounts, the development of national Health Quality and Safety Indicators and the implementation of a national patient experience survey.

Canada has been a leader in consumer participation in decision making about healthcare, both at the individual care level and in policy. In 2002, during the Romanov Commission on the Future of Health Care in Canada, the ‘ChoiceWork dialogue’ methodology was used as a means to engage ‘unorganised’ citizens in meaningful discussions about health care reform. Canada has also been at the forefront of the development and use of decision aids as a means to help consumers and health practitioners make ‘tough’ healthcare decisions. This work has been led by the Patient Decision Aids Research Group within the Ottawa Hospital Research Institute.9

Reforms to the Dutch healthcare system in 2006 aimed to give consumers a more pivotal role in the governance of healthcare and support greater transparency. Alongside major changes to the system of health care insurance, patient experience surveys were introduced as a key quality measure. Surveys are based on the Consumer Quality Index (CQ-Index), a standardised method for developing surveys and measuring healthcare quality from the patient’s perspective. Since the release of publicly accessible performance data, there is some evidence that the use of the surveys have supported quality improvement at the hospital level.

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6 See the PCORI website at http://www.pcori.org
8 ibid, p.10
9 Patient Decision Aids, Ottowa Hospital Research Institute website https://decisionaid.ohri.ca/about.html
Maximising consumer participation: evidence base and examples of better practice

Evidence based approaches to maximising consumer participation, person centred care and patient experience, have been identified through a high level scan of peer reviewed and grey literature. The scan included peer reviewed and grey literature published in English, from Australia, NZ, the UK, US, Canada and the Netherlands, since 2005. These approaches include:

- **strategies to maximise participation at the health system level** to promote consistency and universality, such as establishing principles, legislation, governance guidelines or standards to recognise consumer participation and reporting/evaluation frameworks.

- **strategies to maximise participation at the health service level**, focusing on local requirements to promote consumer participation, such as building staff capacity, using data to drive change, leadership and methods to engage patients, and the use of experience-based co-design as a means to engage consumers as partners in the design, delivery and evaluation of health services.

- **strategies to maximise participation at the level of individual care and treatment, including** health literacy, shared decision making and training of health care professionals to support consumer participation, the implementation of person- and family-centred care, and measurement of patient experience.

Examples of better practice have been drawn from Australia and the international jurisdictions of focus. They include:

- **Policies which promote consumer participation**, including examples demonstrating the inclusion of the principles of consumer participation in overarching standards and frameworks across health care systems

- **Measurement, performance monitoring and consumer choice**, including examples of approaches governing whole system measurement and monitoring of consumer participation and patient-centred approaches and approaches to use information to enable consumer choice and involvement about their care

- **Service planning and financial incentives to support consumer participation**, including examples of contracting arrangements which seek to align financial incentives with promoting and demonstrating outcomes in consumer participation and patient-centred approaches

- **Health literacy and capacity building**, including examples of professional leadership development and approaches to engaging with consumers.

The analysis has also considered the evidence on approaches to achieving diversity and equity in participation, in particular, strategies to maximise the involvement of CALD communities and Aboriginal and Torres Strait Islander peoples. These include the provision of cultural competency training, ensuring that language services are appropriate and accessible, and the development of and support for partnerships with community groups representing diverse patient groups.
1 Introduction

The Victorian Department of Health (the Department) has engaged KPMG to undertake a summative evaluation of the impact of the Doing it with us not for us policy and Strategic direction 2010-13 on the Victorian public healthcare system. Findings from the evaluation will be used to inform the development of a new Victorian public policy on consumer participation.

1.1 The Victorian context
1.1.1 Consumer participation policy in Victoria

Doing it with us not for us

The Victorian Department of Health’s Doing it with us not for us – Participation in your health service system 2006-09: Victorian consumers, carers and the community working together with their health services and the Department of Human Services policy10 (the Victorian policy) was launched in 2006.

The policy sets out the guiding principles of participation for the Victorian public health care system including acute, subacute, mental health, community health, and residential aged care facilities. These principles were developed through a consultation process undertaken in 2005.11

The stated aim of the policy is:

“For consumers, carers and community members to participate with their health services and the Department of Human Services in improving health policy and planning, care and treatment, and the wellbeing of all Victorians.”12

The policy identifies seven objectives to achieve this aim13 shown in Table 2.

Table 2: Seven objectives of the policy

<table>
<thead>
<tr>
<th>Objective 1</th>
<th>To take participation seriously – ‘doing it with us not for us’.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective 2</td>
<td>To share information to create consumer and carer friendly access to services.</td>
</tr>
<tr>
<td>Objective 3</td>
<td>To improve communication between all stakeholders.</td>
</tr>
<tr>
<td>Objective 4</td>
<td>To build the capacity of all stakeholders to undertake participation.</td>
</tr>
</tbody>
</table>

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KPMG and the KPMG logo are registered trademarks of KPMG International. Liability limited by a scheme approved under Professional Standards Legislation.
Objective 5  To integrate participation into the quality and safety program.

Objective 6  To learn from our experiences and the evidence on participation.

Objective 7  To ensure participation resources are available to all stakeholders.

The policy identifies priority actions to be undertaken across the four operational levels of the policy:

- individual care level
- program or department level
- health service organisational level
- Department of Health level.

These actions are intended to provide direction on what needs to be done to meet the policy’s objectives. A description of the priority actions and key implementation tasks is provided in Appendix A.

The policy also outlines a framework for understanding different types of participation. This framework is provided in Appendix B.

The Department updated the policy in 2009 and again in 2011. The current Doing it with us not for us: Strategic direction 2010-13 now includes five participation standards (Table 3), accompanied by specific indicators and targets for health services. All public health services report on these standards and indicators in their service’s annual Quality of Care report.15

Table 3: Participation standards for Doing it with us not for us: Strategic direction 2010-13

| Standard 1 | The organisation demonstrates a commitment to consumer, carer and community participation appropriate to its diverse communities. |
| Standard 2 | Consumers and, where appropriate, carers are involved in informed decision-making about their treatment, care and wellbeing at all stages and with appropriate support. |
| Standard 3 | Consumers and, where appropriate, carers are provided with evidence-based, accessible information to support key decision-making along the continuum of care. |
| Standard 4 | Consumers, carers and community members are active participants in the planning, improvement, and evaluation of services and programs on an ongoing basis. |
| Standard 5 | The organisation actively contributes to building the capacity of consumers, carers and community members to participate fully and effectively. |

14 Victorian Department of Health 2009, Doing it with us not for us: Strategic Direction 2010-13 – Participation in your health service system: Victorian consumers, carers and community working together with their health services and the Department of Health Victorian Government, Melbourne.

15 ibid.
Cultural Responsiveness Framework

In 2009, following a review of CALD and cultural competence reporting requirements, minimum standards and benchmarks for Victorian health services, a cultural responsiveness framework was also developed. The Cultural Responsiveness Framework: Guidelines for Victorian Health Services\(^{16}\) identifies six standards (Table 4) and improvement measures for culturally responsive practice, described below:

<table>
<thead>
<tr>
<th>Standard 1</th>
<th>A whole-of-organisation approach to cultural responsiveness is demonstrated.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standard 2</td>
<td>Leadership for cultural responsiveness is demonstrated by the health service.</td>
</tr>
<tr>
<td>Standard 3</td>
<td>Accredited interpreters are provided to patients who require one.</td>
</tr>
<tr>
<td>Standard 4</td>
<td>Inclusive practice in care planning is demonstrated, including but not limited to dietary, spiritual, family, attitudinal, and other cultural practices.</td>
</tr>
<tr>
<td>Standard 5</td>
<td>CALD consumer, carer and community members are involved in the planning, improvement and review of programs and services on an ongoing basis.</td>
</tr>
<tr>
<td>Standard 6</td>
<td>Staff at all levels is provided with professional development opportunities to enhance their cultural responsiveness.</td>
</tr>
</tbody>
</table>

The framework requires Victorian public health services to submit a three year Cultural Responsiveness Plan.\(^{17}\) Since 2011, reporting on achievements towards the standards is encompassed in health services’ Quality of Care reports. The framework intersects with the Strategic direction 2010-13, specifically with Standard 5, “Measure 5.1 CALD consumer membership and participation is demonstrated in the Community Advisory Committee (CAC) the Cultural Diversity Committee (CDC), or other specified structure [as noted in footnote 4]:- Consumer participation policies and strategies should be linked with those described in the Doing it with us not for us: Strategic direction 2010-13”\(^{18}\).

An overview of the roles and responsibilities under the relevant legislation with respect to consumer participation is provided in Appendix C.

1.1.2 The broader policy and legislative context

There are a number of other legislation, policies and guidelines that complement and integrate with the Doing it with us not for us policy. Table 5 below provides an overview of key legislation;


\(^{17}\) ibid. p.14

\(^{18}\) ibid. p.23
Table 5 outlines Victorian rights charter; and Table 7 provides an overview of other key policy documents relating to consumer participation.

**Table 5: Victorian legislation relating to consumer participation**

<table>
<thead>
<tr>
<th>Legislation title</th>
<th>Description</th>
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<tbody>
<tr>
<td>Health Services (Conciliation and Review) Act 1987</td>
<td>Primary legislation for the establishment and operation of the Office of the Health Services Commissioner (health complaints). Note, at the time of this evaluation this legislation was under review and redevelopment.</td>
</tr>
<tr>
<td>Health Services Act 1988</td>
<td>Primary legislation for health services in Victoria and includes specific requirements relating to consumer participation including the establishment of board Community Advisory Committees</td>
</tr>
<tr>
<td>Health Records Act 2002</td>
<td>Created a framework to protect the privacy of individuals’ health information. The Act gives individuals a legally enforceable right of access to health information about them that is contained in records held in Victoria by the private sector, and establishes Health Privacy Principles (HPPs) that will apply to health information collected and handled in Victoria by the Victorian public sector and the private sector. The access regime and the HPPs are designed to protect privacy and promote patient autonomy, whilst also ensuring safe and effective service delivery, and the continued improvement of health services.(^{19})</td>
</tr>
<tr>
<td>Disability Act 2006</td>
<td>Primary legislation for people with a disability in Victoria. The requirement for all public services to put in place a Disability Action Plan is covered by this Act. Other areas covered by the Act include requirements for the provision of information; mechanisms for representation, direction and accountability, to support the inclusion and participation of people with a disability in the community; states people’s right to access disability services; outlines guiding principle for planning; strengthens rights in residential services; provides for a clearer complaints and review system; includes mechanisms to improve the quality of disability services; and provisions to protect the rights of people subject to restrictive interventions and compulsory treatment. The Disability Amendment Act 2012 came into operation on 1 July 2012. It makes minor changes to the Disability Act 2006.</td>
</tr>
<tr>
<td>Charter of Human Rights and Responsibilities Act 2006</td>
<td>Public authorities in Victoria are required to act consistently with the human rights in this charter.</td>
</tr>
</tbody>
</table>

Provisions of the Act build and expand on the Victorian charter supporting people in care relationships, which has since been updated to reflect the new Act. The Act includes a set of principles about the significance of care relationships, and specifies obligations for state government agencies, local councils, and other organisations that interact with people in care relationships.

The Victorian Government has introduced the Mental Health Bill 2014 into Parliament. It is expected to be passed by parliament, proclaimed and commence as the Mental Health Act 2014 on 1 July 2014. The Bill proposes to establish a recovery-oriented framework and embed supported decision making, reflecting the desire for an increased focus on consumer participation. A presumption of capacity is the foundation of the supported decision model.

**Table 6: Victorian rights charters**

<table>
<thead>
<tr>
<th>Name of Charter</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>The Australian Charter of Healthcare Rights in Victoria (2011)</em></td>
<td>Describes the rights of patients and other people using the Australian healthcare system and what these mean for consumers seeking or receiving care from a Victorian healthcare service. The rights are Access, Safety, Respect, Communication, Participation, Privacy and Comment.</td>
</tr>
<tr>
<td>Victorian charter supporting people in care relationships (2010)</td>
<td>Articulates the rights and responsibilities of people in care relationships and how they can best be supported by organisations, governments and community.</td>
</tr>
</tbody>
</table>

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21 ibid, p.3
<table>
<thead>
<tr>
<th>Policy title</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Better Access to Services – A Policy and Operational Framework: Primary Care Partnerships (2001)</strong>&lt;sup&gt;25&lt;/sup&gt;</td>
<td>Provides a guide to achieving better coordination of services as part of the Primary Care Partnership Strategy. A central focus on consumers is one of the framework’s underlying principles.</td>
</tr>
<tr>
<td><strong>Victorian clinical governance framework: Enhancing clinical care (2008)</strong>&lt;sup&gt;26&lt;/sup&gt;</td>
<td>A framework to guide health services in the adoption, review or further development of clinical government frameworks. Identifies consumer participation as one of the four key domains of quality and safety (the others being clinical effectiveness, an effective workforce and risk management).</td>
</tr>
<tr>
<td><strong>Strengthening consumer participation in Victoria’s public Mental Health Service (2009)</strong>&lt;sup&gt;27&lt;/sup&gt;</td>
<td>A framework for strengthening consumer involvement in treatment and care, development and evaluation of services, and broader system and policy development.</td>
</tr>
<tr>
<td><strong>Improving care for Aboriginal and Torres Strait Islander patients (2009)</strong>&lt;sup&gt;28&lt;/sup&gt;</td>
<td>Aims to improve the quality of care for Aboriginal and Torres Strait Islander patients. Includes four key result areas that form the basis of quality of care reporting by health services.</td>
</tr>
<tr>
<td><strong>Victorian Public Health and Wellbeing Plan 2011-2015</strong>&lt;sup&gt;29&lt;/sup&gt;</td>
<td>The first Victorian Public Health and Wellbeing Plan 2011-2015, developed to meet the requirement under the Public Health and Wellbeing Act 2008 to identify public health priorities to be developed by the state every four years. Increasing the health literacy of all Victorians and supporting people to better manage their own health is one of the plan’s stated goals.</td>
</tr>
<tr>
<td><strong>Koolin Balit: Victorian Government Strategic directions for Aboriginal health 2012-2022</strong>&lt;sup&gt;30&lt;/sup&gt;</td>
<td>Aims for improved health outcomes in partnership with Aboriginal communities.</td>
</tr>
</tbody>
</table>

<sup>24</sup> Note that the 2006 policy document outlined a series of broader policies and guidelines driving participation, in addition to Doing it with us not for us (see page 21 of Doing it with us not for us 2006). This table provides an updated list of the other Departmental pol
<sup>28</sup> Victorian Department of Health 2009, Improving care for Aboriginal and Torres Strait Islander patients, Victorian Government, Melbourne.
Victorian health policy and funding guidelines 2013-2014\textsuperscript{31} Requires health services to comply with the above policies as well as maintain complaints processes, comply with reporting on the Victorian Patient Satisfaction Monitor (VPSM) (from 2014 onwards) and report annually to the community on quality of care.

Victorian Equal Opportunity and Human Rights Commission Guidelines for General Practices: Complying with the Equal Opportunity Act 2010 when providing services (2014)\textsuperscript{32} These guidelines are intended to assist general practices and other primary health care providers in relation to how to take reasonable precautions to prevent discrimination.

\textit{Source: KPMG}

1.1.3 Recent developments

\textit{Victorian Health Priorities Framework 2012-2022}

Following the update to the \textit{Doing it with us not for us} policy in 2010, the Minister for Health released the \textit{Victorian Health Priorities Framework},\textsuperscript{33} The framework sets the overall direction for the Victorian public health system and includes a strong focus on enhancing patient experience, improving health literacy in the community, and tailoring services to community needs.\textsuperscript{34} The seven priority areas outlined in the framework are provided in Box 1 below.

\textit{Box 1: Victorian Health Priorities Framework 2012-2022 Priority Areas}

- developing a system that is responsive to people’s needs
- improving every Victorian’s health status and experiences
- expanding service, workforce and system capacity
- increasing the system’s financial sustainability and productivity
- implementing continuous improvements and innovation
- increasing accountability and transparency
- utilising e-health and communications technology.

\textsuperscript{31} Victorian Department of Health 2013, \textit{Victorian health policy and funding guidelines 2013-13 – Part one: Key}
\textsuperscript{34} VAGO 2012, p.36
Any recommendations made over the course of the evaluation will be considered in the context of the priorities identified within this framework.

**VAGO Report 2012: Consumer Participation in the Health System**

In 2012, the VAGO conducted a performance audit of consumer participation in the Victorian health system. The audit was primarily an audit of the implementation of the *Doing it with us not for us* policy in the hospital sector.

Broadly, the VAGO identified the strengths of the Victorian policy frameworks for consumer participation but also identified a number of areas for improvement at the health service level and by the Department.

The recommendations of the report included the need to evaluate the impact of the Strategic direction 2010–13 (VAGO Recommendation 9) and update the consumer participation policy and guidelines in the context of the new monitoring and accountability required under NSQHS Standards (Standard 2 Partnering with Consumers) and the Victorian Health Priorities Framework (VAGO Recommendation 10).

### 1.1.4 Other recent Departmental activity

The Department is currently undertaking or has recently completed a number of projects related to consumer participation, in addition to the evaluation of *Doing it with us not for us*. These are briefly described below.

**Review of Quality of Care reporting**

In response to the changed quality and safety reporting landscape following the introduction of the NSQHS Standards, the Department has recently initiated a review which aims to establish new guidelines for quality of care reports. This review has included a critical literature review, examining the purposes of quality of care reporting; outlining the evolution of reporting to health care consumers in Victoria, the US and the UK; and discussing how quality of care reports can be more effectively presented and disseminated.

The review includes nine recommendations:

1. **Use the Australian Safety and Quality Framework for Health Care to define and inform the content of future quality of care reports.**

2. **The purpose of future quality of care reports should be for each health service to report to its community on the state of quality and safety of its health care.**

3. **Quality of care reports incorporate common themes from the award judges’ comments including benchmarking and/or identifying trends over time in data, consideration of**

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35 Victorian Department of Health 2011
36 VAGO 2012
37 ibid.
complaint resolution case studies and avoiding producing a public relations, promotional report.

4. Benchmarking data be made available to health services to include in their quality of care report.

5. Make available all quality of care reports through the Department of Health’s website.

6. Health services continue to work towards making quality of care reports as accessible and understandable as possible to their community, using clear formats and layouts.

7. Health services continue to explore how they can better use their websites to promote their quality of care reports, increase readership, gather feedback on their report and enhance dialogue with the community on quality and safety issues.

8. Health services continue to explore cost containment and best value for communication of the state of quality and safety at their health service.38

**Victorian Health Experience Survey**

From 1 January 2014, the Victorian Patient Survey Monitor will be superseded by the Victorian Healthcare Experience Survey (VHES).39 The survey will be used for in-patients, emergency department clients, maternity clients, outpatients, community health service clients and residents and carers of public residential and aged care services.

In line with current international practice, the VHES measures patient experience, rather than patient satisfaction. This is a large extension of the Department’s survey activity, which previously included adult in-patients and outpatients only. Targets are currently being developed for 2014-15. In 2014, the indicator will report health service compliance against participation in the survey.

**Online NSQHS Standards Education Modules**

The Department is currently finalising new online education modules for clinicians for each of the 10 NSQHS standards, which includes two modules for Standard 2 (Partnering with consumers) – entitled Person on Family Centred Care and Partnering with Consumers, looking at the governance, evaluation, policy and planning levels. Modules will be available at http://www.health.vic.gov.au/accreditation/ in early 2014.

**Mental Health Consumer and Carer Program Review**

In 2013, the Victorian Government commenced an integrated review of state-funded mental health consumer peer-support, carer support, consumer, carer and family participation programs and activities.


The review will provide advice on how current Victorian Government investment might more effectively support consumers, their carers and families, and strengthen consumer, carer and family participation. It will focus on recognised best practice in the design and management of programs based on peer support, self-help, advocacy, mental health literacy and information, respite, participation and related concepts. The review is expected to conclude by mid 2014.

Diversity and cultural responsiveness

The Department is undertaking a number of activities to further diversity and cultural responsiveness of the health system. Key activities are outlined below:

Promoting the participation of Aboriginal and Torres Strait Islander peoples

The Victorian Government’s commitment to enabling the participation of Aboriginal and Torres Strait Islander peoples is expressed in the Victorian-funded Closing the Gap programs and the expansion of the Improving Care for Aboriginal and Torres Strait Islander Patients (ICAP) program.

In 2012, the Victorian Government launched Koolin Balit: The Victorian Government’s strategic directions for Aboriginal Health 2012-2022. The document provides a 10-year strategy setting clear directions for improving the health of Aboriginal and Torres Strait Islander people in partnership with the Indigenous community. Improving the continuum of care by addressing risk factors and managing illness better is a key goal of the strategy. The focus on the continuum of care is consistent with the principles of patient- and family-centred care.

VAGO has recently completed an audit assessing the accessibility of mainstream services such as hospitals, maternal and child health services, schools and kindergartens, and community and public housing for Aboriginal Victorians.

The audit found that access to some services, including hospitals, has improved. However overall, there has been little improvement in outcomes, and in some cases, the gap has worsened.

The report contains recommendations that apply to all government departments and agencies responsible for providing services for Aboriginal Victorians, including the Department of Health. A key recommendation included improved data collection and recording processes and broader engagement with the Aboriginal community to inform a better understanding of the community needs.

Refugee and asylum seeker health and wellbeing

The development of an action plan to define the long term strategic vision for how the health system can best meet the health and wellbeing needs of people from refugee backgrounds and

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41 Victorian Department of Health 2012, p.14
42 VAGO 2014, Accessibility of Mainstream Services for Aboriginal Victorians, VAGO, Melbourne.
asylum seekers is currently underway in collaboration with the Victorian Refugee Health Network.43

An audit has also been undertaken by VAGO in relation to the accessibility of government services for migrants, refugees and asylum seekers.

The report noted that the Department of Health has demonstrated that it understands at a strategic level the multiple and significant needs of migrants, refugees and asylum seekers.44 Annual reporting on cultural diversity plans was recommended as a means to support consistent and efficient service planning and provision.45 The report also concluded that improved collection and analysis of data on CALD communities was essential to improving the effectiveness and accessibility of service provision.46

Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) Health and Wellbeing

The GLBTI Health and Wellbeing Ministerial Advisory Committee has established five working groups, which reflect priority issues identified by the committee. The work produced by the group has led to recommendations for consideration by both the Victorian Minister for Health and the Victorian Minister for Mental Health in supporting priority health issues identified by the committee.47

Minority Standards in Health – Second Stage Pilot

The Department is currently working with the WHO Health Promoting Hospitals Task Force on the Migrant Friendly and Culturally Competent Health Care’s Equity Standards Project.

