



# Standard 2

Partnering with  
Consumers

Safety and Quality Improvement Guide



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**Australian Commission on Safety and Quality in Health Care**

GPO Box 5480

Sydney NSW 2001

Email: [mail@safetyandquality.gov.au](mailto:mail@safetyandquality.gov.au)

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# Table of Contents

The National Safety and Quality Health Service Standards	2
Terms and definitions	5
Standard 2: Partnering with Consumers	6
Criterion: Consumer partnership in service planning	10
Criterion: Consumer partnership in designing care	22
Criterion: Consumer partnership in service measurement and evaluation	28
References	38
Appendix A: Key organisations	42
Appendix B: Links to resources	44





## Standard 2: Partnering with Consumers

# The National Safety and Quality Health Service Standards

The *National Safety and Quality Health Service (NSQHS) Standards*<sup>1</sup> were developed by the Australian Commission on Safety and Quality in Health Care (the Commission) in consultation and collaboration with jurisdictions, technical experts and a wide range of other organisations and individuals, including health professionals and patients.

The primary aims of the *NSQHS Standards* are to protect the public from harm and to improve the quality of care provided by health service organisations. These Standards provide:

- a **quality assurance** mechanism that tests whether relevant systems are in place to ensure minimum standards of safety and quality are met
- a **quality improvement** mechanism that allows health service organisations to realise developmental goals.

## Safety and Quality Improvement Guides

The Commission has developed Safety and Quality Improvement Guides (the Guides) for each of the 10 *NSQHS Standards*. These Guides are designed to assist health service organisations to align their quality improvement programs using the framework of the *NSQHS Standards*.

The Guides are primarily intended for use by people who are responsible for a part or whole of a health service organisation. The structure of the Guides includes:

- introductory information about what is required to achieve each criterion of the Standard
- tables describing each action required and listing:
  - key tasks
  - implementation strategies
  - examples of the outputs of improvement processes
- additional supporting resources (with links to Australian and international resources and tools, where relevant).

Direct links to these and other useful resources are available on the Commission's web site:

[www.safetyandquality.gov.au](http://www.safetyandquality.gov.au)

The Guides present **suggestions** for meeting the criteria of the Standards, which should not be interpreted as being mandatory. The examples of suggested strategies and outputs of improvement processes are **examples only**. In other words, health service organisations can choose improvement actions that are specific to their local context in order to achieve the criteria. The extent to which improvement is required in your organisation will heavily influence the actions, processes and projects you undertake.

You may choose to demonstrate how you meet the criteria in the Standards using the example outputs of improvement processes, or alternative examples that are more relevant to your own quality improvement processes.

## Additional resources

The Commission has developed a range of resources to assist health service organisations to implement the *NSQHS Standards*. These include:

- a list of available resources for each of the *NSQHS Standards*
- an *Accreditation Workbook for Hospitals* and an *Accreditation Workbook for Day Procedure Services*
- *A Guide for Dental Practices* (relevant only to Standards 1–6)
- a series of fact sheets on the *NSQHS Standards*
- frequently asked questions
- a list of approved accrediting agencies
- slide presentations on the *NSQHS Standards*.



## Overarching NSQHS Standards

*Standard 1: Governance for Safety and Quality in Health Service Organisations*, and *Standard 2: Partnering with Consumers* set the overarching requirements for the effective application of the other eight *NSQHS Standards* which address specific clinical areas of patient care.

**Standard 1** outlines the broad criteria to achieve the creation of an integrated governance system to maintain and improve the reliability and quality of patient care, and improve patient outcomes.

**Standard 2** requires leaders of a health service organisation to implement systems to support partnering with patients, carers and other consumers to improve the safety and quality of care. Patients, carers, consumers, clinicians and other members of the workforce should use the systems for partnering with consumers.

## Core and developmental actions

The *NSQHS Standards* apply to a wide variety of health service organisations. Due to the variable size, structure and complexity of health service delivery models, a degree of flexibility is required in the application of the standards.

To achieve this flexibility, each action within a Standard is designated as either:

### CORE

- considered fundamental to safe practice

OR

### DEVELOPMENTAL

- areas where health service organisations can focus activities or investments that improve patient safety and quality.

Information about which actions have been designated as core or developmental is available on the Commission's web site.

## Quality improvement approaches in health care

Approaches to improving healthcare quality and safety are well documented and firmly established. Examples of common approaches include Clinical Practice Improvement or Continuous Quality Improvement. The Guides are designed for use in the context of an overall organisational approach to quality improvement, but are not aligned to any particular approach.

Further information on adopting an appropriate quality improvement methodology can be found in the:

[NSW Health Easy Guide to Clinical Practice Improvement](#)<sup>2</sup>

[CEC Enhancing Project Spread and Sustainability](#)<sup>3</sup>

[Institute for Healthcare Improvement \(US\)](#)<sup>4</sup>



# The National Safety and Quality Health Service Standards (continued)

## Roles for safety and quality in health care

A range of participants are involved in ensuring the safe and effective delivery of healthcare services. These include the following:

- **Patients and carers**, in partnership with health service organisations and their healthcare providers, are involved in:

- making decisions for service planning
- developing models of care
- measuring service and evaluating systems of care.

They should participate in making decisions about their own health care. They need to know and exercise their healthcare rights, be engaged in their healthcare, and participate in treatment decisions.

Patients and carers need to have access to information about options and agreed treatment plans. Health care can be improved when patients and carers share (with their healthcare provider) issues that may have an impact on their ability to comply with treatment plans.

- The role of **clinicians** is essential. Improvements to the system can be achieved when clinicians actively participate in organisational processes, safety systems, and improvement initiatives. Clinicians should be trained in the roles and services for which they are accountable. Clinicians make health systems safer and more effective if they:
  - have a broad understanding of their responsibility for safety and quality in healthcare
  - follow safety and quality procedures
  - supervise and educate other members of the workforce
  - participate in the review of performance procedures individually, or as part of a team.

When clinicians form partnerships with patients and carers, not only can a patient's experience of care be improved, but the design and planning of organisational processes, safety systems, quality initiatives and training can also be more effective.

- The role of the **non-clinical workforce** is important to the delivery of quality health care. This group may include administrative, clerical, cleaning, catering and other critical clinical support staff or volunteers. By actively participating in organisational processes – including the development and implementation of safety systems, improvement initiatives and related training – this group can help to identify and address the limitations of safety systems. A key role for the non-clinical workforce is to notify clinicians when they have concerns about a patient's condition.
- The role of **managers in health service organisations** is to implement and maintain systems, resources, education and training to ensure that clinicians deliver safe, effective and reliable health care. They should support the establishment of partnerships with patients and carers when designing, implementing and maintaining systems. Managing performance and facilitating compliance across the organisation is a key role. This includes oversight of individual areas with responsibility for the governance of safety and quality systems. Managers should be leaders who can model behaviours that optimise safe and high quality care. Safer systems can be achieved when managers in health service organisations consider safety and quality implications in their decision making processes.
- The role of **health service senior executives and owners** is to plan and review integrated governance systems that promote patient safety and quality, and to clearly articulate organisational and individual safety and quality roles and responsibilities throughout the organisation. Explicit support for the principles of consumer centred care is key to ensuring the establishment of effective partnerships between consumer, managers, and clinicians. As organisational leaders, health service executives and owners should model the behaviours that are necessary to implement safe and high quality healthcare systems.



# Terms and definitions

**Consumers and/or carers:** Consumers and/or carers are members of the public who use, or are potential users, of healthcare services. When referring to consumers and/or carers, the Commission is referring to patients, consumers, families, carers, and other support people.

**Consumer advisory group:** An advisory group established by a healthcare organisation which comprises consumers and/or carers including those from diverse and hard-to-reach groups who use the organisation's services. The consumer advisory group provides a structured partnership between consumers and/or carers and the health service organisation and may provide advice, direction and guidance to the organisation on safety and quality issues and any other issues identified in its terms of reference.

**Consumer centred care:** A consumer-centred approach to care involves:

- treating consumers and/or carers with dignity and respect
- communicating and sharing information between consumers and/or carers and healthcare providers
- encouraging and supporting participation in decision making
- fostering collaboration with consumers and/or carers and healthcare organisations in the planning, design, delivery and evaluation of health care.

Internationally, the terms patient-based, person-centred, relationship-based, patient-centred or patient- and family-centred care are also used.

**Critical friends group:** A small group of consumers, carers and/or healthcare providers with experience and/or expertise relevant to your healthcare organisation. The group is convened to provide advice and feedback to your healthcare organisation on specific issues, including safety and quality improvement activities.

**Flexible standardisation:** Flexible standardisation recognises the importance of standardisation of processes to improve patient safety across a variety of contexts. The standardisation of any process and related data sets must be designed and integrated to

fit the context of health service organisations, including varying patient and staffing profiles. These vary widely as health service organisations have differing functions, size, locations, structure and service delivery modes. Tools, processes and protocols should be based on best available evidence and the requirements of jurisdictions, external policy and legislation and adapted to the local context.

**Governance:** The set of relationships and responsibilities established by a health service organisation between its executive, workforce, and stakeholders (including consumers). Governance incorporates the set of processes, customs, policy directives, laws, and conventions affecting the way an organisation is directed, administered, or controlled. Governance arrangements provide the structure through which the objectives (clinical, social, fiscal, legal, human resources) of the organisation are set, and the means by which the objectives are to be achieved. They also specify the mechanisms for monitoring performance. Effective governance provides a clear statement of individual accountabilities within the organisation to help in aligning the roles, interests and actions of different participants in the organisation in order to achieve the organisation's objectives. The Commission's definition of governance includes both corporate and clinical governance and where possible promotes the integration of governance functions.

**Health literacy:** Health literacy is the extent to which consumers can obtain, process, and understand information about health care, services and the health system. It also refers to a consumer's capacity to use that information to make decisions about their health care.