Cultural Competence Education for Health Professionals: A Cochrane Review

The Department has researched and published Cultural Competence education for health professionals: A Cochrane Systematic Review, conducted to investigate the effect of cultural competence education interventions for health professionals, to improve outcomes in culturally and linguistically diverse patient groups. The protocol for the review can be found in the Cochrane Library.48

Health Literacy

The Department is currently developing a Health Literacy and Information policy statement as part of the new consumer, carer and community participation in healthcare policy.

44 VAGO 2014, Access to Services for Migrants, Refugees and Asylum Seekers, VAGO, Melbourne, p.11
45 Ibid.
46 Ibid, p.23
Victorian Quality Improvement Framework

The Commission for Hospital Improvement is currently developing a framework to outline the vision, principles and goals for the quality improvement space within Victorian healthcare. The framework will encompass the needs of health consumers, clinicians, administrators and policy makers across all health settings, including public, private and not-for-profit primary health, mental health, aged care and drug and alcohol settings. Consistent with national directions, the framework will address quality, safety, patient experience and desired outcomes. It is expected to be completed in 2014.49

1.2 Purpose and scope of this report

The Current State Report (this report) is the first component of the evaluation. The findings of this report will inform the development of the policy logic and evaluation strategy. The report will also – in conjunction with all other evaluation components – be drawn on throughout the evaluation to inform the final discussion paper, which the Department will use to hold a public consultation on the development of a new policy.

The content of this report relates to Objective 3 and Objective 4 of the evaluation, as described in the Department’s Request for Tender (RFT) (see Appendix D). The report comprises:

- an overview of Victorian, Australian and international public policy on consumer participation (and related terms) in healthcare
- a literature scan to identify best practice and evidence based actions (quality improvement strategies) relating to patient experience, person and family centred care and consumer participation.
- Whilst the scope of this report relates to health systems, it should also be noted that a large degree of work has also been undertaken in relation to consumer participation in the Human Services Sector.

These elements have been integrated to provide an overall picture of the current state of policy and practice approaches to consumer participation, both in Australia and selected international jurisdictions identified as leaders in consumer participation (NZ, the UK, the US, Canada and the Netherlands).

In line with Objective 3, this report includes a preliminary review of the NSQHS Standards (see section 3.1 and Appendix E). Further consideration will be given to opportunities to maximise monitoring and reporting opportunities over the course of the evaluation.

1.3 Terminology and definitions

Terminology

There is a range of terms employed in the literature to describe the more active role that consumers are increasingly being encouraged to play in their own health care and treatment, and health systems more broadly. The following is an overview of the terminology most commonly used in the jurisdictions of focus:

- **Australia**: Consumer and carer participation
- **NZ**: Consumer engagement
- **UK**: Patient and public involvement
- **US**: Patient and family engagement
- **Canada**: Public involvement
- **Netherlands**: Consumer involvement

Note that while recognising the values and assumptions that underpin different terminology, for the sake of simplicity and consistency, the remainder of this report will adopt the term ‘consumer participation’ (the dominant term in the Victorian and Australian policy landscape). For the purpose of this report, it should be assumed that this term is interchangeable with terms that are more dominant in other jurisdictions of focus, including consumer engagement and patient and public involvement.

Definitions

Definitions of key terms, as described in the *Doing it with us not for us* policy,\(^50\) are provided below:

**Participation** occurs when consumers, carers and community members are meaningfully involved in decision-making about health policy and planning, care and treatment, and the wellbeing of themselves and the community. It is about having your say, thinking about why you believe in your view, and listening to the views and ideas of others. In working together, decisions may include a range of perspectives.

**Health services** – includes a hospital, health service (acute/subacute), community health service, mental health service and residential aged care service unless otherwise indicated.

**Consumers** - people who are current or potential users of health services. This includes children, women and men, people living with a disability, people from diverse cultural and religious experiences, socioeconomic status and social circumstances, sexual orientations health and illness conditions.

**Carers** - families and friends providing unpaid care to consumers. Carers may often be receiving a government benefit or allowance.

\(^{50}\) Department of Health 2006
Communities – defined as groups of people who have interest in the development of an accessible, effective and efficient health and aged care service that best meets their needs.

This report also considers terms related to consumer participation, including person- and family-centred care and patient experience. The Victorian policy does not define these terms. The following definitions are widely accepted in the literature:

- **Patient- and family-centred care** ‘is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. Patient- and family-centred care applies to patients of all ages, and it may be practiced in any health care setting.’\(^{51}\)

- The concept of **patient experience** refers to ‘the sum of all interactions, shaped by an organisation’s culture, which influence patient perceptions across the continuum of care.’\(^{52}\) The measurement of patient experience has been the subject of significant research over the last 20 years.

- **Patient experience versus patient satisfaction.** There has been a movement away from measures of patient satisfaction such as broad questions like “how would you rate your care in hospital” to approaches which measure patient experience. Experience questions might, for example, ask patients to report their experiences of a particular service, clinician or specific part of their interaction with health care services. Patient experience questions therefore, seek to elicit information on what actually occurred to the patient, as opposed to the patient’s evaluation of what occurred. Patient experience questions offer benefits over satisfaction based questions by avoiding potentially artificially high positive responses that is, by using factual questions about events and occurrences, thus reducing the subjectivity and other potentials for bias, and providing a much easier way to interpret and respond to patient feedback.

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\(^{51}\) Institute for Patient- and Family-Centred Care website. Institute for Patient- and Family-Centred Care Available at www.ipfcc.org. Accessed 22 January 2014

2 Conceptualising participation

This chapter provides an overview of the evolution of the concept of consumer participation in healthcare. It highlights key influences, drivers and current trends. The chapter also highlights a number of frameworks used to conceptualise different types of consumer participation across the health system.

2.1 Evolution of consumer participation in health care

Key points:

- The development of consumer participation theory and practice has been influenced by a range of factors. These influences are both proactive and reactive, and have been driven by factors both within and external to the health system.
- ‘Consumer participation’ encompasses a broad range of activities. A number of frameworks have been developed to identify what constitutes meaningful participation and what is required to achieve this.

There is increasing recognition across international health systems of the need for the community to be involved in decision-making about the design, delivery, monitoring and improvement of health care services. To this end, consumer participation has been formally and explicitly incorporated into health reform efforts.

There are a number of key influences which have facilitated consumer participation in health care decision-making, planning and policy making. These influences are both proactive and reactive, and have been driven by factors both within and external to the health system. These include:

- Social movements – The health consumer movement is considered reflective of broader rights-based social movements that have emerged since the 1960s. This has involved community advocacy for greater involvement, transparency and accountability in the formulation of government health and social policies, professional regulation, and the design of preventative health and clinical services. The International Covenant on Economic, Social and Cultural Rights is a foundational document, enshrining the right of all people to the highest attainable standard of healthcare. Other key documents, including the Committee on the Elimination of Discrimination against Women (CEDAW), Children’s Rights UN Convention (CROC), Convention on the Rights of Persons with Disabilities (CRPD) and the United Nationals Declaration on the Rights of Indigenous Peoples (UNDRIP) provide guidance on how rights to participation translate for particular groups.

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55 ibid.
56 ibid.
• Rights-based approaches, founded on principles of fairness, respect, equality dignity, and autonomy, continue to inform the consumer participation policy and practice. For example, in the UK, the British Institute of Human Rights and five NHS organisations have worked in conjunction to produce a Human Rights in Healthcare, a framework to assist NHS organisations in developing and applying human rights based approaches (HRBAs) to improve service design and delivery.\(^{57}\)

• **Community development and primary health** – There has been a shift from traditional medical driven models of care to contemporary community-based primary health care models which emphasise person-centred and goal-based approaches to care.\(^{58}\) This has been formalised through a number of international health charters. For example, the International Conference on Primary Health Care Declaration of Alma-Ata (1978)\(^ {59}\), World Health Organization Ottawa Charter for Health Promotion (1986)\(^ {60}\) and the World Health Organization Global Strategy Health for All by the Year 2000 (1986)\(^ {61}\) formally affirmed people’s right and duty to individual and collective participation in the planning and implementation of their healthcare. These international health charters are reflective of trends from a solely curative approach to health needs towards holistic and preventative approaches.

• **Inquiries into medical failures** – Investigation of clinical practices have elevated the importance of informed consent, and escalated expectations for greater consumer involvement in the implementation of professional and service standards and monitoring to improve professional and system accountability.\(^ {62}\)

One of the most recent examples is the investigation into failings at the Mid Staffordshire NHS Foundation Trust. This high profile inquiry followed the publication in 2009 by the Healthcare Commission on severe failings in emergency care provided by the Trust between 2005 and 2008. In the Press Statement issued on the release of the final report of the inquiry by Robert Francis QC, the following core reasons for the failure to patients were quoted:

“The patient voice was not heard or listened to, either by the Trust Board or local organisations which were meant to represent their interests. Complaints were made but often nothing effective was done about them”.\(^ {63}\)

The inquiry identified the need for a strengthened hospital response to concerns and complaints of patients and the local community in addition to a variety of broader recommendations with respect to high quality standards, measures of compliance,


\(^{58}\) ibid.


\(^{60}\) WHO 1986, Ottawa Charter for health promotion WHO, Ottawa

\(^{61}\) WHO 1986, WHO Global Strategy: Health for All by the Year 2000, WHO, Geneva

\(^{62}\) Coney, S. 2004, p.9

openness and transparency, support for nursing, patient centred healthcare leadership and accurate, useful and relevant information.  

In Australia, a number of high-profile, state-based inquiries involving patient care and adverse clinical incidents have acted as a catalyst for an increased focus on patient-centred care. They include incidents at the King Edward Memorial Hospital in Perth, Canberra Hospital, the Royal Melbourne Hospital, Campbelltown and Camden hospitals, Bundaberg Hospital and Queensland (QLD) Health, Royal North Shore Hospital, and, more generally, acute care services provided by NSW Health.  

- **Consumer access to health information** – Over the last few decades there has been a shift in community expectations toward provision of accessible and high quality health information for the purposes of educating and empowering the community on health matters and decisions regarding their health. This has been facilitated through the creation of authoritative websites and resources on the internet and increased information sharing, particularly through social media.  

- **Market approaches to healthcare** – The literature shows that private market approaches to healthcare, such as those in the US, have incorporated the use of financial incentives to drive improvements in consumer experience, choice and quality in a ‘user pays’ system. There are views that private market approaches have weakened the role of community based consumer advocacy organisations. However, market approaches are also recognised as influential in giving prominence to consumer rights, including the right to informed choice, consent and redress in the event of patient satisfaction issues.  

- **Democratic approaches to healthcare** – In the 1990s, service responsiveness emerged as a key success factor in assessing the value of public services to the community as users and citizens contributing to government-funded services through taxation. Democratic approaches emphasise participation as a means to achieve empowerment, equity, transparency and accountability. In line with this, governments have demonstrated

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65 ACSQHC 2011a, *Patient-centred care: Improving quality and safety through partnerships with patients and consumers*, ACSQHC, Darlinghurst, p.37
66 Coney, S. 2004, p.10
67 ACSQHC 2011a, p.15
68 Coney, S. 2004, p.11
71 Ridley, J. and Jones, L. 2002 *User and Public Involvement in Health Services: a Literature Review*, Partners in Charge, Edinburgh, p.20
72 ibid.

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commitments to community involvement in the development and evaluation of public services.

**Patient-centred care and the patient experience** – the concept of patient-centred care has been instrumental in reframing the relationship between consumers and health care practitioners. Patient centred care (or consumer centred care) has been defined as “health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers”.\(^7\) The UK and the US health systems have focused on patient-centred care for some time. In Australia, a patient-centred approach is supported by the Australian Charter of Healthcare Rights, the National Safety and Quality Framework, other national service standards, reports of state-based inquiries, and a range of jurisdictional and private sector initiatives.\(^7\) It is also being recognised as a key input in health service planning activities.\(^7\)

The Picker Institute has been at the forefront of defining the principles patient centred care and providing a basis for developing measures of patient experience. The Picker Institute Principles of Patient-Centred Care (Picker Principles) have been developed and refined over time and now include eight principles, illustrated in Figure 2 below:

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\[^7\] ACSQHC 2011a, p.7

\[^7\] Health Issues Centre (HIC) 2011, ‘The latest evidence and future directions in consumer engagement; It’s possible and it works!’ *Emerging themes from the Health Issues Centre’s Consumers Reforming Healthcare Conference, July 2011*, Health Issues Centre, Melbourne.
Alongside the Picker Principles, the Institute of Medicine’s (IoM) six domains of patient-centred care also represent a generic framework for measuring patient experience. The two approaches are broadly based on the same primary research, namely the IoM’s ‘Crossing the Quality Chasm’ report (2001) and the Picker Institute and Harvard University’s ‘Through the Patients Eyes’. More recent studies, including Boyd (2007), Bruster (2008), Cleary et al, (1991), Coates-Duton & Cunningham-Burley (2009), Coulter (2005), Cronin (2004), Gerteis et al (2003) and Sizmur & Reading (2009) confirm the robustness of the seminal work that underpins the Picker Principles.

As illustrated in Figure 3 below, the domains defined by the Picker Principles have been widely used as the basis for developing measures of patient experience.

Source: Picker Institute77 Alongside the Picker Principles, the Institute of Medicine’s (IoM) six domains of patient-centred care also represent a generic framework for measuring patient experience. The two approaches are broadly based on the same primary research, namely the IoM’s ‘Crossing the Quality Chasm’ report (2001) and the Picker Institute and Harvard University’s ‘Through the Patients Eyes’. More recent studies, including Boyd (2007), Bruster (2008), Cleary et al, (1991), Coates-Duton & Cunningham-Burley (2009), Coulter (2005), Cronin (2004), Gerteis et al (2003) and Sizmur & Reading (2009) confirm the robustness of the seminal work that underpins the Picker Principles.

As illustrated in Figure 3 below, the domains defined by the Picker Principles have been widely used as the basis for developing measures of patient experience.

77 Picker Institute 2013, Principles of Patient Centred Care, Picker Institute (Archived) Available at http://pickerinstitute.org/about/picker-principles/ Accessed 22 January 2014
In the UK, the National Health Service (NHS) patient survey and patient experience framework are based on modified versions of the Picker Principles. Modifications include the addition of elements regarding ensuring dignity, privacy and independence of service users, supporting decision making and supporting self-management.

The American Consumer Assessment of Healthcare Providers and Systems (CAHPS) was developed by Harvard University and based on the Picker Principles. The Dutch Consumer Quality Index (CQ-index) is based on both the CAHPS and the Quality of care through the patient’s eyes (QUOTE) instruments. The recent development of patient experience indicators in New Zealand has been informed by each of these three methods (i.e. the Picker Institute, CAHPS and the CQ-index).

In Australia, several state and territory based surveys reference the Picker Principles. The recently developed Victorian Health Experience Survey has been developed in line with international best practice to reflect evidence-based domains of patient-centred care.

- **Growing healthcare costs** – In recent years, there has been an increased focus on rising health care costs and demand pressures on health systems. Governments have increasingly sought to involve consumers in debates around spending on health, rationing and health
care priorities as a tool to increase the legitimacy of budgeting and funding decisions.\textsuperscript{80} This is consistent with the view that a health system that is closely aligned with needs of its users and clients can be more effective and efficient.\textsuperscript{81}

- **Quality and evidence-based health care** – The emphasis on evidence-based practice and quality improvement has been a key driver of consumer participation for both clinicians and policy makers.\textsuperscript{82} The evolution of consumer participation in Australia has occurred within a quality framework.\textsuperscript{83} Consumer advocacy has encouraged a broadening of the notion of quality to not only include issues of safety but also concepts of acceptability and responsiveness to consumer needs.\textsuperscript{84} The Cochrane Collaboration provides a model of participatory approach to the generation of information to support evidence-based decision making. Objective and accessible evidence is an important tool to support shared-decision making in health care.\textsuperscript{85}

- **Consumer directed care** – Consumer directed care (CDC) is both a philosophy and an orientation to service delivery where consumers, including care recipients and their carers, can choose and control the services they get to the extent that they are capable and wish to do so.\textsuperscript{86} The main objective of CDC is to offer consumers more choice and control than they would have from traditional approaches to care.\textsuperscript{80} CDC is not one model of care, but a continuum of care with the consumer able to direct their level of involvement.

Person-centred approaches are a key feature of successful consumer directed models. CDC necessarily involves more active involvement of the consumer in the planning and design of the supports they receive, and the development of a person-centred individual plan which considers the strengths, needs and goals of an individual, as well as their family/carer and life circumstances.

CDC approaches have been implemented in the UK and are increasingly being adopted in Australia, particularly in the aged care and disability sectors, as seen by the introduction of the National Disability Insurance Scheme (NDIS) and changes to the arrangement of Aged Care Funded Home Care Packages. These changes are outlined in further detail in Section 3.1.

### 2.2 Frameworks for participation

The term ‘consumer participation’ encompasses a vast range of activities. Participation can occur at any level of the health system and these activities can vary in the extent to which they

\textsuperscript{80} Coney, S. 2004, p.12
\textsuperscript{81} Gregory, J. 2007, p.9
\textsuperscript{82} Coney, S. 2004, p.12
\textsuperscript{83} ibid. p.12
\textsuperscript{84} ibid.
\textsuperscript{85} ibid.
\textsuperscript{86} Aged and Community Services Australia (ACSA) 2010, *Guiding principles for consumer directed care*. ACSA
\textsuperscript{87} Tilly, J. & Rees, G. 2007 *Consumer Directed Care: A way to empower consumers?* Alzheimer’s Australia, Paper 11
achieve active involvement by consumers. Different methods of participation serve different purposes and will achieve different outcomes.

This section outlines commonly used frameworks to make sense of the multi-dimensional nature of participation.

### 2.2.1 Levels of participation

“Participation, or should be, something that occurs in every facet of health care and in every encounter between the user and health care services.”

In general, theoretical and policy approaches to consumer participation have been developed to align with various ‘levels’ of the relevant health care system. Most approaches consider three levels at which participation can occur:

- **the individual care level**, focusing on an individual’s involvement in their own health care and treatment, with an emphasis on patient rights and advocacy
- **the health service level**, focusing on consumers’ involvement in service design, delivery and quality improvement, with an emphasis on collaboration and quality
- **the health system level**, focusing on involvement in policy development and research, with an emphasis on systems and co-design, and expertise and evidence respectively.

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88 Gregory, J. 2007, p.3  
89 ibid. pp.16-17  
Note that in some jurisdictions, including Victoria, the health service level is further broken down to distinguish between program or department level (operational focus) and the health service organisational level (strategic focus). NZ’s consumer engagement framework, Partners in Care\(^9\), is an example of a framework that adopts a three-level approach to conceptualising participation.

**Figure 5: Levels of consumer participation, Victoria and New Zealand**

**Identified levels of consumer participation in the Victorian health system\(^9\)**

**Identified levels of consumer participation in the mental health service system\(^9\)**

The Victorian action plan for strengthening consumer participation in mental health services identifies three levels of involvement in the mental health service system:

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\(^9\) HQSCNZ 2012

\(^9\) Victorian Department of Health 2009

2.2.2 Intensity of participation

The breadth of participation activities is often conceptualised as existing on a continuum of intensity. One of the earliest and most frequently cited models of participation is the ‘ladder of citizen participation’. This model considers participation as a continuum spanning from ‘tokenistic’ or passive forms of participation (such as provision of information only, as a necessary but insufficient requirement for participation), through to those which allow service users to take a more active and direct role in decision-making, achieved from ‘partnership’, ‘delegation’ and ultimately ‘citizen control’.

A criticism of this framework is that a hierarchical classification implicitly places a value judgement about the ‘best’ or ‘true’ forms of participation. Specifically, it does not adequately consider that different methods of participation may be more or less appropriate depending on the objectives and intended outcomes.

Individual preferences will also vary in the extent to which individuals want to be involved in decisions about their own healthcare, health services and health policy. With respect to policy, people are unlikely to want to be engaged extensively over every issue, but rather, they want to be engaged appropriately. Good practice indicates that the impact on the community or the more difficult the choices, the more appropriate it is to undertake more intensive and/or extensive engagement. People also differ in their desire and capacity to be actively involved in decisions relating to their treatment and services accessed, with some individuals not considering their experiences as being relevant or significant enough to make an informed decision, preferring to delegate this to experts such as health professionals and government.
These differences can be attributed to factors such as literacy/communication skills, cultural background, and prior interactions with health professionals and government.

Contemporary approaches to conceptualising the intensity of consumer participation have transitioned from a hierarchical classification to discontinuous interactions, with no single methodology and no shared theoretical base.\textsuperscript{101,102} This model was considered in Victoria, with an adaption of this typology incorporated into the \textit{Doing it with us not for us} policy.

An example of this type of framework is the ‘IAP2 Public Participation Spectrum’, developed by the International Association for Public Participation.\textsuperscript{103} The spectrum identifies forms of participation with increasing levels of public impact (progressing across ‘inform’, ‘consult’, ‘involve’, ‘collaborate’ to ‘empower’).

2.2.3 Examples of frameworks for consumer participation

There are a number of alternative frameworks that have been developed to conceptualise consumer participation.

\textit{Framework for consumer engagement in health policy}

Recently, the Australian Institute of Health Policy Studies (AIHPS) developed a framework for describing consumer engagement in health policy. The framework identifies eight interacting issues that influence the practice of consumer engagement.

\textsuperscript{101} Gregory, J. 2007 p.15
\textsuperscript{102} Bishop, P. and Davis, G. 2002 ‘Mapping public participation in policy choices’ \textit{Australian Journal of Public Administration} 61:14-29
This framework synthesises a number of models of participation and may assist policy makers to review consumer engagement practice, to plan consumer engagement programs, and to identify the trade-offs that must be made when conducting consumer engagement. The development of the framework followed a detailed review of the literature on consumer engagement in health policy.

National Framework for Consumer Involvement in Cancer Control

The National Framework for Consumer Involvement in Cancer Control is a good example of how the theoretical approaches to consumer participation can inform practical guidance about how to achieve meaningful consumer participation.

The Framework was developed by Cancer Australia in partnership with Cancer Voices Australia to enhance meaningful consumer involvement at all levels of cancer control to improve outcomes and experiences for people affected by cancer.

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105 ibid. p.iii

106 ibid.

The framework explicitly recognises that not all types of participation are equal: the skills and capabilities that consumers, clinicians and organisations require will vary depending on the level (or ‘intensity’) of consumer involvement and the role that the consumer is playing.

For example, the model in Figure 5 below, sets out the range of consumer involvement opportunities, recognising that a smaller number of consumers and organisations will be leading cancer control activities and the greatest number of consumers will be exchanging information. The model depicts the additional skill sets that consumers need as the extent of control they exercise increases and the organisational supports necessary to sustain effective consumer engagement.

**Figure 5: Consumer involvement capability**

Source: Cancer Australia and Cancer Voices Australia 2011

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108 ibid, p.9

109 ibid, p.9
The Framework also highlights the importance of understanding that consumers are being expected to play.\textsuperscript{110} Five types of consumer involvement roles are set out in Figure 6 below:

\textit{Figure 6: Consumer involvement roles}

![Figure 6: Consumer involvement roles](image)

\textit{Source: Cancer Australia and Cancer Voices Australia 2011\textsuperscript{111}}

Being explicit about the role that consumers are expected to play is necessary to define what attributes they can bring to the role, the preparation that consumers need to participate effectively, and the expectations of clinicians and organisations in relation to helping facilitate effective engagement.

Implementation of the framework is supported by a resource toolkit, developed by the Health Issues Centre. The toolkit includes tools and resources for consumers, policy makers, researchers, CEOs and Executives, service managers and health professionals.\textsuperscript{112}

\textbf{2.2.4 Summary}

The theory and practice of consumer participation has evolved since the 1960s. The developments are reflective of broader social change, democratic movements, and market models, as well as the modernisation and explicit person-centred and quality driven approaches to health care. This has raised community expectations for information and participation in decision making.

The concept of participation is open to a level of interpretation and has not been consistently understood across jurisdictions and health care systems. Hence, a number of frameworks have been developed to classify and stratify consumer participation techniques. These frameworks are based on a number of assumptions in relation to the acceptability of consumer participation in relation to the decision making process at various levels of the health care system.

\textsuperscript{110} ibid, p.10
\textsuperscript{111} ibid, p.11
\textsuperscript{112} Consumer Involvement Toolkit, Cancer Australia website, Available at http://consumerinvolvement.canceraustralia.gov.au/, accessed 5 March 2014
3 Consumer participation policy in Australia

This chapter provides an overview of consumer participation (and related terms) public policy documents in Australia (federal and state based policies) and selected international jurisdictions.

3.1 National consumer participation policy

**National snapshot**

- The recent release of the NSQHS Standards sets out the mandatory expectations of health services in relation to consumer participation in order to meet accreditation requirements. The standards describe explicitly how healthcare organisations should engage with consumers at a governance and organisational level.\(^\text{113}\)

- The standards reflect a commitment to supporting consumer participation articulated in key national policy documents, including:
  - *Australian Charter of Healthcare Rights* (2008)\(^\text{114}\), which supports a shared understanding of the rights of patients and consumers between those seeking health care and those providing healthcare.
  - *Australian Safety and Quality Framework for Health Care* (2010)\(^\text{115}\), intended to guide quality improvement efforts across the health system and promote discussion with consumers, clinicians, managers, researchers and policy makers about how best to form partnerships to improve safety and quality. Consumer centred care is one of the framework’s three core principles.
  - *Australian Safety and Quality Goals for Health Care* were endorsed by the Australian Health Ministers in August 2012. ‘Partnering with consumers’ is one of three goals, alongside safety of care and appropriateness of care.

- A commitment to consumer participation and consumer centred care is reflected in key national healthcare strategies. The *National Primary Health Care Strategy* (2013), the *National Chronic Disease Strategy* (2006), the *Fourth National Mental Health Plan* (2009) and the *Roadmap for National Mental Health Reform 2012-2022* all state that a patient centred approach to health care is needed to improve the quality of health care in Australia.\(^\text{116}\) Aboriginal and Torres Strait Islander primary healthcare policies also reflect patient-centred principles and aim to be community- and family-centred.\(^\text{117}\)

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\(^{113}\) ibid. p.33  
\(^{114}\) ACSQHC 2008  
\(^{116}\) ACSQHC 2011, p.32  
\(^{117}\) ibid. p.35
The introduction of the NDIS and new arrangements for Aged Care Funded Home Care Packages are examples of consumer directed care approaches in Australia.

Key national policy documents and current reform directions are summarised below.

**Australian Charter of Healthcare Rights**

The *Australian Charter of Healthcare Rights* was endorsed in 2008 by the Australian Health Ministers. The charter sets out minimum standards, rights, expectations and entitlements of patients and consumers when seeking or receiving healthcare services. Participation is one of the seven rights, with the others being Access, Safety, Respect, Communication, Privacy, and Comment. With respect to participation, the Charter states that consumers have the right to “join in making decisions and choices about (my) care and about health service planning.”

The Charter is accompanied by guides for consumers, families and carers, and healthcare providers about their roles in realising the Charter. The Charter is primarily a resource for consumers, providing them with a clear understanding of their rights when seeking or receiving services at the level of individual health care and treatment. With respect to healthcare providers, expectations are relatively limited to a focus on the provision of health information, informed consent and awareness of the patient/consumer’s personal circumstances.

The *Australian Charter of Healthcare Rights* has consolidated state based efforts previously required by the Commonwealth. From 1993, all Australian states were required to develop public hospital patient charters to inform patients of their rights, as mandated under the *Australian Healthcare Agreements*. The national charter is intended to supersede these documents. It is expected to be uniformly applicable across all state and territories and all settings of care, including public hospitals, private hospitals, general practice and other community environments.

The Victorian Department of Health has tested the Charter with consumers to ensure its relevance. The Department publishes and distributes the Charter via a web order in English, 25 community languages, Braille and audio. The Department also pioneered the Easy English version of the Charter.

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118 ACSQHC 2008


120 ibid.

Australian Safety and Quality Framework for Healthcare

The Australian Safety and Quality Framework for Healthcare was endorsed by Health Ministers 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, namely, that care is consumer centred, driven by information and organised for safety.\textsuperscript{122}

The framework identifies what the principles mean for a consumer or patient and areas for action by people in the health system. The framework is intended to:

- 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 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 partnership to improve safety and quality.\textsuperscript{123}

Victoria is currently expanding on this framework with the development of the Victorian Quality Framework.

National Safety and Quality Health Service Standards

In 2010 the Australian Health Ministers agreed to the ACSQHC Australian Safety and Quality Health Accreditation Scheme, which was followed in 2011, by the release of the NSQHS Standards. The standards were implemented nationally from 1 January 2013. The ten standards aim to provide a consistent set of mandatory measures of safety and quality, and provide guidance on the benchmark level of care consumers can expect from their health services.\textsuperscript{124}

The standards are compulsory for the majority of public and private health care organisations in order to receive accreditation.\textsuperscript{125}

The health service standards explicitly recognise the role of patients and carers as shown in the statement below:

"Patients and carers have an important role to play in the safe delivery of health care. As a partner with health service organisations and their healthcare providers, patients and carers will be involved in making decisions for service planning, developing models of care, measuring service and evaluating systems of care. They will also participate in making decisions about their own health care and for this they will need to know and

\textsuperscript{122} ACSQHC 2010
\textsuperscript{123} ibid.
\textsuperscript{124} From 1 January 2013, all eligible Victorian Health Services will be assessed against the NSQHS Standards. The scheme applies to all Health Services, including small rural health services, clinical mental health services, and public dental services in community health services. The Victorian Department of Health, as the jurisdictional regulator, has responsibility for verifying the accreditation status of public Health Services in Victoria (Victorian Department of Health 2013, Victorian health policy and funding guidelines 2013-14 – Part one: key changes and new initiatives, Victorian Government, Melbourne.)
exercise their healthcare rights and be engaged in their health care and treatment decisions. Patients and carers will have a need to access information about options and agreed treatment plans. Health care can be improved when patients and carers share – with their health care provider – issues that may impact on their compliance with treatment plans.”

The first two standards – Standard 1: Governance for the safety and quality in health service organisations and Standard 2: Partnering with consumers – relate directly to consumer participation. The remaining eight standards relate to other areas of patient care; importantly seven of these standards also include criteria that describe different requirements for engaging with patients, through communication and the provision of clinical information.

The service standards, relevant criteria and actions required are provided in Appendix F. Given the variable size, structure and complexity of health service delivery models, a degree of flexibility has been built into the standards. Each action within a standard is designated as either core (that is, critical for safety and quality) or developmental (that is, an aspirational target). Details of the accreditation process for Victorian health services are found in the Department’s Accreditation – Performance Monitoring and Regulatory Approach Business Rules.

The NSQHS Standards will be evaluated and reviewed after full implementation and the review is scheduled to commence in 2015 and be completed by 2017.

NSQHS Standards and Victorian standards on consumer participation

Due to the mandatory nature of NSQHS Standards there is some overlap and duplication in the recommended reporting when compared to the Doing it with us not for us: Strategic direction 2010-13.

As discussed in section 1.1.1, the Doing it with us not for us: Strategic direction 2010-13 requires public health services to report against five standards through specific indicators. The five standards are completely or partially addressed by the NSQHS Standards, however, the majority of the priority actions are not assessed for accreditation.

A more detailed review of the areas of overlap between the Victorian and NSQHS Standards relating to consumer participation is provided in Appendix F.

The Department of Health has prepared guidance for Victorian health services to assist in identifying Victorian tools and resources that services can use to demonstrate an action under the NSQHS standards is being met. The Victorian Department of Health Accreditation Resources is available at http://www.health.vic.gov.au/accreditation/resources/victorian-department-of-health.

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126 ACSQHC 2012, p.6
127 ibid. p.3
128 ibid. p.4
National Health Reform Agreement

In 2011, the Council of Australian Governments (COAG) endorsed the National Health Reform Agreement. Equity of access to high quality health care and a commitment to a health system that promotes social inclusion and reduces disadvantage are key principles underpinning the agreement.130

The agreement emphasises the importance of strong accountability and transparency mechanisms, including the introduction of the new NSQHS Standards, and expanded role for the Australian Commission on Safety and Quality in Health Care in developing clinical guidelines, and the jurisdictional requirement for an independent complaints body.

Australian Safety and Quality Goals for Health Care

In August 2012, the Australian Health Ministers agreed to the first set of Australian Safety and Quality Goals for Health Care. ‘Partnering with consumers’ is one of the three goals, alongside safety of care and appropriateness of care.131

Four outcomes are specified under the goal of partnering with consumers:

- Consumers are empowered to manage their own condition, as clinically appropriate and desired
- Consumers and health care providers understand each other when communicating about care and treatment
- Healthcare organisations are health literate organisations
- Consumers are involved in a meaningful way in the governance of healthcare organisations.

Other national strategies

There are a number of national policies that are focused on clinical, service and population health matters which have explicit requirements in relation to consumer participation. Examples include the National Primary Health Care Strategy (2013) and the National Chronic Disease Strategy (2006). Aboriginal and Torres Strait Islander national primary healthcare policies – including the National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013132 – reflect patient-centred principles and also emphasise the importance of a community- and family-centred approach. This involves taking a life course approach, focusing on establishing early life resilience and advantages in child development.133

133 ACSQHC 2011
Directions in Mental Health

The mental health sector has been a leader in driving consumer participation and engagement strategies across Australia.

National Standards for Mental Health Services (2010)

The National Standards for Mental Health Services were updated in 2011 to reflect a changing context and evolving best practice. The standards now include a standard for services that support recovery. They also include standards for the involvement of consumers and carers in the planning, development and evaluation of services.

Roadmap for National Mental Health Reform 2012-2022

In 2012, COAG endorsed the Roadmap for National Mental Health Reform 2012-2022. The Roadmap provides a national framework for the focus or renewal of related policies and strategies, including current and future National Mental Health Plans, cross-portfolio national policies and strategies, and Commonwealth, state and territory policies, strategies and frameworks.

The promotion of person-centred approaches is the first priority identified in the Roadmap for realising the vision of:

“A society that values and promotes the importance of good mental health and wellbeing, maximises opportunities to prevent and reduce the impact of mental health issues and mental illness and supports people with mental health issues and mental illness, their families and carers to live full and rewarding lives.”

The assumptions underpinning this priority are that a person-centred, recovery oriented approach, “allows people flexibility, choice and control over their recovery pathway, and response to each individual’s unique needs, circumstances, life-stage choices and preferences.”

The Roadmap also highlights the importance of recognising that individuals’ life roles – for example, as a parent, partner, employee, community member – influence the expression of their needs, preferences and priorities.

Professional, respectful and collaborative approaches by clinical and non-clinical providers are identified as the building blocks of a person-centred mental health system.

The Roadmap identifies the use of individualised funding mechanisms (such as the NDIS) and opportunities for co-production as key strategies to promote person-centred approaches to mental health. Other strategies included increased availability of prevention and intervention activities, assistance to access national supports, and integrated and recovery-oriented approaches to service delivery.

135 Council of Australian Governments (COAG) 2012, Roadmap for National Mental Health Reform, COAG, Canberra.
136 ibid. p.9
137 ibid. p.6
138 ibid. p.14
139 COAG 2012, p.15
In September 2013, the Expert Reference Group provided recommendations to COAG Working Group on National Mental Health Reform on a national set of targets and indicators to monitor progress towards the Roadmap Vision by all Australian governments. Consumer experience was identified as one of the six domains for change: “More people will have a positive experience of support, care and treatment”.  

**Community Common Care Standards**

The Community Common Care Standards were developed jointly by the Australian Government and State and Territory Governments. The Standards draw together differing standards across the jurisdictions and the Commonwealth into a single set of quality standards that apply to services funded under the Home and Community Care (HACC) Program, packaged care programs (Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) and Extended Aged Care at Home Dementia (EACHD), and the National Respite for Carers Program (NRCP).

They comprise three Standards incorporating 18 expected outcomes. The three Standards are: 1) Effective Management 2) Appropriate Access and Service Delivery and 3) Service User Rights and Responsibilities. Each Standards includes a principle that summarises the intent of that Standard. Partnership is key to Standard 2, with the principle stating that services are “planned, delivered and evaluated in partnership with [the service user] and/or their representative.”

The quality review incorporates a self-assessment (supported by a standardised self-assessment tool), on-site visit by the Quality Review team, delivery of a Quality Review report accompanied by an improvement plan template, and completion of an improvement plan by the service provider (updated annually).

**National Disability Insurance Scheme**

Principles of person and family-centred care are central to the design of the National Disability Insurance Scheme (NDIS). Under the NDIS, individuals will work with a service provider to develop and individual care plan. Individuals can choose their own support providers and whether to self-manage their funding or ask another person or organisation to manage some or all of their funding. The introduction of individualised support arrangements aims to allow individuals, their families and carers to exercise greater choice and control over the ‘who’ ‘when’ ‘how’ and what’ of the support they receive.

The introduction of the first stage of the NDIS in 2013 is reshaping relationships between consumers, service providers and government, and in doing so, service providers are starting to think about the types of skill sets they require in this new environment.

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142 Ibid. p.6

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Consumer directed care approaches in Aged Care

From July 2013 all new Aged Care Funded Home Care Packages allocated to providers must be offered on a CDC basis, with these arrangements expanding to include all existing packages from July 2015. The recent DoHA review of consumer directed care in community aged care services found:

“Even after a short period of operation, CDC appeared to have a positive impact on participants’ level of satisfaction with various aspects of their life. Participants reported increased satisfaction with their ability to participate in social and community activities, their ability to visit family and friends, the quality of their home life and close relationships, and their health and wellbeing.”143

3.1.1 The role of consumer organisations

The Consumer Health Forum of Australia (CHF) is an active contributor to the health policy agenda in Australia. The aim of CHF’s policy activities is to ensure that the consumer perspective is considered and consumer needs are addressed in the development and review of national health policies and reforms. CHF contributes to the policy agenda through submissions to national inquiries, conducting projects in topical policy areas, providing position statements on areas of concern for health consumers, meetings with key stakeholders including government, health professionals and industry bodies, and providing media comment on current health policy issues. Examples of current projects being undertaken by CHF can be found at https://www.chf.org.au/current-projects.php.

3.2 Consumer participation policy in other states and territories

While there is variation in the degree to which other states and territories have progressed consumer participation policies, consumer participation is gaining attention across all Australian jurisdictions as an important quality improvement strategy. An example of this is the content of the recent Innovation in Health Conference which included presentations of quality improvement initiatives relating to participation and patient centred care in Victoria, New South Wales, South Australia and Western Australia.

It is apparent that Victoria introduced consumer participation policies in advance of a number of other jurisdictions, contributing to the shaping of other state consumer participation policies with at least four jurisdictions requesting to use the Doing it with us not for us policy as the bases of their policies. However, with recent national policy developments, particularly the release of the NSQHS standards, it is timely to examine activity elsewhere in Australia.

An overview of key public policy documents of each jurisdiction relating to consumer participation across Australia is provided in the subsequent sections.

143 KPMG 2012, Evaluation of the consumer directed care initiative KPMG
Australian Capital Territory

Australian Capital Territory (ACT) Snapshot

- The Consumer and Carer Participation Framework\(^{144}\) provides high level strategic direction in relation to public health service expectations for consumer engagement. A web-based search did not return any records of existing implementation strategy documents or evaluation of the framework.

- Consumer feedback standards have been in place since 2003 to guide the effective management and use of consumer-initiated feedback. The feedback standards are accompanied by a Service Improvement Tool to support ongoing improvement among health services in consumer feedback practices. The standards are consistent with the former Australian Council of Healthcare Standards (ACHS) Evaluation and Quality Improvement Program (EQuIP).

The ACT Health Directorate released the Consumer and Carer Participation Framework in October 2011. The framework was developed in consultation with consumers and carers, and was guided by a steering group (with representatives from Health Care Consumers Organisation ACT, ACT Mental Health Consumers Network and Carers Act).\(^{145}\) The Framework is a high-level document, providing an overview of the evidence-base around the benefits of consumer participation, outlining common enablers and barriers to effective consumer participation, and highlighting examples of current ACT initiatives that promote participation. The framework is not intended to serve as a practical implementation tool, with the policy stating that implementation and strategy documents will be developed at a later date.\(^{146}\)

The framework refers to a number of national instruments, including the NSQHS Standards, the Charter of Healthcare Rights and the Safety and Quality Framework for Health Care. The framework states that the success of the policy will be evaluated through these existing channels, in addition to a three yearly review process that will be conducted in conjunction with consumers and carers to test the success of the framework and drive continuous improvement.\(^{147}\) A web-based search did not return any information about the review, which is scheduled to take place in 2014.

The ACT Consumer Feedback Standards, developed in 2003, aim to embed consumer feedback as a mechanism for quality improvement in health services.\(^{148}\) The standards were developed as part of the ACT Consumer Feedback Project, a collaborative project undertaken by government, health services and consumer organisations between 2002 and 2003.

Other practices and initiatives established in the ACT to support consumer and carer participation include:

\(^{144}\) ACT Health Directorate 2011, Consumer and Carer Participation Framework, ACT Government, Canberra.
\(^{145}\) ibid.
\(^{146}\) ibid.
\(^{147}\) ibid.
Department of Health, Victoria
Summative Evaluation of Doing it with us not for us
Current State Analysis
July 2014

- implementation of the Australian Charter of Healthcare Rights and Charter on the Rights of Children and Young People in Healthcare Services in Australia
- Consumer, Carer and Community Representative program and Reimbursement Policy
- relationships with consumer advocacy agencies through service funding agreements
- Respecting Patient’s Choices (advanced care planning program that commenced at Canberra hospital in 2006).

3.2.2 Queensland

Queensland (QLD) Snapshot

- Each Queensland local health and hospital network (LHHN) is required under the Health and Hospitals Boards Act 2011 to develop and publish a consumer and community engagement strategy in consultation with local consumers and communities.149
- The peak body, Health Consumers Queensland, has developed a framework to guide and support consumer and community engagement activities undertaken by the LHHNs.
- The approach to engagement is consistent with the Victorian approach. The document includes a set of practice examples at each level of engagement (individual, services, network and system) as a means to support implementation across the three key domains of health service operation (service planning and design, service delivery and service monitoring and evaluation).

QLD health services are currently undergoing a period of transformation driven by the introduction of the Health and Hospitals Network Act 2011. As part of this legislation, health service districts were transferred to local health and hospital networks (LHHN) in July 2012.

Health Consumers Queensland (the peak health consumer organisation), was commissioned by the QLD Department of Health to develop the Consumer and Community Engagement Framework.150 The objective of this framework was to guide and inform LHHN consumer engagement strategies. The framework is conceptualised as a multidimensional framework across three axes. Specifically:

- three key domains of health service operation (service planning and design, service delivery and service monitoring and evaluation);
- four different levels of engagement (individual, services, network, system)
- five elements of engagement based on a continuum that identifies an increasing level of participation (information, consultation, involvement, collaboration and empowerment).151

The framework is underpinned by nine principles of consumer and community engagement that apply across all dimensions of the framework: participation, person-centred, accessible and

149 Health and Hospitals Network Act 2011 (QLD) s.40.
151 ibid, p.12.
inclusive, partnership, diversity, mutual value and respect, support, influence, and continuous improvement. Figures 7 and 8 (overleaf) illustrate the relationship between the principles and the domains, levels and elements of participation.

The policy sets out practical implementation considerations, including a number of practical examples of engagement strategies to facilitate consumer participation in service planning and design, service delivery, and monitoring and evaluation. The framework makes explicit links between the QLD Health and Hospitals Network Act and the NSQHS Standards.

### 3.2.3 New South Wales

**New South Wales (NSW) Snapshot**

- A number of key policy and discussion papers were released around 2001 which raised the profile of the importance of involving consumers and the community in health decisions. However, no specific policy has since been released.

- **NSW 2021**\(^{155}\) is the current overarching ten year strategic plan, requiring all publicly funded health services to drive improvements in patient satisfaction, as measured through comparisons with prior annual results of previous patient experience surveys, and to ensure alignment with the NSQHS Standards.

NSW released a number of reports in 2000 and 2001 which included components of consumer participation, outlined strategic directions and emphasised the importance of consumer input.

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\(^{152}\) ibid, p. 13-14

\(^{153}\) ibid.