**Outputs:** The results of your quality improvement actions and processes. Examples of outputs are provided in this guide. They are examples only and should not be read as being checklists of evidence required to demonstrate achievement of the criterion. Outputs will be specific to the actions, processes and projects undertaken in your context which will be influenced by your existing level of attainment against the criterion and extent to which improvement has been required.

# Standard 2: Partnering with Consumers

**Leaders of a health service organisation implement systems to support partnering with patients, carers and other consumers to improve the safety and quality of care. Patients, carers, consumers, clinicians and other members of the workforce use the systems for partnering with consumers.**

### The intention of this Standard is to:

Create a health service that is responsive to patient, carer and consumer input and needs.

### Context:

This Standard provides the framework for active partnership with consumers by health service organisations. It is expected that this Standard will apply in conjunction with *Standard 1: Governance for Safety and Quality in Health Service Organisations*, in the implementation of all other Standards.

### Introduction

In 1978, the Declaration of Alma Ata stated that *'The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.'*<sup>6</sup> Since then, there has been an emergence of policies promoting the rights and responsibilities of consumers and carers within the healthcare system, and an increasing focus on consumer and carer participation and collaboration in the planning, design, delivery and evaluation of health care. There has been a slow but steady shift towards the recognition that healthcare providers, healthcare organisations, consumers and carers are all partners in the healthcare system.

The way that health care is organised and delivered is important to consumers; both as individuals who may be receiving care and as citizens interested in maintaining the efficiency and effectiveness of the health system. There is evidence to show that the involvement of consumers in service planning, delivery, monitoring and evaluation is more likely to result in services that are more accessible and appropriate for users.<sup>7-8</sup>

Effective partnerships with consumers and carers exist when they are treated with dignity and respect, when information is shared with them and when participation and collaboration in healthcare processes are encouraged and supported to the extent that consumers and carers choose.

Delivering care that is based on partnerships provides many benefits for the healthcare consumer, provider, organisation and system. Evidence is building about the link between effective partnerships, good consumer experience and high quality health care.<sup>9-13</sup> For example there is evidence that the existence of effective partnerships is associated with:

- improved clinical outcomes<sup>14-17</sup> including associations with decreased re-admission rates<sup>18</sup>
- decreased rates of healthcare acquired infections<sup>19-21</sup>
- improved delivery of preventive care services<sup>22</sup>
- improved adherence to treatment regimens<sup>23</sup>
- improved functional status.<sup>19-20</sup>

In addition, studies from the United States have found delivering health care that is based on partnerships can result in reduced hospital costs,<sup>24</sup> lower cost per case and reduced length of stay.<sup>25</sup>

An organisation cannot deliver care that is based on partnerships and addresses the needs and preferences of consumers and carers without seeking out, listening to, understanding and responding to consumer and carer experiences and expectations about health care. It is critical that consumers and carers are involved throughout the continuum of health care safety and quality improvement, as consumers and carers provide a 'reality check' that can help healthcare organisations understand how to make changes to health care that are meaningful to consumers and carers.

### The continuum of participation

There is no single approach to partnering with consumers and carers. There are a range of ways that consumers can be partners in the design, delivery and evaluation of health care.

Table 1 shows one example of a continuum of consumer participation. There are a range of different models used to describe this continuum and a variety of terms used to describe different levels of



engagement. Regardless of the model you use, the *Partnering with Consumers* Standard aims to improve processes of consumer and carer participation from the basic provision of information and basic consumer consultation to the engagement of consumers and carers in partnerships with your organisation.

This Standard aims for meaningful and active consumer participation in your organisation's systems and processes. This may require changes in the way your organisation engages with consumers and carers; however the information and consultation strategies you have used in the past can still contribute to achievement of the Standard. Partnership with consumers and carers involves using multiple strategies and processes to involve consumers and carers in different aspects of your organisations governance and structure.

How you choose to establish partnerships with your consumers and carers needs to reflect your organisation's context, the purpose of the partnership, the desired outcome of the partnership and the environment in which the partnership is operating.

## Not all consumers and carers are the same

When partnering with consumers and carers in governance and improvement activities you need to think about what you want to achieve through the partnership. This will influence the types of strategies you may use and the kind of consumers and/or carers that you will need for this purpose.

There are a variety of types of consumers and carers who may be interested in partnerships with your organisation. Consumers and carers can be people who currently use your health service or people who have used your service in the past; they can be representatives of community groups, consumer groups or disease-based advocacy groups. Consumers and carers can be interested in contributing to your organisation as a patient, as a general consumer of health services or as a citizen interested in improving health care generally. Rather than partnering with only one person it is often useful to include a range of consumers and/or carers in your partnership activities to ensure that different voices and views contribute to the design, delivery and evaluation of health services.

Not all consumers and carers are the same. They possess different skills, experiences, interests and motivations. Consequently it is very important that you:

- match the demands of the partnership with the skills, experience and interests of the consumer or carer
- provide support for consumers and carers involved in partnerships with your organisation.

For example, a consumer representative on a strategic planning committee might require very different skills and experiences compared to a consumer or carer involved in the redesign of a palliative care ward, or a consumer or carer participating in shaping information materials that are understandable to the community.

It is also important to ensure that any consumer who partners with your organisation participates principally in the role of a consumer, and is not conflicted by other roles they may have within your organisation. For example, one of your clinicians may also be a consumer of your organisation's services. However if they are involved in a committee principally as a clinician, they cannot also be considered a consumer representative.

## Implementing systems to partner with consumers

The following pages outline possible actions that health service organisations may need to undertake to achieve the basic requirements for partnerships with consumers at the governance level, in service planning and design. Many of the actions and strategies are interlinked and you may find that a strategy you undertake to meet one required action may also address other similar actions. For example, the process you establish to address Action 2.2.2 (involving consumers and/or carers in safety and quality improvement initiatives) may also address Action 2.8.2 (involving consumers and/or carers in the planning and implementation of quality improvements).

Many of the actions under this standard require the development and implementation of an underpinning policy or process to ensure that consumers are engaged and involved at various levels within your organisation's business and governance structures. However, it is important to note that these strategies need to be considered in the context of your existing organisational policies. Separate policies and processes may not necessarily need to be developed to address each action – it may be more efficient and effective for your organisation to have an overarching



## Standard 2: Partnering with Consumers

governance framework which requires partnerships with consumers and carers, supported by a single consumer and carer engagement policy which could incorporate the strategies for each of the required actions in one document.

The strategies your organisation adopts to meet the required actions in this Standard need to be meaningful, useful and relevant to its overall governance and structure, as well as to the consumers and carers in your community. Local context will significantly influence how you implement key tasks under this Standard, including the types of strategies and activities you may choose to implement. You will need to have an understanding of what your priorities and risks are in this area and consider how these are best addressed. You will also need to regularly review and reassess the appropriateness and effectiveness of the strategies you have chosen, to ensure that you are progressing towards your goals.

### Resources

There are a range of resources listed in this guide. These resources are from Australian and international sources; some have been developed with specific audiences in mind or for specific jurisdictions or organisations. However, many of the tools and strategies identified in these resources can be adapted and applied to different Australian healthcare organisations.

If your organisation is just getting started with involving consumers and/or carers in governance or implementing a consumer and/or carer engagement strategy, the following resources offer a useful starting point:

- [\*Improving health services through consumer participation: A resource guide for organisations \(Aus\)\*](#)<sup>28</sup>
- [\*Enabling the consumer role in clinical governance: A guide for health services \(Aus\)\*](#)<sup>29</sup>
- [\*Online training module: Guideline for consumer representatives \(Aus\)\*](#)<sup>30</sup>
- [\*Advancing the practice of patient- and family-centered care in hospitals: How to get started \(US\)\*](#)<sup>31</sup>
- [\*Advancing the practice of patient- and family-centred care in primary care and other ambulatory settings: How to get started \(US\)\*](#)<sup>32</sup>
- [\*Partnering with patients, residents, and families: A resource for leaders of hospitals, ambulatory care settings and long-term care communities \(US\)\*](#)<sup>33</sup>

The Consumers Health Forum of Australia's *Our Health, Our Community* web site contains a directory of consumer and community organisations with an interest in health care issues.<sup>34</sup> In addition, in Victoria the [\*Finding consumers and carers \(Aus\)\*](#)<sup>35</sup> guide is a state-based listing of similar organisations. There may be equivalent directories available for use in your own state or territory.

In addition, Queensland Health has developed a series of [\*audit tools\*](#)<sup>36</sup> specifically designed for the *National Safety and Quality Health Service Standards*; this includes tools designed for *Standard 2: Partnering with Consumers*.

### Criteria to achieve the Partnering with Consumers Standard:

#### Consumer partnership in service planning

Governance structures are in place to form partnerships with consumers and/or carers.

#### Consumer partnership in designing care

Consumers and/or carers are supported by the health service organisation to actively participate in the improvement of the patient experience and patient health outcomes.

#### Consumer partnership in service measurement and evaluation

Consumers and/or carers receive information on the health service organisation's performance and contribute to the ongoing monitoring, measurement and evaluation of performance for continuous quality improvement.

For purposes of accreditation, please check the Commission's web site regarding actions within these criteria that have been designated as core or developmental.



**Table 1: Continuum of participation**

	Information	Consultation	Partnership	Delegation	Control
<b>Description</b>	The organisation develops or adopts a policy, plan or program and provides information about this to the consumers and/or carers and the community.	The organisation identifies an issue and proposes a policy, plan or program which responds to the issue. It then provides information to consumers and/or carers and the community on that proposal and seeks views and comments with a view to maximising acceptance.	The organisation identifies an issue and presents a tentative policy, plan or program which responds to the issue. The organisation seeks active involvement and feedback from consumers and/or carers and the community which is incorporated into the plan.	The organisation identifies an issue, presents this to consumers and/or carers and the community for them to make decisions or propose actions to address the issue.	The organisation asks consumers and/or carers and the community to identify an issue and make all the key decisions on the development of solutions to address the issue. The organisation supports them to accomplish this.
<b>Examples</b>	<p><b>Giving:</b> Flyers, mailouts, factsheets, press releases, brochures, newsletters, public displays, websites, public meetings</p> <p><b>Gathering:</b> Surveys, phone-ins, focus groups, in-depth interviews, suggestion boxes</p>	<p>Workshops</p> <p>Consumer representatives on management committees, advisory groups</p> <p>Public meetings/patient forums</p> <p>Online discussion groups</p> <p>Circulation of proposal for comment</p> <p>Conferences or seminars</p> <p>Evaluation surveys</p>	<p>Strategic alliances built utilising a combination of other methods (including those mentioned in Information and Consultation) for example:</p> <ul style="list-style-type: none"> <li>workshops</li> <li>consumer representatives on committees or advisory groups</li> <li>round tables</li> <li>patient forums</li> <li>surveys</li> <li>focus groups</li> </ul>	<p>Shifting some or all of decision making on particular issues to consumers. For example: spending on specific budget items, management of particular programs by consumers eg. mental health consumer advisory groups</p>	<p>Community appointed management committees eg. Aboriginal Community Controlled Health Organisations</p>

## Continuum of Participation

Lower



Higher

(Source: This table has been adapted from the Brager and Spechts Ladder of Participation [1973]<sup>26</sup> and Queensland Health's Consumer and Community Participation Toolkit [2007]<sup>27</sup>)



## Standard 2

# Criterion: Consumer partnership in service planning

### Governance structures are in place to form partnerships with consumers and/or carers

Involving consumers in the governance of healthcare organisations is an important part of the process of establishing effective partnerships. Consumers have a unique position and perspective which can help to identify opportunities for improvement at an individual and organisational level, which otherwise might not be identified through usual processes.<sup>37-38</sup> Partnering with consumers in governance is about listening to and using consumer knowledge, skills and experience in a systematic way, to deliver better health care.

Seeking and using consumer and carer feedback through surveys, focus groups, committees, compliments and complaints processes and incident management systems is increasingly being seen as a useful mechanism for establishing partnerships, informing quality improvements and improving patient experience.<sup>39</sup> A 2010 review of patient engagement strategies found that involving user groups in the development of health information and materials was an effective approach for improving patient-provider communication and consequently, partnerships between the health service organisation and consumers and carers.<sup>40-41</sup>

Partnerships with consumers and carers can be demonstrated through strategies such as the involvement of consumers and carers on boards or committees, establishing consumer advisory committees, working with individual patients to shape safety and quality initiatives, seeking and acting on consumer experience feedback or co-opting consumers into the planning and design of health services, among many other approaches.

There is no single 'best' approach to involving consumers in the governance of the organisation. You should choose strategies appropriate for your organisation, taking into consideration factors such as service type, size and complexity. Where possible, the strategies implemented should build on pre-existing structures and may operate across different levels of the organisation.

Actions required	Implementation strategies
<b>2.1 Establishing governance structures to facilitate partnership with consumers and/or carers</b>	
<p><b>2.1.1</b> Consumers and/or carers are involved in the governance of the health service organisation</p>	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Implement a framework which requires the involvement of consumers and/or carers in the clinical and organisational governance of the organisation</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• Review your organisation's governance arrangements to identify the current level of consumer and/or carer partnership and involvement. The following self-assessment tools could be used: <ul style="list-style-type: none"> <li>– Appendix B of <i>Enabling the consumer role in clinical governance (Aus)</i>.<sup>29</sup></li> <li>– Appendix A, B and C of <i>Improving health services through consumer participation (Aus)</i>.<sup>28</sup></li> </ul> </li> <li>• <i>If your organisation has consumer partnerships already embedded within your governance arrangements</i> – the <i>Partnership self-assessment tool (US)</i><sup>42</sup> or the <i>Patient based care challenge (Aus)</i><sup>43</sup> can be used to assess the extent and effectiveness of those partnerships. Using the results of this self assessment, you could also map your existing arrangements against what is required under the Standard, to help identify if new systems or processes are required.</li> <li>• <i>If consumers are not currently involved in the governance of your organisation</i> – you should adapt your current framework, or establish a new framework which requires the active involvement of consumers and/or carers in your organisation's governance structures and arrangements. You may consider partnering with consumers in governance by: <ul style="list-style-type: none"> <li>– involving consumers as representatives on the board or on existing committees. There are a number of resources that describe the steps for involving consumer representatives in committees including <i>Getting started: Involving consumers on committees (Aus)</i>,<sup>44</sup> <i>Consumer participation on committees (Aus)</i>,<sup>45</sup> the <i>Consumer representatives program agency handbook (Aus)</i>,<sup>46</sup> The <i>Improving health services through consumer participation (Aus)</i><sup>28</sup> resource guide also provides ideas on recruiting consumer representatives</li> <li>– creating a new, or using an existing, consumer advisory group to gain advice from consumers about specific issues or a specific project. You will find that many of the resources for involving consumer representatives on committees can be readily applied, including strategies 33 and 29 from <i>Improving health services through consumer participation (Aus)</i>.<sup>28</sup> In addition, the <i>Guide for developing a community-based patient safety advisory council (US)</i><sup>47</sup> is a step-by-step guide for creating an advisory group and contains templates that could be adapted for your organisation</li> <li>– creating a new, or using an existing, 'critical friends' group. This strategy may be more suited to smaller organisations. It involves identifying and approaching a small group of patients and/or carers that use the service to help identify and consider quality improvement strategies together. The <i>Establishing critical friends groups in general practice (UK)</i><sup>48</sup> report describes the steps for creating this type of group</li> <li>– systematically seeking feedback and information from consumers on governance issues. There are many strategies for seeking feedback from consumers, some of which are described in the continuum of participation table on page 9. Guidance on how to use these strategies, and many other ideas, are contained in the following resources: the <i>Improving health services through consumer participation (Aus)</i><sup>28</sup> resource guide, <i>The participation toolkit (UK)</i>,<sup>49</sup> the <i>Consumer and community participation toolkit (Aus)</i><sup>27</sup> and <i>The engagement toolkit (Aus)</i>.<sup>50</sup></li> </ul> </li> <li>• You may also need to consider whether there are barriers to consumer participation, and investigate how you might reduce these barriers. Section Four of the <i>Improving health services through consumer participation (Aus)</i><sup>28</sup> resource guide describes some barriers to partnerships and how to address them.</li> </ul>



Actions required	Implementation strategies
<b>2.1 Establishing governance structures to facilitate partnership with consumers and/or carers</b> (continued)	
<p>(continued)</p> <p><b>2.1.1</b> Consumers and/or carers are involved in the governance of the health service organisation</p>	<ul style="list-style-type: none"> <li>When undertaking formal or informal processes to gather information and feedback from consumers it is important that your organisation documents the strategies used to collect this information. This could be in the form of meeting minutes, reports on workshops, diary notes or other records.</li> </ul> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>policies in place that describe how consumers and/or carers are involved in the governance of the organisation</li> <li>membership of key committees and/or boards includes consumer representation</li> <li>establishment of a consumer advisory group that provides advice to the organisation</li> <li>documented feedback gained from consumers through the organisation's consultation strategies</li> <li>reports or policies that show how consumer feedback is linked to the governance of the organisation.</li> </ul> <p><b>Considerations:</b></p> <p>Your organisation may not need to establish a new policy, procedure or framework to partner with consumers in governance.</p> <p>When looking for ways to involve consumers in the governance of your organisation, think about your existing processes and structures and consider whether they can be used or modified for this purpose.</p> <p>It may be useful to consider taking action in this area first to develop an overall governance framework for partnering with consumers. Specific policies, procedures and activities to meet other criteria in this Standard can then flow from this framework.</p> <p>You may wish to contact consumer organisations to seek advice on how to engage with consumers and carers. A list of consumer organisations can be found at Appendix A.</p> <p><b>Additional resources:</b></p> <p><i>Partnering with patients and families to enhance safety and quality: A mini toolkit (US)</i><sup>51</sup></p> <p><i>Advancing the practice of patient- and family- centered care in hospitals: How to get started (US)</i><sup>31</sup></p> <p><i>Advancing the practice of patient- and family- centred care in primary care and other ambulatory settings: How to get started (US)</i><sup>32</sup></p> <p><i>Case studies of consumer engagement in Australian health policy &amp; related fields (Aus)</i><sup>52</sup></p>
<p><b>2.1.2</b> Governance partnerships are reflective of the diverse range of backgrounds in the population served by the health service organisation, including those people that do not usually provide feedback</p>	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li><b>As part of your governance framework, develop and implement a policy for identifying and involving diverse groups who access your organisation's services</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>You should identify the types of consumers who access your organisation's services. There are a range of sources organisations can – and may already – use to help them understand the types of consumers accessing their services. Approaches could include:             <ul style="list-style-type: none"> <li>undertaking a community profiling project. This involves gathering information about the diversity within the community, its history, social and economic characteristics, the groups and networks used within the community and what social and infrastructure services there are. See <i>The engagement toolkit (Aus)</i><sup>50</sup> for information about how to do this</li> </ul> </li> </ul>