\(^{154}\) ibid.,p.9

into decisions made in the health system.\textsuperscript{24,25,26} These reports are the only consumer participation policies that were able to be sourced through a web search. Based on review of publically available documentation, there have been a number of other initiatives that have incorporated good practice principles of consumer participation. Examples include:

- establishment of formal structures for consumer participation in the organisational structures of NSW Area Health Services;
- explicit focus on patient models of care which emphasis patient centred approaches to service planning;
- conduct of consultation processes to improve the NSW Agency for Clinical Innovation consumer engagement which coordinates the clinical networks entities;\textsuperscript{156}
- the establishment of the NSW Health Care Complaints Commission, which involved substantial consumer involvement; and
- the establishment of the Clinical Excellence Commission (CEC) in 2004. A key role of the CEC is to build capacity for quality and safety improvement in health services.\textsuperscript{157}


3.2.4 Northern Territory

**Northern Territory (NT) Snapshot**

- Patient-centred approaches focus on the involvement of consumers in health care planning and evaluation activities.
- Consumer participation is supported by specific initiatives for improving engagement between Aboriginal and Torres Strait Islander Peoples and health professionals and building capacity and understanding of culturally appropriate care provided by health professionals.

Patient-centred approaches employed by the NT include the direct involvement of consumers by involving patients in the evaluation of services and also families and carers in service planning. In addition, the Northern Territory also conducts patient surveys.\(^{158}\)

Strategies and policies at the system and service level include the requirement for all hospitals to include consumer representation on boards and also in reference and advisory groups. The NT also has a strong focus on diversity and equity in participation at the service and individual levels. Examples include:\(^{159}\)

- Aboriginal Community workers in remote communities to improve communication between patients and health professionals
- developing a specific Indigenous Renal Palliative care Pathway directly with consumers and their families technology tailored to the needs of Aboriginal and Torres Strait Islander Peoples, including Talking Posters which provide health related information in local Aboriginal dialect, and DVDs to assist healthcare workers to understand cultural needs and preferences better.

3.2.5 South Australia

**South Australian (SA) Snapshot**

- All SA public health services need to comply with specific standards outlined in the *Framework for Active Partnership with Consumers and the Community*. The framework is closely linked to the NSQHS Standards and includes reporting requirements.
- The *SA Health Guide for engaging with consumers and the community* has been developed to assist healthcare services in implementing the framework.

In 2012, SA implemented the *Framework for Active Partnership with Consumers and the Community*\(^{160}\) as a means to strengthen and improve the practice of consumer and community engagement processes across SA. It is intended to ensure:


\(^{159}\) Ibid.

\(^{160}\) Ibid.
that there are mechanisms in place to actively engage with consumers and the community in order to meet their needs and develop appropriate service that the methods and practice of consumer engagement are guided by best practice.

All SA Health services are required to adhere to a set of specific standards for partnership, as outlined in Box 2 below. These standards closely align with the principles of the Australian C Charter of Healthcare Rights.

Box 2: Standards – SA Framework for Active Partnership with Consumers and the Community

7. Standards

With the implementation of this framework, all organisations and services in SA Health will ensure:

7.1 All consumers:

- have access to safe, high-quality health care and treatment
- receive information about their healthcare rights
- receive information about their health and their care that is appropriate to their capacity understand and promotes health literacy
- have access to privacy and confidentiality around care and treatment
- are partners in decisions and choices about their individual care and treatment
- give informed consent to decisions about their individual care and treatment
- are informed if something goes wrong, and receive and explanation, apology and support as appropriate.

7.2 Consumers, carers and the community are involved in:

- governance of the healthcare service. This should include engagement with priority setting, planning, quality improvement and evaluation of health services
- activities to improve health literacy. This should include providing feedback on patient information and publications
- the design of care to improve the patient experience and patient health outcomes, by better meeting needs and preferences, through engagement with activities to design or re-design care and how care is provided.

7.3 Consumers and the community are well informed and supported through training and other relevant means to participate in the governance of the health service on behalf of their communities

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7.4 SA Health employees or persons who provide health services on behalf of SA Health understand and respect the role of consumers and ensure processes are used to support consumer engagement.

7.5 Appropriate resources are provided for education and training of employees, consumers and the community on consumer engagement.

7.6 Data from consumer feedback, complaints and patient / consumer experience surveys are used to measure and improve health services. Consumers and communities participate in the evaluation of this data and planning of quality improvement activities. Data and quality improvement action plans are considered by senior management.

The framework outlines specific responsibilities for guidance, implementation and monitoring with respect to these standards across key stakeholders in government and Local Health Network (LHN) executives, management and staff.\(^{161}\)

LHNs are required to report on these standards on an annual basis and the NSQHS Standards 1 and 2. They are also required to report annually and develop an action plan to improve any domains of care that are identified through the SA Consumer Experience Surveillance System (SACCESS) to be below a particular benchmark.\(^{162}\) The adoption of a similar accountability and continuous improvement mechanism may be considered in the development of requirements for the new Victorian consumer participation policy.

To facilitate the implementation of the framework, SA Health has also developed the SA Health Guide for engaging with consumers and the community. This includes toolkits and a resource guide, and is designed to assist health care services in the implementation of the framework, in accordance with best practice. The development of these resources included input from a key consumer who is an Australian ambassador for the WHO Patient Safety Program (as a ‘Patient for Patient Safety’). This individual was also involved in the promotion of the Victorian policy and reporting requirements, enabling key elements of the Victorian approach to be incorporated by SA.

\(^{161}\) ibid.
\(^{162}\) SA Health 2012, p. 7
3.2.6 Tasmania

Tasmanian Snapshot

- Patient-centred approaches to supporting consumer, carer and community engagement are outlined in the *Your Care, Your Say* policy released in 2010. The policy outlines clear objectives, principles and a framework for involvement and is supported by an online toolkit with engagement techniques tailored by degrees of difficulty and cost to implement.

- Initiatives from the action plan have included a state-wide conference to improve an understanding of the patient’s perspective and capacity building amongst healthcare professionals. Other approaches have included a focus on consumer involvement in healthcare planning and increasing health literacy.

Tasmania’s *Your Care, Your Say*, released in 2010 by the Tasmanian Department of Health and Human Services sets out a framework for consumer, carer and community engagement.

Built around four objectives, the framework seeks to encourage consumers, carers and the community to take part in decision making. The four objectives are as follows:163

- **No wrong door** – making sure you can access the services you need.
- **Listening and responding** – involving you in developing responsive, accessible and sustainable health and care services.
- **Capacity building** – making sure we all have the skills, knowledge, and know-how to practice engagement meaningfully.
- **Relationship building** – developing trust and understanding to develop healthier communities.

*Your Care, Your Say* also outlines principles of responsiveness, which include fairness, information sharing, taking responsibility, being supportive, respectful, open and honest, collaborative and willing to learn and a framework across all levels of the healthcare system. Priorities have also been set and a toolkit developed to assist healthcare workers engage with patients, clients and the community. The toolkit is available from the Department’s website and includes engagement techniques by level of difficulty and estimated cost of implementation.164

Initiatives from the action plan include system level approaches, including a state-wide video conference with the aim of improving the understanding of the patient’s perspective and enabling capacity building and information sharing amongst healthcare professionals. Service level approaches have included the involvement of consumers to clinical networks to support healthcare planning through the dual involvement of consumers and clinicians. Individual level

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Approaches have included a focus on health literacy to improve patients’ understanding of medical conditions with the aim of improving decision-making via informed consent.165

### 3.2.7 Western Australia

**Western Australian (WA) snapshot**

- The **Consumer Carer and Community Engagement Framework**166 sets the policy requirements in relation to consumer participation, and incorporates action plans and practical tools to assist with the implementation of consumer engagement activities at individual, program, area health service and departmental levels.
- The WA Department of Health conducted an evaluation of the framework; however, the results are not publicly available. Anecdotal feedback has highlighted the need for a comprehensive implementation process and the need for policy implementation approaches to avoid a reliance on “goodwill and personal interest of champions”.167
- WA Health funds the Health Consumers’ Council of WA, an independent, community-based organisation, to act as a formal point of reference on consumer matters in health policy development, planning and service delivery.168

The **WA Consumer Carer and Community Engagement Framework**169 was launched in 2007. This framework considers consumer participation strategies across four levels of the health system (individual, program, area health service, departmental). The framework's development is a core component of the WA Health reform program. However, it is noted that the framework is not explicitly recognised in the current strategic vision for WA Health outlined in **Working Together – WA Strategic Health Intent 2010-2015**.170

The framework links with existing health policy. It emphasises the need to better engage with CALD communities. The framework articulates linkages with CALD policies, including the **WA Health Aboriginal Cultural Respect Implementation Framework (2005)** and the **Framework for Substantive Equality**.171

The **Consumer Carer and Community Engagement Framework** objective is to make consumer engagement a part of WA health service’s ‘core business’.172 The framework provides an

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168 WA Department of Health 2007, p.11
169 ibid.
172 WA Department of Health 2007
overview of the good practice evidence, outlines key principles of consumer engagement, and includes a number of practical tools to assist health service staff to implement the framework. Examples of tools include action plans templates, a review and recording tool, and ‘how to guides’ for staff to better engage with consumers, carers and communities. Key examples of implementation considerations are outlined below:

- establishment of a Consumer, Carer and Community Engagement Group to work with WA Health to plan, implement and evaluate engagement strategies under the framework
- introduction of Area Health Service consumer engagement teams to support programs for health staff and consumers and carers.

The framework outlines a phased approach to implementation, which includes practical action plans for each level of health services at each phase of implementation. The framework outlines evaluation measures and refers to a formative evaluation process. However, the details of this evaluation and associated results are not publically available.

### 3.3 Summary

A commitment to consumer participation and principles of patient-centred care is a feature of state- and territory-based healthcare policy across Australia, although the pace at which the jurisdictions have progressed their policies and the extent to which performance and accountability frameworks are built-in varies.

While SA’s policy was developed more recently, they have quickly progressed to annual mandatory reporting of specific standards, and have aligned these with the NSQHS Standards. Importantly, they have produced complimentary practical tools to assist health services in implementing the framework.

Tasmania, QLD and the ACT have high-level frameworks for consumer participation in place. QLD requires all LHNs to put in place a consumer participation strategy and have published a framework to guide these strategies. While there are no standards, they have a strong conceptual framework for incorporating activities at various levels of a health service. The Tasmanian framework is also supported by priorities and an online toolkit with engagement techniques tailored by degrees of difficulty and cost to implement.

The NT, while not having an overarching policy, has developed patient-centred approaches focus on the involvement of consumers in health care planning and evaluation activities at the system level and specific initiatives at the system and individual levels for improving engagement between Aboriginal and Torres Strait Islander Peoples and capacity and a better understanding of cultural appropriateness amongst health professionals.

NSW appears to have progressed at a slower rate when compared to other jurisdictions and current policy may need to be reviewed to reflect NSQHS standards and understanding of best practice. Similarly, early action by WA does not appear to have progressed further at this stage.

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173 WA Department of Health 2007
174 WA Department of Health 2013, *Health System Improvement: Consumer, Carer and Community Engagement* Unit Government of Western Australia, Perth.
Overall, all jurisdictions note their commitment to diversity and have in place frameworks for Aboriginal and/or CALD community engagement. However, these generally lack specific direction for implementation.
4 International consumer participation policy

This chapter provides an overview of public policy relating to consumer participation, person and family centred care, and patient experience in health care in selected international jurisdictions: New Zealand, the United Kingdom, the United States, Canada and the Netherlands.

4.1 New Zealand

New Zealand (NZ) Snapshot

- All health services are required to comply with the *Code of Health and Disability Service Consumer Rights* (1996) and the *Health and Disability Service Standards*, in accordance with the Health and Disability Services (Safety) Act 2001. The Code and Standards cover consumer rights (including the right to effective communication; the right to be fully informed; the right to make an informed choice and give informed consent) and standards relating to consumer and family participation in the planning, implementation and evaluation of health services.

- The Health Quality and Safety Commission New Zealand (HQSCNZ) is responsible for coordinating quality and safety across the health and disability sector. This includes leading the consumer engagement program, *Partners in Care*. This four year program (which commenced in 2012) aims to increase consumer participation across all levels of the health system (individual care, health services, and national policy). The program is project-based, with a range of projects being undertaken across three concurrent work streams (increase health literacy, improve consumer participation, and develop leadership capability for providers and consumers).

- The HQSCNZ is also undertaking four connected work programs to improve the measurement and evaluation of quality and safety in the NZ healthcare system. This includes the adoption of Quality Accounts which are based on the Victorian Quality of Care reports. Other work programs include the development of a set of national Health Quality and Safety Indicators, and the implementation of a national approach to the collection, measurement and use of in-patient experience information.

Within NZ the Ministry of Health provides leadership on policies relating to health and disability. The funding and provision of public health services are managed by 20 District Health Boards (DHB). This includes funding of primary care, acute care, public health, aged care and services provided by other non-government health providers including Māori and Pacific providers. The *New Zealand Health Strategy (2000)* and *Maori Health Strategy (2002)* provide the underlying principles that guide health policy development. Specifically in the context of the Maori community *Whanau-Ora: Transforming our futures*, promotes culturally responsive

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and appropriate ways of working. There is a focus on community collaboration when planning services and developing individual care plans.

**Code of Health and Disability Service Consumers Rights (1996)**

The *Code of Health and Disability Service Consumers Rights*\(^{179}\) applies to all health and disability services in NZ. It establishes the rights of consumers and the obligations and duties of health and disability service providers to comply with the code. It is a regulation under the *Health and Disability Commissioner Act*.

The Code includes ten rights of consumers and duties of providers. The rights enshrined in the code are consistent with principles of consumer participation and person and patient-centred care. They include:

- the right to be treated with respect
- the right to freedom from discrimination, coercion, harassment and exploitation
- the right to dignity and independence
- the right to services of an appropriate standard
- the right to effective communication the right to be fully informed the right to make an informed choice and give informed consent
- rights in respect of teaching or research
- the right to complain\(^{180}\)

While ‘participation’ is not an explicit right under the Code, three of the rights (to effective communication, to be fully informed, and to make an informed choice and give informed consent) are critical requirements for participation.

**Health and Disability Service Standards (2008)**

The *Health and Disability Service Standards*\(^{181}\) are mandatory for those services that are subject to the Health and Disability Services (Safety) Act 2001. The standards incorporate the consumer rights outlined in the *Code of Health and Disability Service Consumer Rights* (see above) and specific standards relating to consumer participation in health services (see Table 8 overleaf).

*Table 8: NZ Health and Disability service standards*

| Standard 2.5 | Consumers are involved in the planning, implementation and evaluation at all levels of the service to ensure services are responsive to the needs of individuals. |


\(^{180}\) ibid.

Standard 2.5  |  Family/whānau of choice are involved in the planning, implementation and evaluation of the service to ensure services are responsive to the needs of individuals.

The standards are accompanied by a number of criteria. An audit process requires health services to determine the level of attainment it currently achieves for each relevant criterion. For a list of the criteria relevant to Standards 2.5 and 2.6, refer the New Zealand Health and Disability Service (Core) Standards – Consumer Rights (NZS 8134). 182

**Health Quality and Safety Commission New Zealand**

The HQSCNZ was established under the *New Zealand Public Health & Disability Amendment Act 2010* to lead and coordinate quality improvement initiatives (work programs) across the country’s health system. 183

The Commission’s *Statement of Intent 2011-2014* foregrounds consumer engagement as a critical component of quality and safety improvement, noting the need to:

> “Increase the engagement of consumers in decision-making about the services they use, and to increase consumer literacy and capture consumer experience.” 184

Consumer representation is mandatory in all of the commission’s work programs. 185 To this end, a consumer network has been established to support and guide the Commission’s work. 186

The Commission reports publicly on safety and quality. Improvement in consumer experience (measured by consumer satisfaction survey and other methods) is a key performance measure for the Commission. 187

**Partners in Care: Consumer Engagement Program**

The Commission’s consumer engagement program, *Partners in Care*, was launched in 2012. 188

The program aims to support consumer involvement in individual care; planning, designing and delivery of health and disability services, as well as monitoring and evaluation of the quality of services; and national policy making and planning of services.

The framework sets out a four-year program (now in its third year) with three concurrent work streams each year: increase health literacy, improve consumer participation, and develop leadership capability for providers and consumers. Each work stream has its own set of goals, indicators, measures and evaluation criteria.

The program is project-based. The projects occurring within the three work streams are based on annual themes:

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182 Ministry of Health 2008, pp.15-17
185 HQSCNZ 2013a, p.30
186 ibid.
187 HQSCNZ 2011, p.4
188 HQSCNZ 2012
Year 1: Leadership and awareness-raising about the framework

Year 2: Collaboration

Year 3: Innovation

Year 4: Evaluation

Clinical areas of focus have been selected to align with the Minister of Health’s identified priorities for the Commission (medication safety, surgical safety, hospital-acquired infections and reducing falls).

In August 2013, as part of Partners in Care, the Commission launched an eight-month program for consumers and providers to learn about EBD, a co-design methodology developed in the UK. EBD aims to improve health services through focusing on the experiences of patients, carers and staff as they move through the service and interact with its various parts. Further details of this project are provided in Chapter 5.

Measurement and evaluation activity

The HQSCNZ is undertaking four connected work programs to improve the measurement and evaluation of quality and safety in the NZ healthcare system. Two of the programs are described below.

Quality Accounts

Quality Accounts are currently being adopted in NZ. Quality Accounts require health care providers to give an account for the quality of their services in a similar way to financial accounts. Quality Accounts have been used in the UK for a number of years to increase accountability and transparency of quality and safety across health services (see also section 4.1.2 United Kingdom).

In Victoria public health services have been required to publish a public annual Quality of Care Report since 2000. Health services are required to include within their Quality of Care report an assessment of achievements against Doing it with us not for us standards and indicators. The Department provides minimum guidelines for health services to assist with reporting on an annual basis.

Health Quality and Safety Indicators

NZ has developed a small set of summary indicators to cover an internationally recognised range of aspects of quality, including patient experience. The domains of patient experience have been defined as:

- communication
• partnership
• coordination
• physical and emotional needs.

The data is presented for the country as a whole and will be used to build a picture of the health system’s performance over time.\textsuperscript{192}

\textit{Measuring Patient Experience}

As part of the measurement and evaluation work programs, the HQSCNZ is currently implementing a national approach to the collection, measurement and use of in-patient experience information.\textsuperscript{193} Following the current pilot-testing period, all DHBs will be required to report on national patient experience data for in-patients (some exclusions apply) from 1 July 2014. Reporting will be aligned with the DHB’s existing reporting requirements.

The domains of patient experience captured in the survey align with the Health and Quality Safety Indicators. Further detail regarding progress towards the implementation of the survey is available on the HQSCNZ website.\textsuperscript{194}

\textsuperscript{192} ibid.
\textsuperscript{194} ibid.
4.2 United Kingdom

United Kingdom (UK) Snapshot

- The National Health Service (NHS) has an established commitment to embedding patient centred care in the health system and utilising patient experience as a tool for improving health services.

- The measurement and use of patient experience data as a means to drive quality improvement is built into NHS accountability frameworks at a number of levels. Patient experience is a standard measure in the NHS’ Quality and Outcomes Framework, Quality Accounts and local Commissioning for Quality and Innovation (CQUIN schemes). The National Institute for Health and Clinical Excellence (NICE) has developed clinical guidelines and quality standards for patient experience to guide commissioners and providers in good practice in relation to patient experience.

- NHS Choices website supports consumers to make informed choices about their healthcare provider. Consumers are able to find primary and acute health services in their area, compare performance data of specialist providers, and comment on their experience of particular NHS providers.

- Consumer voice in service monitoring and planning is facilitated by local HealthWatch organisations, which represent consumers on the Health and Wellbeing Boards.

- The NHS has led the use of Experience Based Design which is based on the principle that health services can be improved by focusing on the experiences of patients, carers and staff when heard through narrative, and is based on partnership between patient, carers and staff for co-design and evaluation.\(^\text{195}\)

- In recent years, the UK has put in place ‘pay for performance’ (P4P) initiatives. This includes the Commissioning for Quality and Innovation (CQUIN) framework. Providers who agree to a CQUIN scheme with their funding body have a small proportion of their income made conditional on an agreed package of goals and indicators relating to quality, safety, innovation and patient experience.\(^\text{196}\)

In the UK, public health and social care services are provided ‘free at the point of delivery’ throughout the NHS.

**NHS Constitution (2010)**

The **NHS Constitution**\(^\text{197}\), developed in 2010, outlines the values of the NHS and includes a number of principles that reflect the importance of patient engagement.

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\(^{195}\) NHS Institute for Innovation and Improvement 2009, *The EBD approach: using patient and staff experience to design better healthcare services*. NHS Institute for Innovation and Improvement.

\(^{196}\) ACSQHC 2011, p.15

The Constitution sets out rights to which patients, public and staff are entitled; pledges which the NHS is committed to achieve; and responsibilities, which the public, patients and staff owe to one another to ensure that the NHS operates fairly and effectively. It applies to the Secretary of State for Health, all NHS bodies, private and voluntary sector providers supplying NHS services, and local authorities in the exercise of their public health functions.

A summary of the guiding principles, rights of patient and the public and commitments by the NHS most relevant to consumer participation and patient-centred care is provided below.

**Guiding principles of the NHS include:**

- **Principle 4:** The NHS aspires to put patients at the heart of everything it does.
- **Principle 5:** The NHS works across organisational boundaries in the interest of patients, local communities and the wider population.
- **Principle 6:** The NHS is accountable to the public, communities and patients that it serves.

**Rights of patients and the public include:**

- the right to **informed choice** of health service, general practice and GP;
- the right to **involvement in own healthcare** and in the NHS, including the right to be involved in discussions and decisions about your health and care, and the right to be involved, directly or through representatives, in the planning and development of healthcare services commissioned by NHS bodies; and
- the right to **complaint and redress**.

**Commitments by the NHS England include to:**

- provide information and support to allow scrutiny and influence of the planning and delivery of NHS service;
- work in partnership with service users;
- involve consumers in discussions about planning their care; and
- encourage and welcome feedback on healthcare experiences and use this to improve services.

**NHS Outcomes Framework 2013-14**

The **NHS Outcomes Framework 2013-14** sets out five high-level national outcomes that the NHS should be aiming to improve. Domain 4 “Ensuring that people have a positive experience of care” relates to patient experience in both primary and acute care. While some indicators are...
yet to be developed, most indicators under Domain 4 draw on information from national patient experience surveys.204

These surveys are conducted using standardised questionnaires. All of the hospital-based surveys use methods based on the work of the Picker Institute Europe, which develops, coordinates and implements healthcare surveys based on the eight Picker dimensions of patient centred care (see section 2.1).205 In 2011, the NHS National Quality Board (NQB) agreed on a working definition of patient experience to guide the measurement of patient experience across the NHS. This framework outlines those elements which are critical to patients’ experience across the NHS (see Box 3 below).