Actions required	Implementation strategies
<b>2.1 Establishing governance structures to facilitate partnership with consumers and/or carers</b> (continued)	
<p><i>(continued)</i></p> <p><b>2.1.2</b> Governance partnerships are reflective of the diverse range of backgrounds in the population served by the health service organisation, including those people that do not usually provide feedback</p>	<ul style="list-style-type: none"> <li>– administering a survey to service users to help identify your diverse groups. For guidance on undertaking surveys see Strategy 10 of the <i>Improving health services through consumer participation (Aus)</i><sup>28</sup> resource guide or the ‘Surveys and questionnaires’ section of <i>The participation toolkit (UK)</i><sup>49</sup></li> <li>– using demographic data available from the Australian Bureau of Statistics or state and territory government sources to build an understanding of the background of your organisation’s consumers</li> <li>– networking with other organisations or individuals in your community such as culturally and linguistically diverse community groups, community participation managers, Medicare Locals, Local Hospital Networks, local and state government organisations and professional associations to share knowledge about community needs. The <i>Improving health services through consumer participation (Aus)</i><sup>28</sup> resource guide contains advice on how to effectively network and collect information about the population using your services.</li> </ul> <ul style="list-style-type: none"> <li>• You should review your organisation’s existing policies to identify the level of engagement with hard-to-reach consumers and those from diverse backgrounds in governance arrangements. This could involve reviewing your consumer and carer engagement policies and practices to ensure a diverse range of consumers is included, or talking to staff about how they involve hard-to-reach consumers and/or their carers in safety and quality improvement activities.</li> <li>• <i>If diverse and hard-to-reach consumers and/or carers are not actively engaged in your governance</i> – you should develop or adapt, and implement strategies to engage with these consumers and carers. Approaches which could be used can range from formal activities such as inclusion in boards or committees to informal strategies such as holding a lunchtime consumer and carer session. In addition:             <ul style="list-style-type: none"> <li>– a broad range of ideas for connecting with consumers from a diverse range of backgrounds can be found in: <i>The improving health services through consumer participation (Aus)</i><sup>28</sup> resource guide, <i>The participation toolkit (UK)</i>,<sup>49</sup> the <i>Consumer and community participation toolkit (Aus)</i><sup>27</sup> and <i>The engagement toolkit (Aus)</i><sup>50</sup></li> <li>– <i>Health care providers’ guide to engaging multicultural communities and consumers (Aus)</i><sup>53</sup> and <i>Consumer participation and culturally and linguistically diverse communities (Aus)</i><sup>54</sup> are resources with specific strategies for engaging consumers from culturally and linguistically diverse backgrounds.</li> </ul> </li> <li>• It may be helpful for your organisation to undertake preliminary discussions with community leaders, groups or liaison officers to determine the most appropriate engagement strategies for particular diverse and hard-to-reach groups within your community. This will help identify any particular barriers to participation prior to approaching diverse and hard-to-reach consumers.</li> <li>• When undertaking formal or informal processes to gather information and feedback from diverse or hard-to-reach consumers and/or carers, it is important that you document the strategies used to collect this information.</li> </ul>



Actions required	Implementation strategies
<b>2.1 Establishing governance structures to facilitate partnership with consumers and/or carers</b> (continued)	
<p>(continued)</p> <p><b>2.1.2</b> Governance partnerships are reflective of the diverse range of backgrounds in the population served by the health service organisation, including those people that do not usually provide feedback</p>	<p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>• service profile or other documents that shows the organisation's understanding of the background of consumers accessing the service</li> <li>• policies in place that describe how a diverse range of consumers and/or carers are involved in the governance of the organisation</li> <li>• strategies used to engage with a diverse range of consumers are documented and are linked to the governance framework of the organisation</li> <li>• documented feedback on governance issues from diverse and hard-to-reach consumers</li> <li>• terms of reference describing the responsibilities of committees and boards for partnering with consumers from diverse backgrounds.</li> </ul> <p><b>Additional resources:</b></p> <p><i>Feedback, participation and consumer diversity A literature review (Aus)</i><sup>55</sup></p>
<b>2.2 Implementing policies, procedures and/or protocols for partnering with patients, carers and consumers in:</b> <ul style="list-style-type: none"> <li>• <b>strategic and operational/services planning</b></li> <li>• <b>decision making about safety and quality initiatives</b></li> <li>• <b>quality improvement activities</b></li> </ul>	
<p><b>2.2.1</b> The health service organisation establishes mechanisms for engaging consumers and/or carers in the strategic and/or operational planning for the organisation</p>	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Implement a systematic process for involving consumers and/or carers in strategic and/or operational planning</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should review how consumers and/or carers are currently involved in your organisation's strategic and operational planning. This could include looking at your planning and business processes and talking to your strategic planners and executive about the way planning decisions are undertaken and the extent to which consumers are involved.</li> <li>• <i>If consumers and/or carers are not actively involved in strategic and operational planning</i> – you should develop or adapt and implement a process to achieve this. This could be done by:             <ul style="list-style-type: none"> <li>– involving consumer and/or carer representatives on committees tasked with strategic and operational planning. Many organisations undertake strategic and operational planning through the board or senior executive committees. See <i>Getting started: Involving consumers on committees (Aus)</i>,<sup>44</sup> <i>Consumer participation on committees (Aus)</i><sup>45</sup> or the <i>Consumer representatives program agency handbook (Aus)</i><sup>46</sup> for information on involving consumers in committees, and the <i>Improving health services through consumer participation (Aus)</i><sup>28</sup> for ideas on recruiting consumer representatives</li> <li>– establishing a consumer advisory group to provide input into strategic and operational planning processes. The <i>Guide for developing a community-based patient safety advisory council (US)</i><sup>47</sup> provides information on establishing an advisory group</li> <li>– creating a new, or using an existing, 'critical friends' group. This involves identifying and approaching a small group of patients and/or carers that use your services and using their input to help inform strategic and operational planning. The <i>Establishing critical friends groups in general practice (UK)</i><sup>48</sup> report describes the steps for creating this type of group</li> </ul> </li> </ul>

Actions required	Implementation strategies
<p><b>2.2 Implementing policies, procedures and/or protocols for partnering with patients, carers and consumers in:</b></p> <ul style="list-style-type: none"> <li>• <b>strategic and operational/services planning</b></li> <li>• <b>decision making about safety and quality initiatives</b></li> <li>• <b>quality improvement activities</b></li> </ul> <p style="text-align: right;">(continued)</p>	
<p>(continued)</p> <p><b>2.2.1</b> The health service organisation establishes mechanisms for engaging consumers and/or carers in the strategic and/or operational planning for the organisation</p>	<ul style="list-style-type: none"> <li>– holding a strategic planning day or forum with consumer representative attendance. <i>Improving health services through consumer participation (Aus)</i>,<sup>28</sup> the <i>Consumer and community participation toolkit (Aus)</i><sup>27</sup> and <i>The engagement toolkit (Aus)</i><sup>50</sup> provides advice on how to hold this type of event</li> <li>– conducting a structured consultation process to seek consumer input on key planning activities and incorporate feedback into planning. Strategy 13 of the <i>Improving health services through consumer participation (Aus)</i><sup>28</sup> and <i>The engagement toolkit (Aus)</i><sup>50</sup> describe how you could undertake structured consultation. Although this is often seen as a formalised, large scale process, your organisation could consider conducting a smaller, targeted consultation to gain consumer feedback on specific planning issues. A consultation process is in itself not a partnership with consumers and/or carers. In order for there to be a true partnership, other strategies need to be used in combination with consultation processes.</li> </ul> <ul style="list-style-type: none"> <li>• When undertaking formal or informal processes to gather information and feedback from consumers it is important that you document the strategies used to collect this information. This could be in the form of reports, diary notes, minutes from meetings or other documents.</li> <li>• It is important that, where feasible, information provided by consumers and carers is acted upon by your organisation, and that information on changes which have occurred as a result of consumer and carer advice is fed back to consumers and carers.</li> </ul> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>• policies or processes in place that articulate the role of consumers and/or carers in strategic, operational and service planning</li> <li>• committee terms of reference, membership, selection criteria, papers and minutes that demonstrate consumer engagement in strategic and operational planning</li> <li>• critical friends group established and meetings facilitated with clear objectives and consumer feedback recorded</li> <li>• planning day or forum with consumers and/or carers held with agenda, attendees and feedback documented. Input is incorporated into strategic and operational planning processes</li> <li>• consultation processes held with consumers and/or carers and feedback documented. Input is incorporated into strategic and operational planning processes.</li> </ul> <p><b>Considerations:</b></p> <p>Your organisation may not need to establish a new process, policy and/or framework for involving consumers and/or carers in strategic and operational planning.</p> <p>When looking for ways to involve consumers in planning, think about your existing strategic and operational planning policies and processes and consider whether they can be used or modified to meet this requirement.</p> <p><b>Additional resources:</b></p> <p><i>The participation toolkit (UK)</i><sup>49</sup></p> <p><i>Consumer representatives program: Agency handbook (Aus)</i><sup>46</sup></p>



Actions required	Implementation strategies
<p><b>2.2 Implementing policies, procedures and/or protocols for partnering with patients, carers and consumers in:</b></p> <ul style="list-style-type: none"> <li>• <b>strategic and operational/services planning</b></li> <li>• <b>decision making about safety and quality initiatives</b></li> <li>• <b>quality improvement activities</b></li> </ul>	<p>(continued)</p>
<p><b>2.2.2</b> Consumers and/or carers are actively involved in decision making about safety and quality</p>	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Implement a systematic process for actively involving consumers and/or carers in safety and quality improvement initiatives</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should review how your organisation currently makes decisions about safety and quality including improvement initiatives and identify the extent to which consumers and/or carers are currently involved in these decisions. This could include looking at governance arrangements for decision making, safety and quality structures and committees and examining how your organisation undertakes quality improvement.</li> <li>• If consumers and/or carers are not actively involved in decision making about safety and quality, you should develop or adapt, and implement processes and/or policies which involve consumers and/or carers. This could include: <ul style="list-style-type: none"> <li>– inviting consumers and/or carers onto steering committees for the planning, implementation and evaluation of quality improvement activities. See <a href="#">Getting started: involving consumers on committees (Aus)</a>,<sup>44</sup> <a href="#">Consumer participation on committees (Aus)</a><sup>45</sup> or <a href="#">Improving health services through consumer participation (Aus)</a><sup>28</sup> for information about involving consumers and/or carers in committees</li> <li>– talking with consumers and/or carers in waiting rooms or at informal meetings about quality improvement priorities, projects and opportunities for improving services</li> <li>– establishing a consumer advisory group to provide input into safety and quality processes. The <a href="#">Guide for developing a community-based patient safety advisory council (US)</a><sup>47</sup> is a step-by-step guide for creating an advisory group and contains templates that could be adapted for your organisation</li> <li>– using data about consumer and/or carer experiences to help identify opportunities for safety and quality improvement. This could include identifying issues from patient experience surveys or complaints data or using compliments as case studies to highlight good practice within the organisation. Using data about consumer experiences in itself is not a partnership with consumers and/or carers. In order for there to be a true partnership, other strategies need to be used in combination with data analysis</li> <li>– creating a new, or utilising an existing ‘critical friends’ group, which involves identifying and approaching a small group of patients that use your services and using their input to help make decisions about safety and quality. The <a href="#">Establishing critical friends groups in general practice (UK)</a><sup>48</sup> report describes the steps for creating this type of group</li> <li>– meeting with community and consumer organisations to identify opportunities for quality improvement, and to gain consumer and/or carer input to the planning, implementation and evaluation of safety and quality improvement approaches</li> <li>– holding a workshop with staff and consumers and/or carers to discuss opportunities for improvement and/or to develop safety and quality improvement initiatives. See <a href="#">The participation toolkit (UK)</a><sup>49</sup> for more information on workshops.</li> </ul> </li> <li>• You should document how you have included consumers and/or carers in your organisation’s safety and quality improvement activities. You should provide feedback to consumers, carers and the community about the impact that this involvement has had. For example, describe changes which have occurred in response to feedback through local newsletters, media or your organisation’s web sites, display posters or information sheets within your organisation about how consumers have informed quality in your organisation or provide updates on the impact of consumer partnerships at organisational, community or consumer meetings and events.</li> </ul>

Actions required	Implementation strategies
<b>2.2 Implementing policies, procedures and/or protocols for partnering with patients, carers and consumers in:</b> <ul style="list-style-type: none"> <li>• <b>strategic and operational/services planning</b></li> <li>• <b>decision making about safety and quality initiatives</b></li> <li>• <b>quality improvement activities</b></li> </ul>	
<p>(continued)</p> <p><b>2.2.2</b> Consumers and/or carers are actively involved in decision making about safety and quality</p>	<p>(continued)</p> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>• processes and/or policies in place that describe the level of consumer engagement in safety and quality decision making and quality improvement initiatives</li> <li>• committee terms of reference, membership, selection criteria, papers and minutes reflecting the involvement of consumers and/or carers in decision making about safety and quality</li> <li>• critical friends group established and meetings facilitated with clear objectives and consumer feedback recorded.</li> </ul> <p><b>Considerations:</b></p> <p>Your organisation may not need to establish new policies or processes for involving consumers and/or carers in safety and quality improvement initiatives.</p> <p>When looking for ways to involve consumers and/or carers in safety and quality initiatives think about your existing safety and quality structures and arrangements and consider whether they can be used or modified for this purpose.</p> <p>You may wish to contact your state-based safety and quality organisation to seek advice on how to engage with consumers and carers in safety and quality initiatives. A list of state-based organisations can be found at Appendix A.</p> <p><b>Additional resources:</b></p> <p><i>Consumer representatives program: Agency handbook (Aus)</i><sup>46</sup></p> <p><i>The engagement toolkit (Aus)</i><sup>50</sup></p> <p><i>The participation toolkit (UK)</i><sup>49</sup></p>
<b>2.3 Facilitating access to relevant orientation and training for consumers and/or carers partnering with the organisation</b>	
<p><b>2.3.1</b> Health service organisations provide orientation and ongoing training for consumers and/or carers to enable them to fulfil their partnership role</p>	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Develop (or adapt) and provide access to orientation training and resources for consumers and/or carers who participate in governance, quality and safety or other partnerships with your organisation</b></li> </ul> <p>It is important that consumers and/or carers involved in your organisation's governance process, and those who participate in partnerships regularly, are provided with training and support. This will ensure that these consumers and/or carers are given the best opportunity to contribute meaningfully and effectively to your organisation.</p> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should review your organisation's existing processes for orienting consumers and/or carers who have taken on a partnership role in governance or safety and quality. This could include identifying and reviewing the relevance, accessibility and applicability of induction processes and materials for consumers and/or carers involved in governance including: <ul style="list-style-type: none"> <li>– written information and resources provided on relevant subjects, required skills, roles and responsibilities</li> <li>– training and education</li> <li>– the level of ongoing support.</li> </ul> </li> </ul>



Actions required	Implementation strategies
<b>2.3 Facilitating access to relevant orientation and training for consumers and/or carers partnering with the organisation</b> (continued)	
<p>(continued)</p> <p><b>2.3.1</b> Health service organisations provide orientation and ongoing training for consumers and/or carers to enable them to fulfil their partnership role</p>	<ul style="list-style-type: none"> <li>• <i>If comprehensive orientation, training and resources for consumer and/or carer representatives are required</i> – you should develop, adapt, or facilitate access to orientation, training and resources for consumers and/or carers partnering with your organisation. Strategies could include:             <ul style="list-style-type: none"> <li>– facilitating access to external training programs for consumers and/or carers partnering with the organisation. Many consumer organisations provide consumer representative training. See Appendix A for a list of state based consumer organisations. In addition, the Health Issues Centre has developed Australia's only <a href="#">accredited consumer representative training course (Aus)</a><sup>56</sup></li> <li>– adapting an existing consumer training program to your organisation's requirements. Examples of training programs which could be adapted include <a href="#">Consumer training and mentoring guide (Aus)</a><sup>57</sup> and <a href="#">Advocacy, leadership and community participation (Aus)</a><sup>58</sup></li> <li>– adapting orientation resources for consumer and/or carer representatives. The <a href="#">Guidelines for consumer representatives (Aus)</a>,<sup>59</sup> the <a href="#">Consumer representatives handbook (Aus)</a><sup>46</sup> and the <a href="#">Consumer representative checklist (Aus)</a><sup>60</sup> may be useful resources for your consumers and/or carers.</li> </ul> </li> <li>• The provision of education and training may be more applicable for consumers and/or carers who are involved in formal partnerships with your organisation (such as members of boards or committees). It may not be feasible or appropriate to provide this type of training for consumers and/or carers who are involved in more informal partnerships (such as waiting room discussions, or consultation processes). However it is important that your organisation considers the needs of these consumers and/or carers, and that they:             <ul style="list-style-type: none"> <li>– are aware that the information they provide is separate to the process of providing or receiving care and will not affect their treatment</li> <li>– have an understanding of the process in which they are participating, and how the information they provide will be used</li> <li>– have an opportunity to provide further comment at a later time if they wish</li> <li>– have an opportunity to raise concerns about the process if they wish.</li> </ul> </li> <li>• It is critical that personal information provided by consumers and/or carers in their partnership with your organisation is treated sensitively, and that privacy and confidentiality is maintained. Information on ethical considerations for using patient stories can be found in <a href="#">Guidance on the use of patient stories (UK)</a><sup>61</sup> or <a href="#">A toolkit for collecting and using patient stories for service improvement in WA Health</a>.<sup>62</sup></li> </ul> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>• policies or processes in place that describe the orientation and ongoing training provided to consumers and/or carers who are in partnerships with your organisation</li> <li>• internal orientation and training provided to consumers partnering with your organisation, including documented training attendance, training calendars and training materials</li> <li>• orientation and training provided to consumers partnering with the organisation via an external training provider, including documented training attendance, training calendars and training materials.</li> </ul>

Actions required	Implementation strategies
<b>2.3 Facilitating access to relevant orientation and training for consumers and/or carers partnering with the organisation</b> <span style="float: right;">(continued)</span>	
<p>(continued)</p> <p><b>2.3.1</b> Health service organisations provide orientation and ongoing training for consumers and/or carers to enable them to fulfil their partnership role</p>	<p><b>Considerations:</b></p> <p>Your organisation may not need to establish new policies or processes for training consumers and/or carers to be involved in your organisation's governance.</p> <p>When looking for ways to support and train consumers and/or carers, look at similar organisations, speak to your state-based consumer healthcare organisations and think about how your existing orientation training and resources could be adapted for consumers and/or carers.</p> <p><b>Additional resources:</b></p> <p><i>Consumer participation guide (Aus)</i><sup>63</sup></p> <p><i>Education and training for consumer participation in health care: Resource guide (Aus)</i><sup>64</sup></p>
<b>2.4 Consulting consumers on patient information distributed by the organisation</b>	
<p><b>2.4.1</b> Consumers and/or carers provide feedback on patient information publications prepared by the health service organisation (for distribution to patients)</p>	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Develop and implement a systematic process for sourcing consumer and/or carer feedback about patient information publications</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should review your existing policies or processes for seeking consumer feedback on your patient information publications. This could include identifying the publications your organisation has produced, looking at how they were developed and determining whether consumers and/or carers were involved in their development.</li> <li>• <i>If consumers were not involved in the development of your publications</i> – you should develop and implement a process that involves consumers and/or carers in the development of all relevant new, and review of existing, publications. Consumers could be involved in this process through: <ul style="list-style-type: none"> <li>– electronic, mail or phone surveys of consumers who have used your information publications. Information on undertaking surveys can be found in <i>Improving health services through consumer participation (Aus)</i>,<sup>28</sup> <i>The participation toolkit (UK)</i><sup>49</sup> and the <i>Health literacy universal precautions toolkit (US)</i><sup>65</sup></li> <li>– holding waiting room discussions, focus groups or workshops to develop new materials or modify existing materials. See <i>The participation toolkit (UK)</i><sup>49</sup> for more information on these strategies</li> <li>– attending community meetings to discuss the information needs of consumers, and the barriers and facilitators to understanding health information in the community</li> <li>– making follow-up phone calls to consumers who have been provided with patient information publications, to identify any issues in understanding the information that was provided.</li> </ul> </li> <li>• Further information on involving patients in testing information publications can be found in <i>Health literacy universal precautions toolkit (US)</i><sup>65</sup> and <i>In other words...can they understand? Testing patient education materials with intended readers (US)</i>.<sup>66</sup></li> <li>• <i>If you do not develop your own information publications</i> – you should try to source and use publications that have been developed in partnership with consumers. Organisations may use patient information publications sourced from state and territory health departments, developed by professional associations, purchased from an external provider and a range of other places. Consider the process by which the patient information publication was developed, and if possible, choose resources that have been developed in consultation with consumers. Publications that have been sourced from other organisations may still need to be tested with your local community and adapted.</li> </ul>