**Box 3: NHS Patient Experience Framework definition of patient experience**

- **Respect for patient-centred values, preferences, and expressed needs**, including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making.
- **Coordination and integration of care** across the health and social care system.
- **Information, communication, and education** on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion.
- **Physical comfort** including pain management, help with activities of daily living, and clean and comfortable surroundings.
- **Emotional support** and alleviation of fear and anxiety about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances.
- **Welcoming the involvement of family and friends**, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers.
- **Transition and continuity** as regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions.
- **Access to care** with attention for example, to time spent waiting for admission or time between admission and placement in a room in an in-patient setting, and waiting time for an appointment or visit in the out-patient, primary care or social care setting.

*Source: Department of Health 2011*

Survey results are published to assist patient choice and in support of quality improvement. The results can been found on the Care Quality Commission’s website207 and the NHS Surveys website.208

204 ACSQHC 2011, p.13
205 ibid. p.14
207 See www.cqc.org.uk
208 See www.nhssurveys.uk
NHS Operating Framework 2012-13

The use of patient experience data as a quality improvement tool is a requirement under the NHS Operating Framework 2012-13. The framework requires commissioners and providers to ensure that patient experience and feedback are inherent parts of service design, delivery and improvement. The Framework states that the NHS must collect and use patient experience information to inform service improvement. Specifically:

“NHS organisations must actively seek out, respond positively and improve services in line with patient feedback. This includes acting on complaints, patient comments, local and national surveys and results from ‘real time’ data techniques”

Providers are also required to raise awareness of local feedback options, encourage feedback, and demonstrate to the public that their feedback has been used to improve service quality and patient experience.

NHS Choices

Transparency as a means to build health literacy and promote consumer choice is an integral aspect of the NHS. As identified in the NHS Constitution (see above), all consumers in the UK who need to see a specialist have the right to choose any hospital, including many private and independent sector hospitals that are contracted to provide NHS-funded care. The NHS Choices website is a resource to support the public to make these choices.

The website publishes information on specialist options available. Consumers are able to compare hospitals by various criteria including cleanliness, car parking arrangements, general facilities, availability of Accident and Emergency departments, experience of a particular procedures and, in some cases, survival rates. Consumers are able to rate and comment on their healthcare provider and regular surveys provide information about the availability and uptake of provider of choice.

Consumers are also able to view performance indicators from the national survey data for each hospital. This includes the annual Quality Accounts from all NHS Foundation Trusts.

Commissioning for Quality and Innovation (CQUIN) Framework

The Commissioning for Quality and Innovation (CQUIN) framework, introduced in 2009, aims to improve quality of care in hospitals and other healthcare organisations. Under the framework, providers who agree to a CQUIN scheme with their funding body have a small proportion of their income made conditional on an agreed package of goals and indicators relating to quality, safety, innovation and patient experience.

In additional to locally agreed goals, acute providers must include a specified number of national goals. In 2011/12 one of these goals was to improve responsiveness to personal needs of

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210 ACSQHC 2011, pp.14-15
211 ibid.
212 ibid. p.15
patients. In 2013/14, one of the national goals was to improve the experience of patients in line with Domain 4 of the NHS Outcomes Framework through the application of the Friends and Family Test, which will provide timely, granular feedback from patients about their experience. The selection of this goal was based on findings from the 2011/12 national inpatient survey which showed that only 13 per cent of patients in acute hospital inpatient wards and A&E departments were asked for feedback. Since 2011/12, providers who fail to meet agreed patient satisfaction goals may have a proportion of their contract payment withheld.

**NHS Commissioning Board**

In 2012, reforms to the NHS through the *Health and Social Care Act 2012* resulted in a restructuring of the provision of health services in England. This included an increased focus on patient involvement in their own care and the ‘no decision’ principle; “No decision about us without us”. The restructured NHS led to the establishment of the *NHS Commissioning Board*, to provide national funding and oversight; local *Clinical Commissioning Groups* (CCGs) managing local funding decisions; and *Health and Wellbeing Boards*, that provide a forum for key stakeholders to work together to improve local services and population health. The clauses of the *Health and Social Care Act 2012* that promote patient involvement are outlined in **Box 4** (see overleaf).

**Box 4: Health and Social Care Act 2012**

**Role of the NHS Commissioning Board**

13H Duty to promote involvement of each patient

The Board must, in the exercise of its functions, promote the involvement of patients, and their carers and representatives (if any), in decisions which relate to—

(a) the prevention or diagnosis of illness in the patients, or

(b) their care or treatment.

**Role of the Clinical Commissioning Groups**

14U Duty to promote involvement of each patient

(1) Each clinical commissioning group must, in the exercise of its functions, promote the involvement of patients, and their carers and representatives (if any), in decisions which relate to—

(a) the prevention or diagnosis of illness in the patients, or

(b) their care or treatment.

(2) The Board must publish guidance for clinical commissioning groups on the discharge of their duties under this section.

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214 ACSQHC 2011, pp.16
A clinical commissioning group must have regard to any guidance published by the Board under subsection (2).

Source: Health and Social Care Act 2012

Consumer engagement through the Health and Wellbeing Boards is facilitated through representation by local Healthwatch organisations, established as the “consumer champion” to represent and promote consumer views.\(^{215,216}\) HealthWatch organisations:

- have the power to enter and view services;
- influence how services are set up and commissioned by having a seat on the local Health and Wellbeing Board;
- produce reports which influence the way services are designed and delivered;
- provide information, advice and support about local services; and
- pass information and recommendations to Healthwatch England and the Care Quality Commission.\(^{217}\)

**NICE Clinical Guidelines and Quality Standards on patient experience in adult NHS services**

The National Institute for Clinical Excellence (NICE) takes a collaborative approach to developing clinical guidelines and other products – working with the NHS, social care local authorities, and other public, private and voluntary sectors, including consumers. NICE seeks to ensure that “those that use our guidance, as well as those it affects, are involved every step of the way.”\(^{218}\) This approach is an example of better practice that involves consumers from the ‘agenda setting’ stage.

The NICE clinical guideline on patient experience in adult NHS service (Clinical Guideline CG138) was issued in February 2012. It offers evidence-based advice on ensuring a good experience of care for people who use adult NHS services.

Alongside its clinical guidelines, NICE has also developed quality standards. The Quality Standards describe high-priority areas for quality improvement, which are aspirational but achievable, in a defined care or service area.\(^{219}\) The standards are not mandatory, however the Health and Social Care Act (2012) indicates that the care system should also have regard to

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\(^{216}\) http://www.healthwatch.co.uk/
\(^{218}\) NICE website, Available at http://www.nice.org.uk/aboutnice/, accessed 5 March 2014.
consumers in planning and delivering services, as part of a general duty to secure continuous improvement in quality.\textsuperscript{220}

QS15: Quality standard for patient experience in adult NHS services is intended to provide the NHS with clear commissioning guidance on the components of a good patient experience. It comprises 14 evidence-based statements and associated measures.\textsuperscript{221}

The implementation of the guidelines and achievement of the quality standards is supported by practical tools, including a costing report and a baseline assessment tool. The costing report provides clear advice for health services and commissioners on the cost impact and resource implications of implementing the guidance and quality standard on patient experience.\textsuperscript{222} The baseline assessment tool is an Excel spreadsheet that can be used by organisations to identify whether they are in line with the practice recommended in NICE guidance and help them to plan activity to assist in meeting the recommendations.\textsuperscript{223}

**NHS Business Plan and Everyone Counts: Planning for Patients 2013-14**

The NHS Business plan\textsuperscript{224} and Everyone counts: Planning for Patients 2013/14\textsuperscript{225} set out the future objectives for the NHS over the coming years. Both documents emphasise the importance of consumer participation and the need to work in partnership with patients.

Recently the outcomes of the Mid Staffordshire NHS Foundation Trust Public Enquiry\textsuperscript{226} which detailed a number of failings of the Trust strengthened the importance of responding to concerns and complaints of patients and the local community. Patient experience surveys had highlighted issues with the Trust and there was general disengagement and conflict identified throughout the various consumer engagement forums.\textsuperscript{227} The importance of ensuring that health services are not merely setting up committees but checks are in place to promote quality engagement and enable the right people to be involved was therefore reinforced.

**Focus on NHS Wales – The Listening Organisation**

NHS Wales has developed specific policy guidance with regard to consumer engagement and person centred care. The White Paper *The Listening Organisation: Ensuring care is person*
centred in NHS Wales \[^{228}\] details NHS Wales' commitment to engaging with and listening to patients. This builds on ‘Achieving Excellence in the Quality Delivery Plan for NHS Wales’ where the Welsh Government placed improving patient and user experience at the centre of NHS Wales’s organisations.\[^{229}\] The White Paper, *The Listening Organisation*: identifies that ‘listening skills’ need to be developed and provides high level guidance on incorporating ‘listening’ as an organisation-wide discipline. In addition, the concept of co-production is outlined where citizens are involved in the commissioning, design, delivery and evaluation of services.

The principle of engaging with consumers in the planning and development of health services was established in 2010 in NHS Wales’ *Guidance on Involving Adult NHS Service Users and Carers*\[^{230}\]. This guide was designed to help services users and carers through training to engage with health services.

\[^{229}\] NHS Wales 2013, *The Listening Organisation: Ensuring care is person centred in NHS Wales, Improving Healthcare White Paper Series – No. 11*, NHS Wales, Cardiff, p.2
4.3 United States

**United States Snapshot**

- The Centres for Medicare and Medicaid Services (CMS) and the Agency for Healthcare Research and Quality (AHRQ) routinely collect patient experience data from hospitals, clinician group practices and health insurance plans using the Consumer Assessment of Healthcare Providers and Systems surveys (CAHPS). CAHPS are a ‘family’ of standardised surveys developed by Harvard University and based on the Picker Principles.

- Comparisons between providers are able to be made over time using the CAHPS Benchmarking database. This national repository for CAHPS surveys holds over 13 years of survey data and is a key resource for policy makers to monitor the nation’s progress toward improved healthcare quality.

- The web-based tool ‘Hospital Compare’ uses information from the Hospital Outcomes of Care Measures, CAHPS and hospital-CAHPS (H-CAHPS) surveys to provide information about how well hospitals care for patients with certain medical conditions or surgical procedures.

- Physician Compare allows individuals to search for a physician or other healthcare professional by specialist, type of professional, location, gender and whether the professional accepts the Medicare-approved amount as payment in full on all claims. The tool also provides information on languages spoken, group practice locations, education and hospital affiliation. Since January 2013, CMS has been required to also make information on physician performance publicly available through Physician Compare.

- Financial incentives are used in the US to promote patient feedback. This includes direct financial incentives for providing information, via the Reporting Hospital Quality Data for Annual Payment Update Initiative (from 2008) and a two per cent penalty on income reimbursement for Medicare patients (from 2010).

- The AHRQ has recently developed a guide for patient and family engagement comprising tools, materials and training for patients, family members, health professionals, hospital leaders and individuals with responsibility for implementation.

Due to the lack of a universal health care system in the US, policies on consumer engagement may be centrally driven through either state or federal legislative policy. Consumer organisations, lobby groups and healthcare providers also play an active role in shaping the direction of the health care. This section focuses on federally driven policy initiatives.

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231 ACSQHC 2011, p.15
232 ibid.
233 ibid.
National policies and frameworks

Patient Safety and Quality Improvement Act 2005

Federally, the Patient Safety and Quality Improvement Act 2005 aims to mark a shift towards patient-centred care. The Act refers to patient-centeredness, patient satisfaction, patient experience of care, patient engagement and shared decision-making in its provisions and has mandated the use of measure for the quality of care, public reporting, and performance payments. There is a focus on measuring patient experience as a means to improve quality and facilitate patient centred care.

Patient Protection and Affordable Care Act 2010

The federal Patient Protection and Affordable Care Act 2010 defines a focus on patient centred care including satisfaction, experience, engagement and shared decision-making.

Consumer Assessment of Healthcare Providers and Systems survey program (CAHPS)

Patient experience data is routinely collected in the US by the CMS and the AHRQ. The collection of patient experience data has been expanded under the Patient Protection and Affordable Care Act 2010.

The CAHPS was developed by Harvard University and is based on the Picker Principles. It comprises a range of surveys to enable patients’ healthcare experiences to be evaluated across hospitals, clinical groups’ practices and health insurance plans.

Hospitals use the H-CAHPS survey to measure patient experiences across the following seven domains:
1. Communication with doctors
2. Communication with nurses
3. Responsiveness of hospital staff
4. Communication about medicines
5. Pain control
6. Cleanliness and quietness of physical environment
7. Discharge information.

The survey provides an overall assessment rating and an assessment of the likelihood or willingness of patients who participated in the survey to recommend the service to other people. A shorter, real-time version of the survey has also been developed.

Comparisons are able to be made overtime using the CAHPS Benchmarking database. This national repository for CAHPS surveys holds over 13 years of survey data. This database is a key resource for the AHRQ’s National Healthcare Quality Report and National Healthcare Disparities

234 Patient Protection and Affordable Care Act 2010
235 ACSQHC 2011, p.14
Report, annual reports used by policy makers to monitor the nation’s progress toward improved healthcare quality.

Patient experience surveys are also being developed with focus on specific diseases. This includes a patient experience survey for cancer patients, supported by the National Cancer Institute and the AHRQ.236

**P4P Initiatives**

Financial incentives are used to promote the use of patient experience feedback as a mechanism for quality improvement. This comprises incentives provided to doctors and hospitals that submit data on quality measures, including patient experience, to the CMS.237

Incentives aim to facilitate the provision of hospital data include quality, mortality, and H-CAHPS via Hospital Compare. This includes direct financial incentives for providing information, via the Reporting Hospital Quality Data for Annual Payment Update Initiative (from 2008) and a two per cent penalty on income reimbursement for Medicare patients (from 2010).238

Incentive arrangements are also in place for doctors associated with Medicare and Ambulatory surgical centres and other health organisations, who must also meet Medicare P4P reporting and performance targets as prescribed in the *Tax Relief and Health Care Act 2006* and *Patient Protection and Affordable Care Act 2010*, respectively.239

**Hospital Compare**

The web-based tool ‘Hospital Compare’ uses information from the Hospital Outcomes of Care Measures, CAHPS and H-CAHPS surveys to provide information on hospital care provided to patients for certain medical conditions or surgical procedures across 4,000 Medicare-certified hospitals across the country.240

The objectives of Hospital Compare are to help consumers make decisions about where they receive their health care and to encourage hospitals to improve the quality of care they provide. Information is provided with respect to the indicators outlined in **Box 5** below (see overleaf):

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236 ibid.
237 ibid.
238 ibid.
239 ibid.
Box 5: Hospital Compare – Information available to consumers

**Timely and effective care:** How often and how quickly each hospital gives recommended treatments for certain conditions like heart attack, heart failure, pneumonia, children’s asthma, and for surgical patients.

**Readmissions, complications and deaths:**
- How each hospital’s rates of readmission and 30-day mortality (death) rates for certain conditions compare with the national rate.
- How likely it is that patients will suffer from complications while in the hospital.
- How often patients in the hospital get certain serious conditions, that might have been prevented if the hospital followed procedures based on best practices and scientific evidence.

**Use of medical imaging:** How a hospital uses outpatient medical imaging tests (like CT scans and MRIs).

**Survey of patients’ experiences:** How recently-discharged patients responded to a national survey about their hospital experience. For example, how well a hospital’s doctors and nurses communicate with patients and how well they manage their patients’ pain.

**Number of Medicare patients:** How many people with Medicare have had certain procedures or have been treated for certain conditions at each hospital.

**Medicare payment:** Information about how much Medicare pays hospitals.

Source: Medicare.gov

Physician Compare was launched in December 2010 under the Patient Protection and Affordable Care Act 2010. This tool is available on the US Government Medicare website, and allows individuals to search for a physician or other healthcare professional by specialist, type of professional and location. Additional search criteria allow the user to search by gender and whether the professional accepts the Medicare-approved amount as payment in full on all claims. The tool also provides information on languages spoken, group practice locations, education and hospital affiliation. Since 2013, CMS has been required to also make information on physician performance publicly available through Physician Compare.

**Guide to Patient and Family Engagement in Hospital and Quality and Safety (2013)**

The AHRQ (part of the US Department of Health and Human services), recently developed the guide as a resource for health services to promote working in partnership with patients and families to improve quality and safety. The aim is to help hospitals engage patients and families, respond to health care reform and accreditation standards, improve results of the CAHPS and financial performance.

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241 ACSQHC 2011, p.15
242 ACSQHC 2011, p.15
The guide focuses on four primary strategies for promoting patient and family engagement, namely:

- Encourage patients and family members to participate as advisors.
- Promote better communication among patients, family members, and health care professionals from the point of admission.
- Implement safe continuity of care by keeping the patient and family informed through nurse bedside change-of-shift reports.
- Engage patients and families in discharge planning throughout the hospital stay.243

The development of the guide was informed by an environmental scan of current literature, tools, and resources available to engage patients and families in their care in the hospital setting. The scan included:

- A framework that describes how patient and family engagement can lead to improved quality and safety
- A description of factors that influence patient and family engagement, including characteristics and perspectives of patients, families, health care professionals, and hospital organizational and cultural factors
- Hospital-based methods and materials currently being used to engage patients and families in the safety and quality of care, and
- An analysis of what materials are needed but do not currently exist.

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4.4 Canada

**Canadian Snapshot**

- Canada has a strong tradition of public involvement in public policy, including health policy. Health Canada’s Public Involvement Framework guides the department’s public involvement.

- Canada has been a leader in consumer participation in decision making about healthcare, both at the individual care level and in policy.
  - For example, in 2002, during the Romanov Commission on the Future of Health Care in Canada, the ‘ChoiceWork dialogue’ methodology was used as a means to engage ‘unorganised’ citizens in meaningful discussions about health care reform. The outcomes of this process led to an increased focus on public involvement in the Canadian health system.
  - Canada has also been at the forefront of the development and use of decision aids as a means to help consumers and health practitioners make ‘tough’ healthcare decisions. This work has been led by the Patient Decision Aids Research Group within the Ottawa Hospital Research Institute.

Canada is a federated system. The division of powers between the central and provincial governments on matters pertaining to health is similar to that of Australia. Like Australia, primary responsibility for the management and delivery of health rests with the provincial governments. Federal health care initiatives focus on broader system-wide principles and objectives. However, while in Australia changes such as the introduction of five-year Australian health Agreements have increased Commonwealth powers; in Canada, provinces continue to dominate. In the context of consumer engagement, the Office of Consumer and Public Involvement, a subsidiary of Health Canada’s Health Products and Food Branch, was established to:

- support Canadians in understanding how decisions are made about drugs and health products through the provision of information; and

- ensure consumers perspectives are considered in the decision-making process through the provision of opportunities to be involved through forums such as expert advisory committees and public advisory committees.

In 2012, the Office of Consumer and Public Involvement piloted a ‘Patient and consumer participation pool’ (the Pool). Information from the Health Canada website indicates that the pool consisted of 50-100 consumers who were provided with training and tools to allow them

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244 Patient Decision Aids, Ottawa Hospital Research Institute website https://decisionaid.ohri.ca/about.html


to meaningfully participate in consultations that relate to health products and food. A web-based search did not return further information on the outcomes of this pilot project.

**Public Involvement Framework and Health Canada Policy Toolkit for Public Involvement**

The overarching policy framework for public involvement in healthcare is outlined in the Public Involvement Framework and the Health Canada Policy Toolkit for Public Involvement. These policies provide a guide to the department’s public involvement with the aim to integrate the public in the decision making process. This is based on the idea of engaging the public across the five levels of Health Canada’s public involvement continuum, as described in Figure 9 below. The purpose of the toolkit is to provide additional support and resources to facilitate public involvement.

**Figure 9: Health Canada’s model of public involvement**

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250 It is noted that currently all policy relating to the Office of Consumer and Public Involvement is archived in Health Canada’s website. It has not been superseded.
251 Office of Consumer and Public Involvement, 2000
When useful:

<table>
<thead>
<tr>
<th>Inform or Educate</th>
<th>Gather information</th>
<th>Discuss</th>
<th>Engage</th>
<th>Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>• When factual information is needed to describe a policy/process</td>
<td>• When the purpose is to listen</td>
<td>• When a two-way information exchange is needed</td>
<td>• When the Department needs citizens to talk to each other about complex issues</td>
<td>• When the Department wants to empower citizens and groups to manage the process</td>
</tr>
<tr>
<td>• When a decision has already been made</td>
<td>• When the policy is being shaped</td>
<td>• When people have an interest in an issue and are likely to be affected by the outcome</td>
<td>• When there’s a capacity to shape policies</td>
<td>• When groups and citizens have accepted the challenge of developing solutions themselves</td>
</tr>
<tr>
<td>• When there’s no opportunity to influence the outcome</td>
<td>• When there’s no firm commitment to do anything</td>
<td>• When there’s an opportunity to influence the outcome</td>
<td>• When there’s an opportunity for shared agenda-setting and open timeframes</td>
<td>• When the Department is ready to be an enabler</td>
</tr>
<tr>
<td>• If the issue is simple</td>
<td></td>
<td>• When input may shape the policy</td>
<td></td>
<td>• When there is agreement to implement the solutions</td>
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<tr>
<td>• In a crisis</td>
<td></td>
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</table>

Source: adapted from Patterson Kirk Wallace, as cited in Health Canada 2000

**Consumer participation in policy: ChoiceWork Dialogue**

The Romanow Commission on the Future of Health Care in Canada resulted in increased research and advocacy for public engagement in the development of policy. This included the use of the “ChoiceWork dialogue” method which involved a full day of dialogue with representative cross sections of the Canadian population. Twelve dialogue sessions were held across Canada, each with about 40 ‘citizen’ participants.

The use of the “ChoiceWork” dialogue proved a valuable approach to eliciting the views of ‘unorganised’ citizens (i.e. those not engaged through consumer organisations or other representative groups) in relation to major reform issues. There was significant cost involved in running the dialogues but the results had a marked influence on the Commission’s report.

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Firstly, the report redefined the role of the citizen, from a passive consumer of healthcare services to active participant in the governance of the health system. Secondly, the report echoed the demand for participants for transparency and accountability. The push to increase public involvement, specifically in local decision making, was strengthened by its inclusion as an objective of health system restructuring and the creation of regional health authorities in Canada.

4.5 Netherlands

Netherlands Snapshot

- Recent reforms in the Netherlands have given consumers a more pivotal role in the governance of health care: in a demand-driven system, consumers are one of the market parties alongside care providers and insurers.
- Greater transparency in healthcare is a stated government policy goal. A number of initiatives have been put in place to support this, including the development of the CQ-Index (introduced in 2006). The index is a standardised method for developing surveys and measuring healthcare quality from the patient’s perspective based on the American CAHPS and the Dutch QUOTE (Quality of care through the patient’s eyes) instruments. Since the release of publically accessible performance data, there is some evidence of it supporting quality improvement at the hospital level.
- The Netherlands has a strong focus on health literacy. This includes specific work to improve health communication for migrants and minority groups, often in foreign languages, using information materials and involving mediators, interpreters and trainers.