Actions required	Implementation strategies
2.4 Consulting consumers on patient information distributed by the organisation (continued)	
<p>(continued)</p> <p><b>2.4.1</b> Consumers and/or carers provide feedback on patient information publications prepared by the health service organisation (for distribution to patients)</p>	<p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>• policies or processes in place that describe how consumers are involved in providing feedback on patient information publications</li> <li>• consumer feedback about patient information publications is sought, documented and incorporated into the revision of publications</li> <li>• piloting and testing process held and consumer feedback about patient information publications documented and incorporated into the revision of publications</li> <li>• evaluation of the organisation's existing patient information publications being undertaken, documented and appropriate revisions made in response to consumer feedback.</li> </ul> <p><b>Considerations:</b></p> <p>Your organisation may not need new processes to involve consumers and/or carers in information publication development and review.</p> <p>When looking for ways to involve consumers in the development and review of information publications think about your existing publication development and review processes to see whether they can be adapted to involve consumers and/or carers.</p> <p><b>Additional resources:</b></p> <p><i>Evaluating health information with consumers (Aus)</i><sup>67</sup></p> <p><i>Well-written health information: A guide (Aus)</i><sup>68</sup></p> <p><i>How to present the evidence for consumers: preparation of consumer publications (Aus)</i><sup>69</sup></p>
<p><b>2.4.2</b> Action is taken to incorporate consumer and/or carers' feedback into publications prepared by the health service organisation for distribution to patients</p>	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Use the feedback provided by consumers and/or carers to inform the development and refinement of patient information publications</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should review your existing processes for incorporating consumer feedback into the development of patient information publications. After identifying how you gain consumer feedback, look at how you use, and report on the use of, information provided by consumers. Feedback from consumers could be: <ul style="list-style-type: none"> <li>– directly incorporated into the development of patient information publications. For example, feedback might indicate that language needs to be modified so that the information is understandable for consumers with low levels of literacy</li> <li>– used as a basis for the development of new publications. For example, feedback might indicate that there are gaps in the information provided and that an additional publication is required in order to avoid misunderstanding by consumers and/or carers</li> <li>– analysed by committees or groups tasked with the development of patient information publications to identify key themes for action. For example, a significant number of consumers may be experiencing a similar misunderstanding which might require changes in broader programs and policies</li> <li>– used as a basis for a broader organisation-wide communication strategy or policy to address health literacy barriers. See <i>Health literacy environment of hospitals and health centers (US)</i><sup>70</sup> for information on identifying health literacy barriers within your organisation</li> </ul> </li> </ul>

Actions required	Implementation strategies
<b>2.4 Consulting consumers on patient information distributed by the organisation</b> (continued)	
<p>(continued)</p> <p><b>2.4.2</b> Action is taken to incorporate consumer and/or carers' feedback into publications prepared by the health service organisation for distribution to patients</p>	<ul style="list-style-type: none"> <li>Once you have refined a publication based on consumer feedback you should show the revised document to consumers to check that you have interpreted their feedback correctly and made appropriate changes to the publication. This could be on a one-on-one basis, through committee meetings, discussions in waiting rooms or workshops.</li> <li>You should provide feedback to the community about the kinds of changes you have made to your publications in response to their consumer and/or carer feedback and input. This could be through information and updates in newsletters, meetings or through reports provided to the people who were involved in the identification, development and implementation of changes to patient information publications.</li> </ul> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>policies or processes in place that describe how feedback provided by consumers is linked to the development of patient information publications</li> <li>committee terms of reference, membership, selection criteria, papers and minutes that describe discussions with consumers and/or carers and the use of their feedback on publications</li> <li>an action plan or other planning document for incorporating consumer input into patient information publications</li> <li>an evaluation undertaken of externally sourced patient information publications prior to use by your organisation. The evaluation process is documented</li> <li>records of publications that have changed in response to consumer and/or carer feedback.</li> </ul> <p><b>Considerations:</b></p> <p>Your organisation may not need to develop new processes or structures to incorporate consumer and/or carer feedback into the development and refinement of patient information publications.</p> <p>When looking at the way you currently develop or refine publications think about ways in which consumers and/or carers can be involved in existing structures or processes.</p> <p><b>Additional resources:</b></p> <p><i>Health literacy universal precautions toolkit (US)</i><sup>65</sup></p>



## Standard 2

# Criterion: 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

Internationally there has been increasing focus on partnering with consumers through health service redesign, co-design or experience-based design projects. There is now emerging evidence that involving consumers in the planning and design of health service environments and services can have significant benefits in terms of strengthening relationships between staff and consumers,<sup>71-72</sup> as well as helping to reorient services to the needs and preferences of the consumer.<sup>72</sup> Design or redesign activities include improvement initiatives that change the way a process is undertaken to increase its efficiency, continuity, appropriateness, effectiveness, consumer focus and/or safety. These activities can vary in scope from designing new units such as emergency departments, to making changes to patient flow processes in outpatient clinics, to reviewing issues associated with patients not arriving for appointments.<sup>73</sup>

A recent evaluation of an experience-based design program by the King's Fund in the UK found that the project improved staff and consumer skills and communication, and also improved consumer's experience of services. However the evaluation also noted that staff commitment, engagement, leadership and support for systemic change were important factors in achieving these improvements.<sup>74-75</sup> This builds on similar projects which have been undertaken within Australia including:

- NSW Health's experience-based co-design projects within emergency departments, which found that using an experience-based co-design approach achieved practical solutions which enabled staff to reflect on and improve work practices, and led to better consumer experiences and more efficient patient flow.<sup>76-77</sup>
- Flinders Medical Centre Redesigning Healthcare Program, which applied lean thinking and experience-based design principles to improve patient flow and resulted in improved communication and teamwork within teams, and between staff and consumers.<sup>78</sup>

There are many well established redesign and experience-based co-design methodologies which have been used within Australia and overseas. Some key resources that describe these methodologies include:

- [A toolkit for redesign in health care \(US\)](#)<sup>79</sup>
- [The King's Fund experience based design toolkit \(UK\)](#)<sup>80</sup>
- [Emergency surgery redesign: Toolkit for implementation in NSW hospitals \(Aus\)](#)<sup>81</sup>
- [Health service co-design toolkit \(NZ\)](#)<sup>73</sup>

Communication is critical to patient centred approaches and establishing partnerships with consumers and carers. A 2010 review by the Picker Institute Europe of 'best buys' for consumer engagement found that one of the most effective change mechanisms for improving patient provider communication is education and training for healthcare providers.<sup>40</sup> There is some evidence that upskilling health service providers in multidisciplinary collaboration, consumer partnerships and consumer centred practice provides effective preparation for contemporary consumer centred care.<sup>82</sup> However, one English study<sup>83</sup> identified that lack of knowledge about how to train health professionals to deliver consumer centred care and achieve partnerships with consumers was a barrier to change.

The authors suggested that to address this issue greater use could be made of patients as teachers and that both real and simulated patients have a potentially useful part to play in education and training for healthcare professionals.

Actions required	Implementation strategies
<b>2.5 Partnering with consumers and/or carers to design the way care is delivered to better meet patient needs and preferences</b>	
<b>2.5.1</b> Consumers and/or carers participate in the design and redesign of health services	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Implement a systematic process for involving consumers and/or carers in the identification, development and implementation of design and redesign approaches</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should review your organisation's existing processes for the identification, development and implementation of design and redesign approaches to determine the level of consumer and/or carer involvement. This could include looking at your strategic and/or operational planning processes, your quality improvement processes and/or talking to staff about how they involve consumers and/or carers in design and redesign approaches. Design and redesign approaches could include the improvement of the physical environment, systems and processes.</li> <li>• If consumers and/or carers are not currently involved in your organisation's healthcare design and redesign approaches, you should develop or adapt, and implement a process to partner with consumers in design and redesign approaches undertaken by your organisation. This could include:             <ul style="list-style-type: none"> <li>– involving consumers and/or carers in the group of people responsible for steering the development and implementation of any design approaches. This may be done by involving consumers and/or carers in steering committees for design approaches, establishing new or using existing consumer advisory groups to provide advice on design approaches, accessing networks of consumers and/or carers (such as state-based consumer organisations) to provide feedback throughout design projects, or undertaking consultation with individual consumers and/or carers throughout design projects. Information on how to engage with and gain feedback from consumers can be found in <i>The participation toolkit (UK)</i>.<sup>49</sup></li> <li>– involving consumers in the redesign methodology and processes. This may be done by sourcing information from consumers and/or carers about their experiences of health care, including their perspectives about the types of changes which would improve their healthcare experience. Your organisation could gain information about consumer experiences by:                 <ul style="list-style-type: none"> <li>• undertaking patient experience surveys or requesting consumers and/or carers complete feedback forms that include information about design of the environment and services. Your state health department may be able to provide information on patient experience surveys</li> <li>• using complaints feedback as a basis for identifying issues or compliments for identifying good practice. It may also be possible to follow up with consumers and/or carers who have concerns to discuss opportunities for improvement</li> <li>• convening formal focus groups or holding informal discussions with consumers in waiting rooms to gain feedback. See Step 5 in <i>A toolkit for redesign in health care (US)</i><sup>79</sup></li> <li>• speaking with consumer advisory groups, consumers on steering committees or consumers involved in key organisational structures</li> <li>• mapping the patient journey by following consumers and/or carers through your service to identify where workflow systems and the environment might be improved. See the <i>Health literacy environment of hospitals and health centers (US)</i><sup>70</sup></li> <li>• meeting with consumers and/or carers and community representatives at community events to discuss their experiences and opportunities for improvement.</li> </ul> </li> </ul> </li> </ul>



Actions required	Implementation strategies
<b>2.5 Partnering with consumers and/or carers to design the way care is delivered to better meet patient needs and preferences</b> (continued)	
<p>(continued)</p> <p><b>2.5.1</b> Consumers and/or carers participate in the design and redesign of health services</p>	<ul style="list-style-type: none"> <li>When undertaking formal or informal processes to gather information and feedback from consumers, it is important that you document the strategies used to collect this information. This could be in the form of meeting minutes, reports on workshops, diary notes or other records.</li> <li>It is critical that information provided by consumers and/or carers about their experiences is treated sensitively, that privacy and confidentiality is maintained and that consumers and/or carers are supported to share their experiences and stories to the extent that they are comfortable. Information on ethical considerations of using patient stories can be found in <a href="#">Guidance on the use of patient stories (UK)</a><sup>61</sup> or <a href="#">A toolkit for collecting and using patient stories for service improvement in WA Health</a>.<sup>62</sup></li> <li>You should provide feedback to consumers and/or carers about the kinds of design changes which have been made in response to their feedback and input. This could be through information and updates on design projects in newsletters, local newspapers, radio, television or on your web site. Information could also be provided to consumers and/or carers through meetings or reports provided to the people who were involved in the identification, development and implementation of design projects.</li> </ul> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>membership of groups tasked with steering design and redesign approaches include consumers and/or carers</li> <li>agenda items, minutes and other meetings records which describe discussions and consumer involvement in the planning of the design or redesign of the health service</li> <li>project plans which include information on how consumers and carers have been involved in the development of the design or redesign approaches</li> <li>reports from designers and architects outlining how they have responded to consumer suggestions for improvements</li> <li>records of focus groups, proposals sent to consumers and carers for comment and other activities focusing on eliciting consumer perspectives.</li> </ul> <p><b>Considerations:</b></p> <p>Your organisation may not need to establish new processes, bodies or structures to partner with consumers in design and redesign. When looking for ways to access information about consumer experience, and to involve consumers in design processes, think about your existing policies, processes, structures and activities and consider whether they can be used or modified for this purpose.</p> <p>You may wish to contact your state-based safety and quality organisation to seek advice on how to engage with consumers and carers in design and redesign. A list of state-based organisations can be found at Appendix A.</p> <p><b>Additional resources:</b></p> <p><a href="#">National Health Service – Patient Experience Surveys web site (UK)</a><sup>84</sup></p> <p><a href="#">Hospital Care Quality Information from the Consumer Perspective – web site (US)</a><sup>85</sup></p> <p><a href="#">Health literacy universal precautions toolkit (US)</a><sup>65</sup></p> <p><a href="#">The King’s Fund Experience based design toolkit (UK)</a><sup>80</sup></p>

Actions required	Implementation strategies
<b>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</b>	
<p><b>2.6.1</b> Clinical leaders, senior managers and the workforce access training on patient-centred care and the engagement of individuals in their care</p>	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Develop (or adapt) and provide access for the workforce to training and resources on consumer centred care and partnering with consumers</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should develop or adapt, and provide training, resources and continuing professional development for staff which includes education on partnering with consumers, consumer centred care and valuing consumer perspectives and experiences. This may involve:             <ul style="list-style-type: none"> <li>– creating or modifying training sessions and resources for staff on consumer centred care and partnerships. One locally tailored example is the <a href="#">Banyule Nillumbik Primary Care Alliance Consumer participation resource and training kit for service providers (Aus)</a><sup>86</sup></li> <li>– providing access to externally developed training resources on consumer centred care and partnerships including online and written resources. An example of external accredited training is the <a href="#">Health Issues Centre Consumer Leadership and Consumer Engagement training (Aus)</a><sup>56</sup></li> <li>– inviting consumers to speak to the workforce about their experience of the healthcare service. Information on using patient stories can be found in <a href="#">Guidance on the use of patient stories (UK)</a><sup>61</sup> or <a href="#">A toolkit for collecting and using patient stories for service improvement in WA Health</a><sup>62</sup></li> <li>– including information about partnerships and consumer centred care in existing workforce and practice development programs</li> <li>– providing support for the workforce to attend external training or conferences on consumer centred care and partnerships</li> <li>– inviting experts to come and talk to the workforce about consumer centred care and partnerships.</li> </ul> </li> <li>• When developing, adapting or refining training curricula, materials and resources on consumer centred care or partnerships, consider how your organisation could involve consumers and/or carers in the development of materials and resources. This could be by engaging with consumers on committees and advisory groups to provide feedback on structure and content of training, seeking out consumers and/or carers who are able to provide stories of their experience, or inviting consumers and/or carers to attend and review the training session to ensure it reflects their needs and perspectives. Information on how to engage with and source feedback from consumers can be found in <a href="#">The participation toolkit (UK)</a>.<sup>49</sup></li> </ul> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>• training curricula, resources or materials that include sections on consumer centred care, partnerships and consumer perspectives are utilised for orientation and ongoing training</li> <li>• scheduled training that includes sections on consumer centred care, partnerships and consumer perspectives</li> <li>• resources on consumer centred care, partnerships and consumer perspectives that are developed and disseminated</li> <li>• evaluation and feedback from participants on training that includes sections on consumer centred care, partnerships and consumer perspectives is analysed and used to refine training</li> <li>• feedback from consumers and/or carers involved in developing training and/or resources is analysed and used to refine training.</li> </ul>



Actions required	Implementation strategies
<b>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</b> <span style="float: right;">(continued)</span>	
<p>(continued)</p> <p><b>2.6.1</b> Clinical leaders, senior managers and the workforce access training on patient-centred care and the engagement of individuals in their care</p>	<p><b>Considerations:</b></p> <p>Your organisation may not need to establish new training or resources for this action.</p> <p>When looking at training for staff in patient centred care and partnerships think about your current training curricula and resources and identify whether existing training and resources can be used or modified to address this action.</p> <p><b>Additional resources:</b></p> <p><a href="#">Education and training for consumer participation in health care: Resource guide (Aus)</a><sup>64</sup></p> <p><a href="#">Consumer Participation in Primary Care – Training modules A-D (Aus)</a><sup>87</sup></p>
<p><b>2.6.2</b> Consumers and/or carers are involved in training the clinical workforce</p>	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Implement a policy which includes the involvement of consumers and/or carers in the design and delivery of workforce training</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should develop or adapt your organisation's policy or processes on clinical staff training to include the involvement of consumers and/or carers. Strategies to involve consumers and/or carers in the development of training could include: <ul style="list-style-type: none"> <li>– having consumers and/or carers involved in committees or advisory groups tasked with developing or reviewing training materials and resources. See <a href="#">Getting started: involving consumers on committees (Aus)</a>,<sup>44</sup> <a href="#">Consumer participation on committees (Aus)</a><sup>45</sup> or <a href="#">Improving health services through consumer participation (Aus)</a><sup>28</sup> for information about involving consumers and/or carers in committees</li> <li>– informally talking with consumers and/or carers within waiting areas about what they would include in consumer centred care and partnership training for the clinical workforce</li> <li>– convening focus groups or workshops to seek consumers' and/or carers' advice on critical information, resources and strategies for training the clinical workforce in consumer centred care and partnerships. See <a href="#">The participation toolkit (UK)</a><sup>49</sup> for information on convening focus groups and workshops</li> <li>– approaching community groups or local consumer organisations to provide feedback and input into the development of training materials and resources</li> <li>– inviting consumers and/or carers to attend and review the training session to ensure it reflects their needs and perspectives.</li> </ul> </li> <li>• You should involve consumers in the delivery of training on consumer centred care, partnerships and consumer perspectives. This could include: <ul style="list-style-type: none"> <li>– inviting consumers and/or carers to present on their experiences. Information on collecting patient stories can be found in <a href="#">Guidance on the use of patient stories (UK)</a><sup>61</sup> or <a href="#">A toolkit for collecting and using patient stories for service improvement in WA Health (Aus)</a><sup>62</sup></li> <li>– using video or audio recordings of personal stories from consumers and/or carers. Information on collecting patient stories can be found in <a href="#">Guidance on the use of patient stories (UK)</a><sup>61</sup> or <a href="#">A toolkit for collecting and using patient stories for service improvement in WA Health</a><sup>62</sup></li> <li>– undertaking exercises where staff 'live in the patients shoes' to gain an understanding of the experience of consumers and/or carers. Examples of staff exercises can be found in <a href="#">Patient-centered care improvement guide (US)</a><sup>88</sup></li> </ul> </li> </ul>

Actions required	Implementation strategies
<b>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</b> <span style="float: right;">(continued)</span>	
<p>(continued)</p> <p><b>2.6.2</b> Consumers and/or carers are involved in training the clinical workforce</p>	<ul style="list-style-type: none"> <li>• When involving consumers and/or carers in the planning, delivery or review of workforce training, it is important to document the strategies used and the information collected from consumers and/or carers. This could be in the form of reports, diary entries, meeting agendas or minutes or other equivalent records.</li> <li>• If consumer and/or carer stories are used within training, it is critical that this information is treated sensitively, that privacy and confidentiality is maintained and that consumers and/or carers are supported to share their experiences and stories to the extent that they are comfortable. Information on ethical considerations of using patient stories can be found in <a href="#">Guidance on the use of patient stories (UK)</a><sup>61</sup> or <a href="#">A toolkit for collecting and using patient stories for service improvement in WA Health</a>.<sup>62</sup></li> </ul> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>• agenda items, minutes or other records of meetings involving consumers indicating that training curricula were discussed and feedback provided by consumers</li> <li>• records of focus groups, community meetings or discussions involving consumers and/or carers where feedback on training curricula and materials has been sought</li> <li>• project plans, communication strategies or consultation plans detailing involvement of consumers in the development of training curricula and/or materials</li> <li>• feedback from consumers and/or carers involved in developing training and/or resources</li> <li>• records of training provided by consumers.</li> </ul> <p><b>Considerations:</b></p> <p>Your organisation may not need to establish new processes or structures to undertake this work.</p> <p>When looking at involving consumers in developing and delivering training for staff in patient centred care and partnerships, think about your current processes for training and identify whether they can be used or modified to address this action.</p> <p><b>Additional resources:</b></p> <p><a href="#">Education and training for consumer participation in health care: Resource guide (Aus)</a><sup>64</sup></p> <p><a href="#">Consumer Participation in Primary Care – Training modules A-D (Aus)</a><sup>67</sup></p>



## Standard 2

### Criterion: Consumer partnership in service measurement and evaluation

#### Consumers and/or carers receive information on the health service organisation's performance and contribute to the ongoing monitoring, measurement and evaluation of performance for continuous quality improvement

Over the last decade there has been an increasing focus on measuring the experience of consumers and carers across the acute, primary and aged care sectors. Significant work has been undertaken internationally, particularly in the United States and England, in developing and applying validated patient experience measurement tools.<sup>41</sup> Evidence is building on the association between consumer experiences of care and quality of care.<sup>16-17</sup> Feedback sourced using patient experience measurement tools is being used to inform policy and quality improvements across different levels of the health system. This includes a move towards increased public reporting of data, as well as utilisation of this information at the local level for improvement purposes.