Dutch Health Insurance Act 2006

The Dutch healthcare system underwent major reform though the Dutch Health Insurance Act in 2006 and is now funded through an insurance market system. It is made up of a combination of universal care funded by a state controlled mandatory insurance scheme, for longer term, chronic care, while shorter term care (primary and hospital care) is funded by compulsory private health insurance. The majority of Dutch hospitals are privately owned and managed not-for-profit entities, employing self-employed specialists.

Insurers are able to negotiate with providers on price and quality, with the public able to choose the provider they prefer. In order to facilitate this choice there is a focus on increasing the provision of publically available information particularly regarding price and quality. The

254 Maxwell J, Rosell S, Forest P-G. 2003
255 ibid.

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government is primarily responsible for regulating this insurance market.\textsuperscript{259} The Dutch Health Care Inspectorate and the Ministry of Health, Welfare and Sports have also taken various initiatives to increase health care transparency to support patients’ involvement in their care.

**Consumer Quality Index (CQ-Index)**

One such initiative is the introduction of the CQ-Index. The CQ-Index is a standardised method for developing surveys and measuring healthcare quality from the patient’s perspective. The methodology is based on the American CAHPS and the Dutch QUOTE instruments. It entails a unique combination of questions on the frequency with which quality criteria are met and the importance of aspects according to patients.\textsuperscript{260} This system is now being implemented under auspices of the Dutch Centre for Consumer Experience in Health Care in several sectors of the Dutch health care system.\textsuperscript{261} The CQ-Index has been modified for a variety of community services, care settings and condition-specific patients’ groups including rheumatoid arthritis, cataracts, hip and knee surgery, and breast cancer.

The results of the CQ-Index have informed service improvement, policy development, and health insurance provider negotiations. Since the release of publically accessible performance data, there is some evidence of it supporting quality improvement at the hospital level.\textsuperscript{262}

**Health literacy initiatives**

The Netherlands Alliance for Health Literacy was founded in 2010 and brings together patients, providers, health institutions, health insurance providers, academia, industry and the business community.\textsuperscript{263}

In 2011, the National Health Council produced advice for the Minister of Health on tackling limited literacy in the health sector in order to improve informed consent.\textsuperscript{264} Specific work is also done to enhance health communication for migrants and minority groups, often in foreign languages, using information materials and involving mediators, interpreters and trainers. Based on research into inequities in health, the health communication programs were broadened to people with limited literacy to ensure that these groups could access health services adequately.

The Netherlands are also participating in the European Health Literacy Project.\textsuperscript{265} The project is in its early stages and aims to establish a network for health literacy in Europe and adapt an instrument for measuring health literacy in Europe.\textsuperscript{266}
4.6 Summary

All jurisdictions reviewed have an overarching framework in place to guide consumer involvement in their respective healthcare systems.

In the UK and the US, this has occurred within a framework of patient-centred care. These jurisdictions have three main policy drivers to embed a patient-centred approach within the healthcare system, namely mandatory requirements to collect and publish patient experience data; facilitating choice of service provider through the provision of publicly available performance information; and the incentivisation of patient-centred approaches by linking strong performance on measures of patient experience with remuneration.

The HQSCNZ has adopted a project-based approach to improving consumer engagement across the NZ health system. The Partners in Care framework incorporates a program of EBD projects, bringing together consumers and clinicians/managers to lead service improvement through consumer experience. Partners in Care explicitly sets out to build the evidence-base in NZ for effective engagement and its contribution to health outcomes. NZ is also undertaking a series of connected programs to improve the measurement and evaluation of quality and safety in the healthcare system, including the adoption of Quality Accounts, the development of national Health Quality and Safety Indicators and the implementation of a national patient experience survey.

Canada offers examples of strategies to involve consumers in the development of health policy, for example through the ChoiceWork dialogue to engage consumers in discussions about health reform.

Reforms in the Netherlands have given consumer a more pivotal role in the governance of health care. Greater transparency in healthcare has been supported through the introduction of patient experience surveys based on the CQ-Index. Since the release of publicly accessible performance data, there is some evidence of it supporting quality improvement at the hospital level.
5 Maximising Consumer Participation: Evidence based approaches

This section outlines evidence-based approaches to maximising consumer participation, person and family centred care, and patient experience.

5.1 Evidence based approaches to promote consumer participation

This section presents evidence based approaches and strategies identified in the literature to promote consumer participation, person and family centred care and patient experience. It draws on a recent paper by ACSQHC reviewing approaches in Australia and internationally to promote patient-centred care. The paper by the ACSQHC identified a series of system-oriented and service-oriented recommendations to foster patient-centred care in the Australian healthcare system. An overview of these recommendations is provided in Appendix F. Further evidence has been drawn from other peer reviewed and grey literature.

The information is organised according to levels within the health care system; at the system level, service level, and individual level and also whole of system approaches.

The evidence-based approaches and strategies have been used to identify examples of better practice from Australia and international jurisdictions.

5.1.1 Effective ways to improve patient experience

This section draws on a review conducted in 2010 by the Picker Institute Europe (Picker Europe) of the body of evidence for strategies to promote consumer participation which is applicable to whole of system approaches.

The Picker Europe evaluated 31 systematic and high-quality narrative reviews of initiatives to improve patients’ experience, including studies of direct and indirect feedback from patients (including patient experience and satisfaction surveys); service user involvement in evaluations; consultation styles; and communication skills training. Each study was graded according to four outcomes: impact on patients’ knowledge, impact on patients’ experience, impact on service use and costs, and impact on health behaviour and health status.

According to the Picker Europe review, the most effective ways to improve patient experience are patient-centred consultation styles, communication training for health professionals and patient feedback (surveys, focus groups, complaints) with public reporting of performance data.267 These methods are discussed in further detail across the different levels of the health care system.

5.2 Approaches by level of the health care system

5.2.1 Consumer participation at the system level

<table>
<thead>
<tr>
<th>Key approaches and strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Features considered important at the system level for a patient-centred approach include:</td>
</tr>
<tr>
<td>✓ patient-centred care as a dimension of quality in its own right</td>
</tr>
<tr>
<td>✓ standardised performance monitoring and measurement</td>
</tr>
<tr>
<td>✓ capacity building through research.</td>
</tr>
</tbody>
</table>

Patient-centred care is a dimension of quality in its own right

In 2001, the Institute of Medicine’s report *Crossing the Quality Chasm* identified patient-centred care as one of six quality aims for improving care. More recently, the literature has re-affirmed...
the need to ensure patient-centeredness is recognised as a dimension of quality in its own right, rather than as a means to other desired aims, such as safety and effectiveness.\textsuperscript{268}

The benefits of a patient-centred approach, defined as a dimension of quality in its own right, recognises the strong evidence that it can lead to improvements in health care quality and outcomes by increasing safety, cost effectiveness and patient, family and staff satisfaction.

**Standardised performance monitoring and measurement**

The measurement of processes and outcomes associated with quality, safety and experience of care helps to embed patient-centred care in the healthcare system.\textsuperscript{269} Linking funding and accreditation to patient satisfaction measurements; accountability through public reporting; and the development of standardised measures to facilitate comparison and benchmarking are important strategies to ensure measurement and monitoring activity is used to drive improvement.\textsuperscript{270}

All Australian states are increasing their activity in measuring healthcare quality, especially patient experiences. Most jurisdictions collect a variety of patient feedback, including national and local survey data, complaints data and web-based feedback.\textsuperscript{271} The introduction of the NSQHS Standards is likely to assist in progress towards more standardised measures and approaches.

There are examples of increasing transparency in performance reporting in Australia. For example, in 2010, the New South Wales Bureau of Health Information\textsuperscript{272} 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.\textsuperscript{273}

**Capacity building through research**

Much of the literature in Australia relating to consumer participation and patient-centred care focuses on general emerging principles and practices. There is a need for further research and evaluation to determine best practice as a basis to develop tools, models and educational strategies to promote consistent and evidence-based practices.\textsuperscript{274}

\textsuperscript{268} Berwick, D.M. 2009 'What ‘patient-centred’ should mean: confessions of an extremist' *Health Affairs* 28(4):w555-w565

\textsuperscript{269} Institute for Patient- and Family-centred Care in ACSQHC 2011, p.48

\textsuperscript{270} ibid.

\textsuperscript{271} ibid.


\textsuperscript{273} ibid.

\textsuperscript{274} ACSQHC 2011, p.48

\textsuperscript{275} ACSQHC 2011, p.50
In Australia and overseas, there is a growing focus on engaging consumers in health research. Examples of forums that are facilitating meaningful consumer involvement in research are provided below.275

**National Health and Medical Research Council**

Figure 11: Consumer participation in research – an example from the US

**Patient Centred Outcomes Research Institute**

The Patient-Centred Outcomes Research Institute (PCORI) is an independent, not-for-profit health research organisation in the US. The Institute was authorised by the *Patient Protection and Affordable Care Act* of 2010. Its mission is to fund research that offers patients and care givers the information they need to make important health care decisions. PCORI pursues this mission through the following four mutually supportive activities:

Table 2: PCORI's Path from priorities to research patients can use

1. Identify National Priorities for research
2. Create a Research Agenda based on identified priorities
3. Fund research consistent with these priorities and agenda
4. Provide patients and care givers with useful research information

Source: PCORI 2012

PCORI focuses on comparative clinical effectiveness research (i.e. studies that compare options for preventing and diagnosing disease and providing treatment and care).

Research topics can be initiated by either investigators, or by consumers and other stakeholders. When proposals for research are initiated by investigators, PCORI requires that consumers and stakeholders be involved in each step of the research process, from proposal development to research design and dissemination of the study results.276 An overview of the PCORI research prioritisation process undertaken for the inaugural research cycle in 2012-

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276 ‘How we select research topics’ *Patient-Centred Outcomes Research Institute* website Retrieved from http://www.pcori.org/funding-opportunities/funding-announcements/how-we-select-research-topics/ on 3 March 2014
Recent research topics include:

- **Creating a ‘Zone of Openness’ at the doctor’s office** – California researchers are developing a tool to help clinicians’ invite patients’ point of view, to assist in overcoming patients’ fear that disagreeing with the doctor will reduce their quality of care.\(^{277}\)

- **The Decision is Yours: Engaging patients in depression treatment choices** – A tribal-run health care system in Alaska found that depression treatment wasn’t working well, in part because patients weren’t taking their medications. Researchers are now developing a decision-support tool to help patients to participate in, and stick with, care decisions.\(^{278}\)

- **What do patients and caregivers want in mobile health apps? Ask them** – Researchers are consulting with patients and caregivers as a first step in developing new mobile tools for stroke survivors.\(^{279}\)

In Australia, the National Health and Medical Research Council (NHMRC) published *Statement of consumer and community participation in health and medical resources* (2002), in collaboration with the Consumers Health Forum (CHF).\(^{280}\) in 2004, published two resources for researchers and consumers to implement the statement. The statement was developed in response to the express desire of consumers for more direct and meaningful involvement in research, including involvement in decisions about research priorities, and the development of specific research questions, design of research projects, and dissemination of results.\(^{281}\)

An article following the Involving People in Research Symposium held in Perth in 2008, presented a number of practical examples of how the Statement on Participation is contributing to collaborative research involving consumers and researchers. The article also highlighted opportunities to build on the contribution of the Statement as a tool for increasing consumer participation in research. The article suggested a need to reprioritise consumer involvement in research as an issue of focus for the Consumer Health Forum.\(^{282}\)

Current examples of consumer involvement in research in Victoria are provided in Box 6 (see page 93) and Box 9 (see pages 98-99).
Box 6: Evaluating Effectiveness of Participation in Victoria

**Evaluating Effectiveness of Participation (EEP)**

The Department of Human Services’ (now Department of Health) Quality and Safety Branch funded four Victorian health services in 2007-2008 and 2010-2011 to evaluate consumer participation (‘Evaluating Effectiveness of Participation’ (EEP) projects).

The projects were:

- **Cobram District Hospital (and Yarrawonga District Health Service)** – Does nursing home case management influence family (or other care-giver) involvement in the care of residents; family-staff relationships, and family satisfaction with nursing home care?

- **Peter MacCallum Cancer Centre** – How can consumers best be empowered to participate in the medication reconciliation process on admission and discharge from an acute care episode to reduce medication errors?

- **South West Healthcare Psychiatric Services Division (and Safe Hill Carers Service Inc.)** – What is the impact of consumer and carer delivery of training on clinician attitude, confidence and satisfaction?

- **Orbost Regional Health (and Yarram and District Health Service)** – will a model of community participation that uses formalised capture and management of anecdotal data to nurture continuous dialogue between the health service and its community result in improved staff awareness/value and increased community involvement/appraisal?  

The Cochrane Consumers and Communication Review Group was engaged to support the EEP projects. The resources developed by the Review Group included a description and examples of controlled before-and-after (CBA) study design and a framework for evaluating consumer participation. The Review Group also identified lessons on the support required by health services to develop and conduct EEP projects, and produced an illustrative map of research questions, interventions, outcomes and tools used by each of the four projects.

**Financial incentives**

Experience from the UK and the US suggests that funding arrangements can provide an effective mechanism for incentivising consumer involvement and patient-centred approaches. In these jurisdictions, defining patient experience as a key outcome metric has enabled the use of financial incentives to drive improvements in patient-centred care.

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285 ACSQHC 2011, p.15
Contracting systems that focus on patient-centred values and incorporate patient experience and outcomes would be expected to:

- increase the quality of outcomes of care delivery
- provide the optimal value of care delivery
- reduce the price of care delivered.

Measurement of patient experience and outcomes would be clustered around the disease/condition categories as opposed to simply the silo of a provider only focus. This is an important concept and part of broader opportunity to pay providers to deliver high quality and innovate, rather than simply paying for services. More broadly, patient experience and consumer participation is part of a wider approach to improving the value of payment arrangements of health services. Contracted services should make sense from the patient’s point of view, from a clinical perspective and promote integration of services. This involves a clear definition and measurement approach to what patients and professionals aim to achieve in delivering care and enabling continuity of outcomes.

5.2.2 Consumer participation at the service level

Key approaches and strategies

There are a number of characteristics common to health service organisations that are considered to have successfully adopted a patient-centred approach. These include:

- committed senior leadership
- using data to drive change
- engaging patients, family and carers as partners
- building staff capacity and a supportive work environment
- accountability at all levels
- a learning culture. \(^{286}\)

Most importantly, a systematic approach to implementation, that integrates consumer participation strategies and actions across the organisation is critical to embed participation approaches and patient-centred care as ‘business as usual’.

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Committed senior leadership

The literature suggests that professional and cultural barriers are an impediment to consumer participation in health services.287,288,289,290 These barriers are related to both real and perceived time and resource pressures and the cultural shift toward recognising consumers as “actively engaged health care participants”291 as opposed to passive recipients of health care. This is consistent with VAGO findings in relation to consumer participation in the Victorian health system, whereby “audited health services reported that a major cultural shift, particularly among frontline clinical staff, is required to put consumer participation at the forefront of healthcare.”292

Leadership has a critical role to play in setting priorities and communicating the need for change across all levels of the health service.293,294 Designating a senior manager or executive with responsibility for implementing consumer participation policy and strategy and designating champions (clinical and executive) who model patient-centred behaviour are important strategies to support organisational change (see Box 7 below).295

Box 7: Value of dedicated patient experience leadership – lessons from the US

The Beryl Institute’s 2013 report on the state of patient experience in American hospitals found that strong, visible support ‘from the top’ was the most common driver of success in patient experience efforts.296 On the other hand, diffused focus on experience efforts was identified as hindering progress: the top two roadblocks to improved patient experience were that ‘leaders appointed to drive patient experience are pulled in too many directions’ and ‘other organisational priorities reduce emphasis on patient experience’.297

The importance of focused and committed executive-level leadership is reflected in the increasing number of healthcare organisations with dedicated patient leadership roles as their primary resource for addressing patient experience. The 2013 report found that while committees remain the most popular structure for delivering improved patient experience (22 per cent), an increasing number of organisations are investing in dedicated patient

287 Dunn, N. 2004 ‘Practical Issues around putting the patient at the centre of care’, Journal of the Royal Society of Medicine, 96(7):325-327
289 Shepherd 2001 in Ridley, J. and Jones, L. 2002, p.39
291 VAGO 2012, p.1
292 ibid, p.ix
295 ACSQHC 2011, p.51
297 ibid, p.21
experience C-suite roles. An increasing proportion of these roles have ‘patient experience’ in their title, for example, Chief Experience Officers (CXOs) or Patient Experience Leaders.

The overall results from the study reflect an increasing recognition by healthcare organisations for the need for full commitment to patient experience, either in time or resources; although not all organisations have yet been able to act on this recognition.

Using data to drive change

Internationally, few health service organisations have adequate systems for coordinating patient experience data collection, assessing its quality, or learning from and acting on the results in a systematic way. The use of patient surveys and complaints data to reveal large scale trends is an important tool to assist with service planning and governance. To monitor performance of hospital departments and wards, more detailed information about specific aspects of patients’ experiences is likely to be useful. To this end, using patients’ personal stories have been shown to have a direct impact on those responsible for care (see Boxes 8 and 9 below).

Box 8: Measuring patient centred care – a review of the evidence

“Much remains to be done to promote a truly person-centred health system – and to measure the extent to which this is happening. In order to understand which strategies are most effective and the extent to which care is person-centred, robust measurement approaches are needed.”

A review was recently undertaken in the UK of commonly used approaches and tools to help measure patient centred care. The rapid review summarised 23,000 studies about measuring person-centred care or its components.

The three most commonly researched ways to measure patient-centred care are 1) surveys and interviews with people using health services, 2) surveys of clinicians and 3) observations of clinical encounters.

The review found that while there are a large number of tools available to measure person-centred care, there is no agreement about which tools are most worthwhile and there is no ‘silver bullet’ or best measure that covers all aspects of person-centred care. As a result, a combination of methods and tools is likely to provide the most robust measure of person-centred care.
The review noted that surveys alone do not provide the ‘full picture’ of person-centred care. Interviews with patients and clinicians and observations of clinical encounters can therefore build on survey data to provide a more detailed picture.

The review also noted the absence of a universally agreed definition of ‘person-centred care’ makes it difficult to determine the most appropriate way to measure it. The review suggested that reaching an agreed definition will help clarify what is trying to be achieved and how to get there.

**Box 9: Measuring patient experience – what is the best approach?**

1. **10 things to consider when planning how to measure patient and carer experience**

   1. Consider how patient experience is being defined to inform exactly what needs to be measured.
   2. Think about why patient experience is being measured and how the information will be used.
   3. Assess whether it would be useful to combine approaches so that both qualitative and quantitative material is collected.
   4. Consider whether to ask everyone using the services or only a sample to provide feedback.
   5. Thank about whether the best time to collect feedback is immediately after using the services, when experiences are fresh in people’s minds.
   6. Allocate enough time at the outset to plan and test measurement methods, particularly if these will be used for many years to monitor change over time.
   7. Think about how the end result needs to be presented for various audiences as this may shape how data are collected. Potential outputs include statistical averages, in-depth quotes or graphs.
   8. Make sure that there is appropriate infrastructure at an organisational level to analyse and use patient experience information.
   9. Make sure that patients, carers, managers and health professionals are all comfortable with why feedback is being collected and how it will be used. Staff need to be on board as well as patients.
   10. Ensure that patient experience measures are seen as one component of a broader framework of measurement and that all of the approaches work well together, without excessive burden for either staff or patients.

These 10 recommendations were developed based on an evidence scan undertaken by the Health Foundation that included 328 empirical studies in 2013.

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Engaging consumers as partners

There is an increasing focus on strategies to ensure the contribution of patients to service level improvements. Strategies include:

- partnering in service redesign and co-design projects;
- engaging consumers in incident investigation systems and processes;
- establishing and involving consumers in open disclosure processes following adverse events;
- involving consumers in educational programs for healthcare professionals and administrative leaders;
- establishing and escalation of care for deteriorating patients; and
- involving consumers at the governance level.308

There is an increasing focus in Australia and overseas on co-design as a method for service design and practice improvement. An overview of the Experience-Based Design methodology, developed in the UK, and examples of its application in Victoria (through the Mental Health Experience Co-Design project) and NZ (through the Partners in Care projects) are provided in Boxes 10, 11 and 12 below.

Box 10: Experience-Based Design

Experience-Based Design

EBD is a co-design methodology developed in the UK. It aims to improve health services through focusing on the experiences of patients, carers and staff as they move through the service and interact with its various parts. EBD is based the following principles:

- Partnership between patients, staff and carers;
- An emphasis on experience over attitudes or opinions;
- Using narrative and storytelling to identify ‘touch points’ (that focus patients on specific aspects of a services and the corresponding emotions);
- An emphasis on co-designing services;
- Integrated systematic evaluation of improvements and benefits.

The lessons gained gathering these experiences influence service development and improvement.309

Experience from the UK, Australia and New Zealand is showing EBD to be an effective approach to service design.

308 ACSQHC 2011, p.51
309 NHS Institute for Innovation and Improvement 2009
Mental Health Experience Co-Design (MH ECO)

MH ECO is an innovative research method that brings together consumers, carers and service providers to co-design mental health services. MC ECO applies the most recent theory and practice of Experience-Based Design in health service quality improvement.

Funded by the Victorian Department of Health, the project involves eight mental health services across Victoria. The role of consumers and carers in co-designing services is a key initiative has been drafted into the strategic plan of the Victorian Mental Health reform, which is gaining national and international attention.310

Consumer Research and Evaluation Unit (CREU)

MH ECO is co-facilitated by the Consumer Research and Evaluation Unit and the Carer Research and Evaluation Unit. The Units were established with the commencement of the MH ECO in 2006. They sit within the Victorian peak bodies for mental health consumers and carers namely, the Victorian Mental Illness Awareness Council (VMIAC) and the Victorian Mental Health Carers Network (VMHCN), and are affiliated with the Centre for International Mental Health at the University of Melbourne.

These Units represent a unique model for the creation and dissemination of mental health research. They comprise teams of skilled researchers and evaluators, whose basis for their work is the lived experience of mental illness or caring for someone with a mental illness.311 Since they were established, the Units have been commissioned by a range of service providers and peak bodies to conduct mental health-related research and evaluation activities.

The Units advocate for research that is initiated, designed, controlled and conducted by consumers and carers, and for new methods and approaches to research developed from the perspective of consumers and carers.

New Zealand

A recent example of the HSQC’s consumer engagement projects is the Partners in Care: Consumers and clinical co-designing services project.312 This eight month program, for consumers and providers to learn about EBD, is based on the UK NHS EBD program.

Findings from a review of the program in 2012 were positive. Participants who undertook the program reported:

- a noticeable shift in their view of EBD from being something that is important to something that is essential for service delivery improvement;

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312 HQSCNZ 2013, Partners in Care: Consumers and clinicians co-designing services
• excellent feedback about the opportunity to apply the EBD tools; and
• significant achievements around gaining new knowledge, first time experience of working with consumers, success of overcoming challenges and personal development opportunities.313

The Commission invites consumers and clinicians/managers to work in pairs on a project of their choice. Past projects include:

• **Venous thromboembolism risk post-surgery, Southern Cross Hospitals Limited:** Consumer engagement to reduce avoidable death from blood clots post-surgery. This included involving patients in service improvement and directly in the design of patient information.

• **Oncology patient’s experience of the radiation mask, Wellington Hospital:** The aim was to understand patients’ experience of the mask, before, during and after treatment to help staff improve the experience for patients. This project identified the level of distress experienced by patients and suggested improvement to limit this distress.

• **Peer support in mental health services, Wanganui DHB:** Gathering feedback to improve understanding of peer support in mental health services. This resulted in secondary services commitment to help facilitate the integration of the peer support role into their units and increased clarity on how primary health services can utilise and integrate peer support.

• **Health Literacy Medication Project:** The development, trial, and evaluation of a health literacy learning package to improve the way pharmacists communicate with consumers. A three step approach was adopted: Step 1 Find out what people know, Step 2 Build health literacy skills and knowledge, Step 3 Check you were clear.

Note that clinical areas of focus for Partners in Care projects have been chosen in line with priorities identified by the Minister for Health for the Commission, namely, medication safety, surgical safety, hospital acquired infections and reducing falls.314

**Building staff capacity and a supportive work environment**

Patient-centred organisations focus on increasing their staff’s skills to support patient-centred care delivery.315 Strategies to support this include training in communication skills and techniques, including for patients with specific communication needs; training in patient centred values; integrating discussion of patient-centred values into staff orientation sessions; and ensuring consumer involvement in staff education and training.316
Recognising the link between staff experience and patient experience is also important. Exemplary patient-centred health services achieve this by:

- visibly celebrating the successes of staff in improving patient experience; and
- using staff feedback (for example through surveys) on the work environment to improve work culture and processes.

**Accountability at all levels**

Organisations that successfully engage consumers and integrate patient-centred care establish clear lines of accountability for staff at all levels. Strategies to support this include:

- incorporating responsibility for improving patient care experience in job descriptions;
- considering patient feedback during staff performance reviews, including sharing patient stories;
- including performance metrics and providing performance incentives for the demonstration of patient-centred practice at both the staff and governance levels;
- incorporating consumer participation and patient experience metrics into unit, department and organisational performance monitoring and reporting; and
- ensuring agenda for board or governance committee meetings include a strong emphasis on quality issues, including patient experience.

**A learning culture**

Organisations that have strong consumer participation and patient-centred care practices have a culture of learning and strongly supporting change and improvement. These organisations have systems, mechanisms and processes in place that are used to continually improve the capability of those who work with it or for it. In addition, they are adaptive to external forces, able to promote individual and collective learning, and use these lessons to improve outcomes.

### 5.2.3 Consumer participation in individual care

**Key approaches and strategies**

- At the individual level, key elements of a patient-centred approach include:

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318 Luxford, K., Safran, D., Delbanco, T., 2011
319 ibid.
320 Luxford, K., Safran, D., Delbanco, T., 2011
322 Luxford, K., Safran, D., Delbanco, T., 2011
Focus on health literacy, including well-written health information, the use of web-based information sources, virtual support, and tailored information for groups with low levels of health literacy

Training for health professionals in patient-centred consultation styles and communication

Strategies to support shared decision-making and self-management (e.g. coaching, question prompts, decision aids)

Participation at the individual care level focuses on consumers’ ability to play an active role in protecting their health, choosing appropriate treatment for episodes of ill health, and managing chronic disease. Health literacy, capacity for shared decision-making and capacity for self-management of chronic conditions are therefore key aspects of participation at this level. Strategies, initiatives and programs shown to be effective in these areas are described below.

Building Health Literacy

Health literacy is fundamental to service user involvement. Unless people can access, understand, evaluate and use basic health information, they will not be able to make appropriate decisions about their health and health care. Strategies that have been shown to be effective building health literacy include:

1. written information that supplements clinical consultations;
2. web sites and other electronic information sources;
3. personalised computer-based information and virtual support; and
4. tailored information for individuals with low levels of health literacy.

Ensuring individuals have the necessary skills and capacity to engage with health service providers as equal partners is critical to effective engagement. The provision of access by health services to relevant orientation and training for patients, families and carers engaging in partnership with their organisation can be an effective means to support meaningful engagement. Training programs run independently of health services also exist to provide consumers with the skills needed to engage with health services and advocate for greater consumer involvement (for example, training run by the Health Issues Centre in consumer leadership).

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325 Coulter and Ellins 1997
327 Coulter and Ellins 1997
328 ACSQHC 2011, p.51
329 ACSQHC 2011, p.52
There is a significant amount of activity occurring within Australia to address health literacy, however much of this work remains disconnected and systems to support improvement vary at the local, regional and state/territory level and are absent nationally. In 2013, the ACSQHC prepared a consultation paper which highlights key areas where action is needed to a coordinated and consistent approach to health literacy in Australia. Written submissions were sought up to 30 August 2013. The submissions will be used to inform the next phase of work, which will involve developing a national approach to health literacy.

**Training for health professional in communication**

Consumers increasingly expect information and involvement in decision making related to their healthcare. As consumer expectations change, there is a need to ensure healthcare professionals receive training in the principles and practice of consumer participation and patient-centred care (See Box 13 below).

While a partnership approach to consumer participation is becoming more prominent on the agenda in medical education, a study found that skills gaps, a general lack of awareness of needs and few examples of good practice exist. Extending the role of consumers in clinical education has been identified as an important strategy to build the skills of healthcare professionals in this area.

**Box 13: Always Events – a tool for learning**

Tools and resources can help organisations focus on the processes and behaviours required to make patient-centred care the norm. For example, tools that help clinicians understand the elements of good communication.

The Picker Institute developed the concept of Always Events® as an organising principles for these practices. An Always Events® is defined as ‘those aspects of the patient and family experience that should always occur when patients interact with healthcare professionals and the delivery system’. They are so important to patients and families that health care providers must perform them consistently for every patients, every time.

The initiative is now led by the Institute for Healthcare Improvement which has developed a toolkit for health services to understand what an Always Event is, how to select a set of practices for an Always Event initiative, and the steps for implementing the initiative.

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332 ibid.

333 ACSQHC 2011, p.54


335 ibid.
Strategies to support shared decision-making and self-management

Personalised computer-based information and virtual support are increasingly being used to increase access to health information. ‘Armchair involvement’ is a term originating in the UK and used to describe the use of technology to improve engagement. 336 This encompasses information, feedback and participation. The NHS Institute has discussed the relative benefits of a range of engagement tools including apps on mobile phones, booking services through digital TVs, podcasts and websites, consumer generated online content and electronic patient records.337

5.3 Whole of system approaches

Diversity and equity in consumer participation applies to all levels of the health system and is described in these terms below.

5.3.1 Diversity and equity in participation

Research in Australia has identified the link between culture, language and patient safety outcomes. 338 The VAGO report outlined typical barriers that CALD consumers can face when engaging with health services, including:

- lack of familiarity with the local health system, services available to them and how to access them (service level);
- different concepts of health and illness which may affect understanding of treatment and impact compliance (individual level);
- language and cultural barriers to understanding information, developing trusting relationships with health professionals, and providing informed consent (service and system levels); and
- lack of understanding of consumer rights and responsibilities (system level).

Research by the Health Issues Centre (2008) identified the following enablers to CALD participation339:

- cultural competency training;
- collection and use of demographic and service utilisation data;
- accessible and appropriate language services;
- accessible and appropriate health information;
- partnerships with community groups/ethno-specific agencies;
- workforce diversity;

336 NHS Institute for Innovation and Improvement 2007, Armchair involvement: practical technology for improving engagement, NHS Institute for Innovation and Improvement.
337 ibid.
338 VAGO 2012, p.16
• whole-of-community approach; and
• organisational commitment with adequate resourcing.

These enablers have implications across all levels within the health care system.

**Empowerment approaches: lessons from the UK’s ‘Altogether Better’ initiative**

Altogether Better uses a community health champion model to increase the voice of patients and communities in shaping health and social care services. The initiative aims to empower people in communities that are ‘seldom heard’ (or hard to reach) who experience high levels of ill-health.

The initiative takes an empowerment approach, comprising three strategies:

- building knowledge and awareness
- increasing self esteem, confidence and social networks, and
- challenging culture and opening up the system.

This involves four stages:

**Stage 1:** Engagement and recruitment of individuals from target communities through a range of techniques, including through existing community infrastructure, publicity and word of mouth.

**Stage 2:** Training and support which is flexible according to individual and community needs, context and aspirations.

**Stage 3:** Flexible support for the individual to carry out volunteer activities using their own skills and ability to relate to their communities influencing friends, families and wider communities.

**Stage 4:** Supporting individuals to carry on along pathways to further education, employment and enterprise.

An evaluation of the Altogether Better community health champion model undertaken in 2009 by the Centre for Health Promotion Research, Leeds Metropolitan University, reported a number of positive outcomes from the program. These included positive health benefits for the champions themselves as well as their communities, and evidence that increased confidence as a result of participation in the initiative contributed to individual and community empowerment over time.

Evidence suggests that the community health champion model is likely to be most effective with hard to reach groups, as they have the potential to help reduce barriers to participation and can contribute to reducing health inequalities.

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5.4 Learning from Australia and overseas: examples of better practice

This section highlights specific examples of better practice in relation to the promotion of consumer participation, person and family centred care and patient experience, drawn from Australia and the international jurisdictions of focus.

The examples have been grouped into four themes, shown in the table below, to summarise the range of evidence based approaches from the previous section. It is recognised that there are interrelationships between themes and also the evidence. Thematic groups are therefore not necessarily mutually exclusive.

Table 9: Thematic summary of best practices to promote consumer participation based on evidence based approaches

<table>
<thead>
<tr>
<th>Themes of best practices to promote consumer participation</th>
<th>Evidence based approaches to consumer participation</th>
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</thead>
<tbody>
<tr>
<td>1. Policies which promote participation</td>
<td>• Patient centred care as a dimension of quality in its own right</td>
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<tr>
<td>2. Measurement, performance monitoring and consumer choice</td>
<td>• Patient feedback</td>
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<td></td>
<td>• Standardised performance monitoring and measuring</td>
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<tr>
<td></td>
<td>• Research</td>
</tr>
<tr>
<td>3. Service planning and financial incentives to support consumer participation</td>
<td>• Leadership</td>
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<tr>
<td></td>
<td>• Using data to drive change</td>
</tr>
<tr>
<td></td>
<td>• Capacity building</td>
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<td></td>
<td>• Co-design</td>
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<tr>
<td>4. Health literacy and capacity building.</td>
<td>• Health literacy</td>
</tr>
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<td></td>
<td>• Diversity and equity in participation</td>
</tr>
<tr>
<td></td>
<td>• Communication and training for health professionals</td>
</tr>
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<td></td>
<td>• Shared decision making</td>
</tr>
</tbody>
</table>

The relationship between the thematic better practices and evidence based approaches is depicted in the figure below.
5.4.1 Policies which promote participation

Examples of policies which promote participation include the following:

**Australia**

- The inclusion of patient-centred care as one of three dimensions of safety and quality in the *Australian Safety and Quality Framework for Health Care* is consistent with a whole of health service response to policy development to promote participation. Similarly, the *National Safety and Quality Health Service Standards* include two specific standards which relate directly to consumer participation.

**United Kingdom**

- The NHS Outcomes Framework sets out the overarching performance indicators for the NHS across five domains of health. One of these domains (domain 4) includes “ensuring that people have a positive experience of care”. This indicator reflects the pursuit of measuring patient experience as distinct from other outcome measures in health. Additionally, patient experience is also defined as a quality standard by NICE to provide commissioning guidance on the components of good patient experiences.

**New Zealand**

- Actively engaged consumers require access to a range of information. The Ministry of Health has recently produced a policy regarding sharing of information through IT systems, *Sharing Health Information: Toward better, safer care*.  

Canada

- Funded by Health Canada, the Patient-Centred Care: Better Training for Better Collaboration Program 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 inter-professional collaborative practice is challenging in many ways, it offers a true opportunity to prepare future health professionals for contemporary patient-centred practice. 343

5.4.2 Measurement, performance monitoring and consumer choice

Examples of measurement approaches, performance monitoring and consumer choice which promote participation include the following:

United Kingdom

- Patient experience is a key domain within the NHS Outcomes Framework. This includes the collection of patient experience information in real time and use for service improvements. This is supported by the NHS National Quality Board’s Patient Experience Framework which helps to guide measurement across the NHS. The collection of patient experience from national surveys is published as a resource to improve patient experience and quality and safety.

- Consumer choice is facilitated by the right of patients to choose any hospital for their NHS-funded care and NHS Choices, which provides information on specialist options and performance information from national hospital surveys so that the public can make informed choices about where they receive care. Consumers are able to compare hospitals by various criteria, including cleanliness, car parking arrangements, general facilities and, in some cases, survival rates. Consumers are also able to rate and comment on their healthcare and see whether staff from the hospital agreed that if a friend or relative needed treatment they would be happy with the standard of care provided by the hospital.

United States

- Patient feedback collected using the CAHPS enables comparisons to be made over time from a central repository containing 13 years of survey data. This database is a key resource for the AHRQ’s National Healthcare Quality Report and National Healthcare Disparities Report, which is used by policy makers to monitor progress toward improved quality in healthcare.

- Doctors who report quality measures for service covered by Medicare and Ambulatory surgical centres and other health organisations must also meet Medicare P4P reporting


344ACSQHC 2011, p.48
and performance targets. In addition, financial incentives are available improved coordination of patients with chronic conditions.

- Like NHS Choices, the web-based tool ‘Hospital Compare’ uses information from the Hospital Outcomes of Care Measures, CAHPS and H-CAHPS surveys to provide information on hospitals’ care provided to patients across certain medical conditions or surgical procedures. The objective of Hospital Compare is to help consumers make decisions about choices of where to receive their health care and encourages hospitals to improve the quality of care they provide.

- Physician Compare was launched in December 2010 under the Patient Protection and Affordable Care Act 2010. This tool, available on the US Government Medicare website, allows individuals to search for a physician or other healthcare professional by specialist, type of professional and location. Additional search criteria allow the user to search by gender and whether the professional accepts the Medicare-approved amount as payment in full on all claims. The tool also provides information on languages spoken, group practice locations, education and hospital affiliation.\(^\text{345}\)

- Since 2013, CMS has been required to also make information on physician performance publicly available through Physician Compare.\(^\text{346}\)

**New Zealand**

- A key goal of Partners in Care is to develop the evidence base for best practice in consumer engagement. Evaluation is a core component of the program. Indicators and measures for evaluation of all projects funded by the Commission and the overall achievement of the funded projects will be reviewed in year four.\(^\text{347}\)

**The Netherlands**

- The CQ-Index system aims to support patients to make their own choices about their care and also to provide information for care providers to improve their services, to policy makers to aid in determining policy, and for health care insurers to use in their negotiations with healthcare organisations.

\(^{345}\) ACSQHC 2011, p.15
\(^{346}\) ibid.
\(^{347}\) HQSCNZ 2012, p.1
5.4.3 Service planning and financial incentives to support consumer participation

Examples of service planning and financial incentives to support consumer participation include the following:

**United Kingdom**

- Clinical Commissioning Groups (CCGs), when contracting with health care providers, must ensure that patient experience and feedback are inherent parts of service design, delivery and improvement. Service providers are required to raise awareness of local feedback options, encourage feedback, and demonstrate to the public that their feedback has been used to improve service quality and patient experience.

- A major P4P initiative – the Quality and Outcomes Framework – commenced in 2004. The performance of general practitioners (GPs) was measured using 134 quality indicators and linked to performance payments. The initiative evidenced modest improvements in measured quality of care. However, overall, evidence to support the program is mixed.

- The Commissioning for Quality and Innovation (CQUIN) framework, introduced in 2009, aims to improve quality of care in hospitals and other healthcare organisations. Providers who agree to a CQUIN scheme with their funding body have a small proportion of their income made conditional on an agreed package of goals and indicators relating to quality, safety, innovation and patient experience.  

**United States**

- Financial incentives are used in the US to promote patient feedback. This includes direct financial incentives for providing information, via the Reporting Hospital Quality Data for Annual Payment Update Initiative (from 2008) and a two per cent penalty on income reimbursement for Medicare patients (from 2010).

- Private providers have also introduced financial incentives to promote a focus on meeting quality improvement goals.

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5.4.4 Health literacy and capacity building

Examples of health literacy and capacity building to support consumer participation include the following:

**Australia**

- The Health Issues Centre provides a nationally accredited course on consumer engagement and leadership for consumer representatives and community leaders, with the aim of equipping participants with foundation skills and knowledge to promote consumer engagement to other consumers and health personnel.\(^{350}\)

**United Kingdom**

- NHS Wales has developed specific policy guidance with regards to consumer engagement and person centred care. The white paper *The Listening Organisation: Ensuring care is person centred in NHS Wales*\(^{351}\) details NHS Wales’ commitment to engaging with and listening to patients. This builds on ‘Achieving Excellence in the Quality Delivery Plan for NHS Wales’ where the Welsh Government placed improving patient and user experience at the centre of NHS Wales organisations.\(^{352}\) The White Paper, *The Listening Organisation*: identifies where ‘listening skills’ need to be developed and high level guidance on incorporating ‘listening’ as an organisation-wide discipline. In addition, the concept of co-production is outlined where citizens are involved in the commissioning, design, delivery and evaluation of services.

- The principle of engaging with consumers in the planning and development of health services was established in 2010 in NHS Wales’ *Guidance on Involving Adult NHS Service Users and Carers*.\(^{353}\) This guide was designed to help services users and carers through training to engage with health services.

**United States**

- Project LEAD run by the National Breast Cancer Coalition (USA) provided consumers with the skills to be active participants in research, quality improvement and evidence-based decision making in health care.\(^{354}\)

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\(^{352}\) NHS Wales 2013, p.2


5.5 Summary

The key points in relation to maximising consumer participation from a review of the evidence base and best practice strategies are summarised as follows:

- Evidence based approaches to promote consumer participation encompass all levels of health care systems. System level approaches are important where consistency and universality are important, such as establishing principles or standards to recognise patient-centred care or measurement frameworks. Service level approaches provide scope for individual health care services to focus on local requirements to promote consumer participation, such as building staff capacity, using data to drive change, leadership and methods to engage patients, family and carers as partners. Individual approaches may include health literacy, shared decision making and training of health care professionals to support consumer participation. Approaches may also be relevant at more than one level or across all levels, such as approaches that promote diversity and equity in consumer participation.

- Best practices examples reflecting evidence based approaches to promoting consumer participation are prevalent across a number of jurisdictions, but especially in the UK. Best practice examples have been categorised into the following groups:
  - *Policies which promote consumer participation*, including examples demonstrating the inclusion of patient-centred care in overarching standard and frameworks across health care systems.
  - *Measurement, performance monitoring and consumer choice*, including examples of approaches governing whole system measurement and monitoring of consumer participation and patient-centred approaches and approaches to use information to enable consumer choice and involvement about their care.
  - *Service planning and financial incentives to support consumer participation*, including examples of contracting arrangements which seek to align financial incentives with promoting and demonstrating outcomes in consumer participation and patient-centred approaches.
  - *Health literacy and capacity building*, including examples of professional leadership development and approaches to engaging with consumers.
6 Next steps

This report has provided a high level review of the current state of consumer participation policies and practices in Australia and selected international jurisdictions.

The information gathered through the current state analysis will be drawn on throughout the evaluation, but particularly in the development of the policy logic and evaluation strategy (Phase 2b).

Figure 13: Summative evaluation of doing it with us not for us

Phase 2b will be followed by the evaluation conduct, including the assessment tool and survey, desktop review and consultations, as summarised in the figure above. These stages will inform the outcome summit, discussion paper and recommendations to assist the Department hold a public consultation on the development of a new policy.
### Doing it with us not for us priority actions and key implementation tasks

#### Figure 14: Doing it with us not for us priority actions and key implementation tasks by level of the Victorian health service system

<table>
<thead>
<tr>
<th>Individual care</th>
<th>Program or department</th>
<th>Health service organisation</th>
<th>Department of Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Promote the rights and responsibilities of patients to the community, consumers and carers.</td>
<td>6. Involve consumers, carers and community members from the planning stage through to evaluation and monitoring.</td>
<td>12. Integrate participation of consumers, carers and community members, representatives or nominees into the quality and safety program</td>
<td>18. Use the same processes of working with and accessing consumers, carers and community members, representatives or nominees across the Department of Health</td>
</tr>
<tr>
<td>2. Communicate clearly and respectfully with consumers and carers.</td>
<td>7. Create welcoming and accessible services for the diverse members of your community.</td>
<td>13. Community representatives or nominees to be involved in the review of system level issues regarding consumer and carer feedback and complains</td>
<td>19. Provide support, guidance and resources to health services and consumers, carers and community members on participation.</td>
</tr>
<tr>
<td>3. Provide accessible information to consumers, carers and community members about health care and treatment.</td>
<td>8. Provide training to staff in communication skills and how to involve consumers and carers in decision making.</td>
<td>14. Include the involvement of consumers, carers, community members, representatives or nominees in all aspects of the organisation’s planning and development.</td>
<td>20. Provide training and education to Department of Health staff on how to use the different types of participation, and evidence-based participation and communication.</td>
</tr>
<tr>
<td>4. Communicate and provide information about treatments and care to consumers and carers that is developed with consumers and, where appropriate, carers.</td>
<td>9. Promote the importance of consumer and carers providing feedback to improve services.</td>
<td>15. Provide staff training and education on how to use different types of participation.</td>
<td>21. Encourage health services to evaluate and monitor participation within a quality improvement framework.</td>
</tr>
<tr>
<td>5. Listen and act on the decisions the consumer and, where appropriate, their carer(s) make about their care and treatment.</td>
<td>10. Establish links with community organisations to provide emotion support and ongoing information to consumers and carers.</td>
<td>16. Ensure position descriptions include participation components.</td>
<td>22. Encourage the inclusion of participation skills and knowledge in the tertiary education of health professionals.</td>
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</tr>
<tr>
<td></td>
<td>11. Involve consumers, carers and community members in the development of clinical guidelines and research</td>
<td>17. Evaluate, monitor and report on participation to the community and the Department of Health.</td>
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<tr>
<td></td>
<td>23. Advocate for a whole of Department of Health policy on participation.</td>
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</tbody>
</table>

**Key Implementation Tasks:**

- Provide and promote the new Australian health care charter for Victorian public health services to all consumers
- Use the *Well-written health information: a guide* (Currie et al 2000) in the development of health information and the Checklist to review your documents
- Use consumer experience and satisfaction surveys to improve service delivery, and make welcoming and accessible services for all members of our diverse community
- Resource consumers, carers and community members to participate on your quality, ethics and governance committees
- Consult with consumers, carers and your community in developing and reviewing your strategic plan, designs and Community Participation Plan.
- Produce with your community an annual Quality of Care Report
- Ensure you work with your diverse community members to build your Cultural Responsiveness and Disability Action plans.
- Promote the use of Department of Premier and Cabinet Guidelines for the appointment and remuneration of part-time non-executive directors of state government boards and members of statutory bodies and advisory committees.
- Offer to all Department of Health staff training on working with consumers, carers and community members on departmental committees.
- Appropriately identify *doing it with us not for us* as part of the policy context in the development of new health policies, guidelines and resources.

*Source: Victorian Department of Health 2009b*
## B Types of participation

*Figure 15: Types of participation as described in the ‘Doing it with us not for us’ Consultation Paper*

<table>
<thead>
<tr>
<th>Intensity of participation</th>
<th>Objective</th>
<th>Tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information</td>
<td>• To support participation</td>
<td>• Public information campaigns</td>
</tr>
<tr>
<td></td>
<td>• To convey facts</td>
<td>• Health consultation</td>
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<td></td>
<td>• To educate</td>
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<tr>
<td>Consultation</td>
<td>• To gauge reaction to a proposal/care plan/treatment plan and invite feedback(^{355})</td>
<td>• Key contacts</td>
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<td></td>
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<td>• Surveys</td>
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<td></td>
<td></td>
<td>• Interest group meetings, focus groups</td>
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<td></td>
<td></td>
<td>• Public meetings</td>
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<td></td>
<td></td>
<td>• Discussion papers</td>
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<tr>
<td></td>
<td></td>
<td>• Public hearings</td>
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<tr>
<td></td>
<td></td>
<td>• Consumer (patient) and carer (family) meetings</td>
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<tr>
<td></td>
<td></td>
<td>• Health consultation</td>
</tr>
<tr>
<td>Partnership</td>
<td>• To involve consumers, carers and representatives in aspects of government or health service organisational decision making</td>
<td>• Advisory boards</td>
</tr>
<tr>
<td></td>
<td>• To involve consumers, carers and representatives in health carer or treatment decision making</td>
<td>• Community advisory committees (CACs)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Policy community forum</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Shared decision making</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Community development</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Patient-centred care</td>
</tr>
<tr>
<td>Delegation</td>
<td>• To hand control to a board of community representatives within a specified framework</td>
<td>• Public enquiries</td>
</tr>
<tr>
<td></td>
<td>• To ensure policy options are formulated at arm’s length from partisan politics</td>
<td>• Impact assessment studies</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Health service boards</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Ethics committee</td>
</tr>
<tr>
<td>Control</td>
<td>• To hand control of an issue to the electorate</td>
<td>• Referenda</td>
</tr>
<tr>
<td></td>
<td>• To hand control of an issue to the consumer of healthcare</td>
<td>• Community-elected board of management</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Advance care planning</td>
</tr>
</tbody>
</table>

*Source: Victorian Government Department of Health 2009\(^{356}\)*

\(^{355}\) NB: Consultation is only participation when information gathered can influence subsequent policy, care and treatment choices

\(^{356}\) Department of Health 2005
C Consumer participation in Victoria: Roles and Responsibilities

The report of the Victorian Auditor-General’s Office on consumer participation in the Victorian healthcare system provides an overview of the roles and responsibilities of different members of the healthcare system with respect to consumer participation.357 An updated summary is provided below.

Roles and responsibilities

Department of Health

The Quality, Safety and Patient Experience Branch within the department is responsible for implementing, managing and monitoring the Doing it with us not for us policy. This includes building the capacity of health services to implement consumer participation, and reviewing their performance. The department has a number of specific consumer participation activities.358

Participation Advisory Committee

In 2006, the department established the Participation Advisory Committee. Its purpose is to advise the department on the implementation of Doing it with us not for us. The committee was involved in setting the standards and indicators in the strategic direction 2010–13. Members include:

• consumers
• community representatives from CACs
• representatives from peak consumer groups
• representatives from health services
• a departmental staff member
• the Health Services Commissioner.359

Victorian Patient Satisfaction Monitor

Since 2000, the department has contracted a company to administer the VPSM. The VPSM measures feedback from adult patients about their stay in Victorian public health services.

From 1 January 2014, the VPSM will be superseded by the Victorian Healthcare Experience Survey (VHES).360 In line with current international practice, the VHEMI measures patient

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357 VAGO 2012, pp.3-5
358 VAGO 2012, p.3
359 VAGO 2012, p.4

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experience, rather than patient satisfaction. Targets are currently being developed for 2014-15. In 2014, the indicator will report health service compliance with participation in the survey.361

Supporting and promoting consumer participation

The department supports and promotes consumer participation by strengthening the evidence base and sharing knowledge across the sector. Such activities include:

- funding the Health Issues Centre to promote consumer participation, provide training and undertake research
- funding research by the Centre for Health Participation and Communication
- hosting consumer participation forums for health sector staff and consumers
- providing web-based and printed information and resources.362

Health services

Victorian public health services have a range of consumer participation responsibilities set out in legislation, as well as policy and funding requirements. Figure 16 summarises key consumer participation responsibilities.

Figure 16: Health service consumer participation responsibilities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Description</th>
<th>Requirement sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community advisory</td>
<td>Public health service boards must establish a CAC to provide direction,</td>
<td>• Health Services Act 1988</td>
</tr>
<tr>
<td>committee</td>
<td>leadership and advocacy to increase consumer participation.</td>
<td>• Victorian health policy and funding guidelines</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Community advisory committee guidelines</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Victorian public health services</td>
</tr>
<tr>
<td>Community participation</td>
<td>Shows how consumer participation will be integrated into health service</td>
<td>• Community advisory committee guidelines:</td>
</tr>
<tr>
<td>plan</td>
<td>operations, planning and policy development. The plan is developed by the</td>
<td>Victorian public health services</td>
</tr>
<tr>
<td></td>
<td>board in partnership with the CAC.</td>
<td>• How to develop a community participation plan</td>
</tr>
</tbody>
</table>

361 ibid.
362 VAGO 2012, p.4
### Activity

<table>
<thead>
<tr>
<th>Activity</th>
<th>Description</th>
<th>Requirement sources</th>
</tr>
</thead>
</table>
| Quality of care report                            | Describes health service quality and safety systems, and outcomes to consumers. Report achievements against *Doing it with us not for us* participation indicators. | - Victorian health policy and funding guidelines  
- *Doing it with us not for us: Strategic Direction 2010-213*  
- *Quality of care reports 2012-13* |
| Complaint processes                                | Health services are required to have effective and responsive complaints processes.                                      | - Victorian health policy and funding guidelines                                      |
| Cultural diversity plan                           | Aims to assure health services cater appropriately for CALD communities.                                                     | - Victorian health policy and funding guidelines  
- Cultural responsiveness framework                |
| Key result area actions for the Improving Care for Aboriginal and Torres Strait Islander Patients (ICAP) program | Aim to improve identification, access, the cultural sensitivity of care, and participation of Aboriginal and Torres Strait Islander patients. | - *Improving Care for Aboriginal and Torres Strait Islander Patient (ICAP) guidelines* |
| Mental health consumer and carer participation plan| Aims to direct consumer participation within mental health services, including involvement of consumers in their treatment and care, and in the planning, development and evaluation of local mental health services. | - *Strengthening consumer participation in Victoria’s public mental health services – Action Plan* |

**Source:** VAGO 2012[^1]

[^1]: VAGO 2012, p.5
D  Objectives 3 and 4 of the summative evaluation

The Current State Report directly contributes to Objectives 3 and 4 of the evaluation, as specified in the Department’s Request for Tender (No. C2777).

Figure 17: Objectives 3 and 4 of the summative evaluation of the Doing it with us not for us policy

**Objective 3:** Review the Victorian, Australian and international public policy on consumer participation (and related terms) in healthcare to inform the new Victorian policy on consumer participation (VAGO Recommendations 10, 8 and 7).

- Conduct a situational desk top audit of Victorian, national and international consumer participation (and related terms) public policy documents.
- Specifically, review the National Safety and Quality Health Service Standards and the Victorian Health Priorities Framework to maximise monitoring and reporting opportunities and contextualise recommendations, respectively.
- Based on the Objective 3 findings make recommendations for a new Victorian consumer participation policy.

**Objective 4:** Identify best practice and evidence based actions (quality improvement strategies) by which consumer participation, person and family centred care and patient experience can be maximised across the four levels of the policy (VAGO Recommendations 10 and 7).

- Review the peer reviewed literature and grey literature about patient experience, person and family centred care and consumer participation improvement strategies/actions/programs for the period 2005 to 2013.\(^{364}\)
- Review all current Community Participation Plans, all Evaluating Effectiveness of Participation projects, biennial consumer participation conference presentations and abstracts and Victorian Public Health Care Award submissions for patient experience, person and family centred care and consumer participation improvement strategies and actions.
- Based on the Objective 4 findings make recommendations for a new Victorian consumer participation policy.

Source: Department of Health 2013

Full details of the scope of this report are provided in chapter 1.2, including those aspects of Objective 4 which could not be included at the present time.

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\(^{364}\) This will build on from the literature reviews conducted as part of the consultation phase and development of the 2006 policy and the current development of the health literacy and information policy statement being undertaken by the Department of Health.
### Overview of NSQHS Standards 1 and 2

**Standard 1: The governance for safety and quality in health service organisation standards**

Patient rights and engagement: Patient rights are respected and their engagement in their care is supported

<table>
<thead>
<tr>
<th>This criterion will be achieved by:</th>
<th>Actions required:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.17 Implementing through organisational policies and practices a patient charter of rights that is consistent with the current national charter of healthcare rights</td>
<td>1.17.1 The organisation has a charter of patient rights that is consistent with the current national charter of healthcare rights</td>
</tr>
<tr>
<td></td>
<td>1.17.2 Information on patient rights is provided and explained to patients and carers</td>
</tr>
<tr>
<td></td>
<td>1.17.3 Systems are in place to support patients who are at risk of not understanding their healthcare rights</td>
</tr>
<tr>
<td>1.18 Implementing processes to enable partnership with patients in decisions about their care, including informed consent to treatment</td>
<td>1.18.1 Patients and carers are partners in the planning for their treatment</td>
</tr>
<tr>
<td></td>
<td>1.18.2 Mechanisms are in place to monitor and improve documentation of informed consent</td>
</tr>
<tr>
<td></td>
<td>1.18.3 Mechanisms are in place to align the information provided with their capacity to understand</td>
</tr>
<tr>
<td></td>
<td>1.18.4 Patients and carers are supported to document clear advance care directives and/or treatment-limiting orders</td>
</tr>
<tr>
<td>1.19 Implementing procedures that protect the confidentiality of patient clinical records without compromising appropriate clinical workforce access to patient clinical information</td>
<td>1.19.1 Patient and clinical records are available at the point of care</td>
</tr>
<tr>
<td></td>
<td>1.19.2 Systems are in place to restrict inappropriate access to and dissemination of patient clinical information</td>
</tr>
<tr>
<td>This criterion will be achieved by:</td>
<td>Actions required:</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>1.20 Implementing well designed, valid and reliable patient experience feedback mechanisms and using these to evaluate the health service performance</td>
<td>1.20.1 Data collected from patient feedback systems are used to measure and improve health services in the organisation</td>
</tr>
</tbody>
</table>

**Standard 2: Partnering with consumers**

**Consumer partnership in service planning: governance structures are in place to form partnerships with consumers and carers**

<table>
<thead>
<tr>
<th>This criterion will be achieved by:</th>
<th>Actions required:</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 Establishing governance structures to facilitate partnerships with consumers and/or carers</td>
<td>2.1.1 Consumers and/or carers are involved in the governance of the health service organisation</td>
</tr>
<tr>
<td></td>
<td>2.1.2 Governance partnerships are reflective of the diverse range of backgrounds in the population served by the health service organisation, including those people who do not usually provide feedback</td>
</tr>
<tr>
<td>2.2 Implementing policies, procedures and/or protocols for partnering with patients, carers and consumers in:</td>
<td>2.2.1 The health service organisation establishes mechanisms for engaging consumers and/or carers in the strategic and/or operational planning for the organisation</td>
</tr>
<tr>
<td>• strategic planning and operational/services planning</td>
<td>2.2.2 Consumers and/or carers are actively involved in decision making about safety and quality</td>
</tr>
<tr>
<td>• decision making about safety and quality initiatives</td>
<td></td>
</tr>
<tr>
<td>• quality improvement activities</td>
<td></td>
</tr>
<tr>
<td>2.3 Facilitating access to relevant orientation and training for consumers and/or carers partnering with the organisation</td>
<td>2.3.1 Health service organisations provide orientation and ongoing training for consumers and/or carers to enable them to fulfil their partnership role</td>
</tr>
<tr>
<td>2.4 Consulting consumers on patient information distributed by the organisation</td>
<td>2.4.1 Consumers and/or carers provide feedback on patient information publications prepared by the health service organisation (for distribution to patients)</td>
</tr>
<tr>
<td></td>
<td>2.4.2 Action is taken to incorporate consumer and/or carers feedback into publications prepared by the health service organisation for distribution to patients</td>
</tr>
</tbody>
</table>
Standard 2: Partnering with consumers

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.

<table>
<thead>
<tr>
<th>This criterion will be achieved by:</th>
<th>Actions required:</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.5 Partnering with consumers and/or carers to design the way care is delivered to better meet patient needs and preferences</td>
<td>2.5.1 Consumers and/or carers participate in the design and redesign of health services</td>
</tr>
<tr>
<td>2.6 Implementing training for clinical leaders, senior management and the workforce on the value of and ways to facilitate consumer engagement and how to create and sustain partnerships</td>
<td>2.6.1 Clinical leaders, senior managers and the workforce access training on patient-centred care and the engagement of individuals in their care</td>
</tr>
<tr>
<td>2.6.2 Consumers and/or carers are involved in training the clinical workforce</td>
<td></td>
</tr>
</tbody>
</table>

Standard 2: Partnering with consumers

Consumer partnership in service measurement and evaluation

<table>
<thead>
<tr>
<th>This criterion will be achieved by:</th>
<th>Actions required:</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.7 Informing consumers and/or carers about the organisation’s safety and quality performance in a format that can be understood and interpreted independently</td>
<td>2.7.1 The community and consumers are provided with information that is meaningful and relevant on the organisation’s safety and quality performance</td>
</tr>
<tr>
<td>2.8 Consumers and/or carers participating in the analysis of safety and quality performance information and data, and the development and implementation of action plans</td>
<td>2.8.1 Consumers and/or carers participate in the analysis of organisational safety and quality performance</td>
</tr>
<tr>
<td>2.8.2 Consumers and/or carers participate in the planning and implementation of quality improvement</td>
<td></td>
</tr>
<tr>
<td>2.9 Consumers and/or carers participating in the evaluation of patient feedback data and development of action plans</td>
<td>2.9.1 Consumers and/or carers participate in the evaluation of patient feedback data</td>
</tr>
<tr>
<td>2.9.2 Consumers and/or carers participate in the implementation of quality activities relating to patient feedback data</td>
<td></td>
</tr>
</tbody>
</table>
E.2 Review of NSQHS Standards against Victorian standards

The following tables identify the areas of overlap between the National Safety and Quality Health Service Standards and the Standards and Priority Actions identified in the Doing it with us not for us: Strategic Direction 2010-13.

**Victorian standards/actions which must be achieved by health services as part of accreditation**

<table>
<thead>
<tr>
<th>Victorian standard / action</th>
<th>Relevant NSQHS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>S1</strong>: the organisation demonstrates a commitment to consumer, carer and community participation appropriate to its diverse community</td>
<td>1.17.1, 1.17.2, 1.17.3, 1.18.3</td>
</tr>
<tr>
<td><strong>S2</strong>: Consumers and, where appropriate, carers are involved in informed decision-making about their treatment, care and wellbeing at all stages and with appropriate support</td>
<td>Partially: NSQHS 1.18 requires patients and carers to be partners in the planning for their treatment)</td>
</tr>
<tr>
<td><strong>S4</strong>: Consumers, carers and community members are active participants in the planning, improvement, and evaluation of services and programs on an on-going basis</td>
<td>2.1.1, 2.1.2, 2.2.1, 2.2.2, 2.4.1, 2.4.2, 2.5.1, 2.8.1, 2.8.2, 2.9.1, 2.9.2</td>
</tr>
<tr>
<td><strong>Priority action</strong>: Communicate and provide information about treatments and care to consumers and carer that is developed with consumers and, where appropriate, carers</td>
<td>1.18.1</td>
</tr>
<tr>
<td><strong>Priority action</strong>: Integrate participation of consumers, carers and community members, representative or nominees into the quality and safety program</td>
<td>2.8.1, 2.8.2</td>
</tr>
<tr>
<td><strong>Priority action</strong>: Community representatives or nominees to be involved in the review of system level issues regarding consumer and carer feedback and complaints</td>
<td>2.9.1, 2.9.2</td>
</tr>
</tbody>
</table>
Standards/Actions which extend the mandatory NSQHS Standards (are partially assessed by NSQHS standards)

<table>
<thead>
<tr>
<th>Victorian standard / action</th>
<th>Relevant NSQHS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>S2:</strong> Consumers and, where appropriate, carers are involved in informed decision-making about their treatment, care and wellbeing at all stages and with appropriate support</td>
<td>Partially, not assessed beyond 1.18.1</td>
</tr>
<tr>
<td><strong>S3:</strong> Consumers, and where appropriate, carers, are provided with evidence-based, accessible information to support key decision-making along the continuum of care</td>
<td>1.17.2, 1.17.3, 1.18.2</td>
</tr>
<tr>
<td><strong>S5:</strong> The organisation actively contributes to building the capacity of consumers, carers and community members to participate fully and effectively</td>
<td>2.3.1</td>
</tr>
</tbody>
</table>

**Priority action:** Promote the rights and responsibilities of patients to the community, consumers and carers

| Priority action: Evaluate, monitor and report on participation to the community and the Department of Health | Consumer participation actions as required for NSQHS accreditation |

Actions which are not assessed for NSQHS standards

**Actions**

**Priority action:** Provide accessible information to consumers, carers and community members about health care treatment

**Priority action:** Listen and act on the decisions the consumer and, where appropriate, their carers make about their care treatment

**Priority action:** Involve consumers, carers and community members from the planning stage through to evaluation and monitoring of programs and departments

**Priority action:** Create welcoming and accessible services for the diverse members of your community

**Priority action:** Provide training to staff in communication skills and how to involve consumers and carers in decision making
Priority action: Promote the importance of consumer and carers providing feedback to improve services

Priority action: Establish links with community organisations to provide emotional support and ongoing information to consumers and carers

Priority action: Involve consumers, carers and the community members in the development of clinical guidelines and research

Priority action: Include the involvement of consumers, carers, community members, representatives or nominees in all aspects of the organisation’s planning and development

Priority action: Provide staff training and education on how to use different types of participation

Priority action: Ensure position descriptions include participation components

Consumer participation in the Department of Health

Consistent with the NSQHS the Department of Health has made consumer participation in many areas of health care mandatory. However, there are no requirements of the department to incorporate the same processes of working with and accessing consumers required of health services. The strategic direction 2010-13 outlines six priority actions that should be implemented by the department to lead, support and encourage consumer participation. The action ‘encourage health services to evaluate and monitor participation within a quality improvement framework’ is partially addressed through the introduction of the NSQHS standards.

In order to increase consumer participation the Department of Health is expected to follow priority actions which align with the actions being undertaken but health services including:

- using the same processes of working with and accessing consumers, carers and community members, representatives or nominees across the Department of Health,
- providing training and education to Department of Health staff on how to use the different types of participation, and evidence-based participation and communication, and
- advocating for a whole of Department of Health policy on participation.

The effective implementation of the remaining 2 priority actions of the department will support health services in achieving improved consumer participation through providing support, guidance and resources to health services and encouraging the inclusion of participation skills in the tertiary education of health professionals.
Recommendations of the ACSQHC review of patient-centred care approaches

A discussion paper by the Australian Commission on Safety and Quality in Healthcare, released in September 2010, surveyed the current state of patient-centred approaches to care and initiatives being undertaken overseas and in Australia.365

The discussion paper included a series of recommendations to foster patient centred care in Australia, at the policy and service level.366 The recommendations (described below) were drawn out of lessons on best practice identified by leading patient-centred care organisations:

Policy level

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

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

- 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’.

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

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

Organisational level

Healthcare service executives and managers should:

- 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.

- Ensure that organisational approaches to quality improvement include feedback about patient care experience — alongside clinical and operational data — when determining health service action plans.

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

- Develop a shared patient-centred mission that senior leaders continually articulate to staff to promote the implementation of patient-centred care.

365 ACSQHC 2011
366 ibid. p.8
• Develop and implement policies and procedures for involving patients, families and carers in their own care and, at a service level, in policy and program development, quality improvement, patient safety initiatives and healthcare design.

• Ensure that the service meets the ACSQHC National Safety and Quality Healthcare Service Standard for ‘Partnering with Consumers’.

• Resource patient-centred changes to care delivery based on patient feedback and consumer input.

• Implement training strategies tailored to building the capacity of all staff to support patient-centred care.

• Focus on work environment, work culture and satisfaction of staff as an integral strategy for improving patient-centred care.

• Workforce surveys and review of staff recruitment and retention rates should be undertaken at regular intervals to monitor work environment.

• Integrate accountability for the care experience of patients into staff performance review processes.

• Foster a culture of learning within the organisation, equally learning from successes and failures, including tragic events, to promote patient-centred care.
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