Partnering with consumers and/or carers in the review and analysis of performance monitoring data, and in the application of that feedback to quality activities, provides a valuable opportunity to engage consumers in quality improvement. For example, your patient experience survey may identify communication as a key issue; however, there may not be enough detail to understand how it could be addressed. By involving consumers and carers in the process of analysing feedback you can use their expertise to guide the development of appropriate improvement strategies. By partnering with consumers and carers in these processes you can improve the interpretation and application of consumer and carer feedback, which in turn has potential to increase the likelihood of selecting appropriate and acceptable quality improvement activities for implementation.

Actions required	Implementation strategies
<b>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</b>	
<p><b>2.7.1</b> The community and consumers are provided with information that is meaningful and relevant on the organisation's safety and quality performance</p>	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>As part of your governance framework, implement a policy for providing safety and quality performance information to the community, consumers and carers</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should review how your organisation currently provides information on safety and quality performance to the community. This could include looking at your communication strategies, frameworks for partnering with consumers and publications produced by your organisation, and talking to relevant members of the workforce about how they communicate with the community.</li> <li>• <i>If your organisation does not currently provide safety and quality performance information to your community</i> – you should develop or adapt, and implement a communication plan that details how your organisation will provide information to the community about safety and quality performance. An example of a communication plan can be found at the <a href="#">Project Management Docs web site (US)</a>.<sup>89</sup> In addition, Part 2 of <a href="#">Review of existing models of reporting to consumers on health service quality (Aus)</a><sup>90</sup> provides a framework for delivering information on health service quality to consumers.</li> <li>• Strategies for communicating safety and quality performance information to your community could include: <ul style="list-style-type: none"> <li>– providing information or reports on your organisation's web site or contributing information to the <a href="#">MyHospitals web site www.myhospitals.gov.au</a><sup>91</sup></li> <li>– making posters on safety and quality performance and displaying them in your organisation</li> <li>– developing information sheets on safety and quality performance for consumers and/or carers to read within waiting areas</li> <li>– being interviewed about safety and quality performance for community radio, newspapers and television articles</li> <li>– authoring items in local community and business newsletters on safety and quality performance.</li> </ul> </li> <li>• When developing information materials for consumers, you should use health literacy tools and strategies to ensure that the information is understandable, accessible and meaningful to those with low levels of health literacy. Tools to reduce barriers to health literacy can be found in the <a href="#">Health literacy universal precautions toolkit (US)</a>.<sup>65</sup></li> <li>• You should develop or strengthen connections with local community groups, community representatives and representatives of diverse and vulnerable groups to identify opportunities to share information about safety and quality performance.</li> <li>• Strategies for linking with communities can be found in Chapter 8 of <a href="#">Feedback, participation and consumer diversity (Aus)</a>.<sup>55</sup> Examples of how you could engage with your community include: <ul style="list-style-type: none"> <li>– attending and presenting information on your organisation, including safety and quality performance information, at local community meetings or events</li> <li>– attending and presenting information on your organisation, including safety and quality performance information, at local business groups meetings or local consumer organisation meetings</li> <li>– inviting local community groups or community representatives to attend your organisation's meetings or events where safety and quality performance information is discussed</li> <li>– inviting consumer and/or community representatives to be part of your governance arrangements. See strategies provided in Action 2.1.1.</li> </ul> </li> </ul>



Actions required	Implementation strategies
<b>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</b> (continued)	
<p>(continued)</p> <p><b>2.7.1</b> The community and consumers are provided with information that is meaningful and relevant on the organisation's safety and quality performance</p>	<ul style="list-style-type: none"> <li>Using these relationships, work with local community groups, community representatives and representatives of diverse and vulnerable groups to review the content and format of the information provided to the community on the safety and quality performance of your organisation. You should seek feedback to ensure the information is meaningful, understandable and relevant to community members including those with low health literacy. Tools to improve communication effectiveness can be found in the <a href="#">Health literacy universal precautions toolkit (US)</a>.<sup>65</sup></li> </ul> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>communication and/or consultation policy or strategy that describes the processes for disseminating information on safety and quality performance to the community</li> <li>records of safety and quality performance information published in newsletters, newspaper articles, radio items, web site or other local media</li> <li>records of focus groups, meetings with consumers and committee meetings where safety and quality performance information has been discussed</li> <li>records of improvements made to dissemination of safety and quality information based on feedback from consumers, carers and community groups.</li> </ul> <p><b>Considerations:</b></p> <p>Your organisation may not need to establish new policies and/or processes for communicating with the community about safety and quality performance information.</p> <p>When looking at developing and implementing strategies for delivering information on safety and quality performance, think about your current communication processes to identify whether they can be used or modified to address this action.</p> <p><b>Additional resources:</b></p> <p><a href="#">Health literacy environment of hospitals and health centers (US)</a><sup>70</sup></p> <p><a href="#">How to present evidence for consumers (Aus)</a><sup>69</sup></p>

Actions required	Implementation strategies
<b>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</b>	
<b>2.8.1</b> Consumers and/or carers participate in the analysis of organisational safety and quality performance	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Implement a process for involving consumers and/or carers in the review and analysis of organisational safety and quality performance information</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should review your organisation's current policies and/or processes and structures (such as committees and working groups) which have been established to oversee organisational safety and quality performance information and identify the level of consumer and/or carer involvement. This could involve:             <ul style="list-style-type: none"> <li>– making a list of your current committees or groups involved in reviewing organisational safety and quality performance information, and identifying the level of consumer involvement</li> <li>– talking to the workforce who are involved in reviewing organisational safety and quality performance information to find out how they work with consumers and/or carers</li> <li>– look at your policies or processes to identify whether there is currently a requirement for consumer involvement in the review of organisational safety and quality performance information.</li> </ul> </li> <li>• <i>If consumers are not currently involved in the review of organisational safety and quality performance information – adapt current, or establish new, processes and structures to involve consumers and/or carers. This may include:</i> <ul style="list-style-type: none"> <li>– inviting consumers and/or carers to become members of new or existing groups responsible for reviewing organisational safety and quality performance information. Information on involving consumers in committees can be found in <a href="#">Getting started: involving consumers on committees (Aus)</a>,<sup>44</sup> <a href="#">Consumer participation on committees (Aus)</a><sup>45</sup> or <a href="#">Improving health services through consumer participation (Aus)</a><sup>28</sup></li> <li>– holding individual or group discussions with consumers and/or carers on organisational safety and quality performance. See <a href="#">The participation toolkit (UK)</a><sup>49</sup> for information on convening focus groups and workshops</li> <li>– providing information and training for consumers to assist with understanding data and measurement in your organisation</li> <li>– providing organisational safety and quality performance information to local community and consumer groups for feedback.</li> </ul> </li> <li>• When undertaking formal or informal processes to gather information and feedback from consumers, it is important that your organisation documents the strategies used to collect this information. This may be within your organisation's governance framework, or in consultation plans, communication plans or project plans, or may involve reports or written feedback from consumers and/or carers.</li> </ul>



Actions required	Implementation strategies
<b>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</b> (continued)	
<p>(continued)</p> <p><b>2.8.1</b> Consumers and/or carers participate in the analysis of organisational safety and quality performance</p>	<p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"><li>• record of review of processes and structures which consider organisational safety and quality performance information to identify level of consumer and/or carer involvement</li><li>• project plans, consultation plans, communication plans or reports on the process for reviewing organisational safety and quality performance information</li><li>• membership of groups tasked with overseeing organisational safety and quality performance information includes consumers and/or carers</li><li>• agenda items, minutes and other records of meetings demonstrate involvement of consumers in the analysis of organisational safety and quality performance information</li><li>• consumer and/or carer feedback on their involvement in reviewing organisational safety and quality performance information.</li></ul> <p><b>Considerations:</b></p> <ul style="list-style-type: none"><li>• Your organisation may not need to establish new processes or strategies for involving consumers in the analysis of organisational safety and quality data. When looking at ways of involving consumers, think about your current processes and structures for reviewing safety and quality performance data and identify whether they can be used or modified to address this action.</li></ul> <p><b>Additional resources:</b></p> <p><i>Feedback, participation and consumer diversity (Aus)</i><sup>55</sup></p> <p><i>Consumer and community participation toolkit (Aus)</i><sup>27</sup></p>

Actions required	Implementation strategies
<b>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</b> (continued)	
<b>2.8.2</b> Consumers and/or carers participate in the planning and implementation of quality improvements	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Implement a process for involving consumers and/or carers in the planning and implementation of quality improvements</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should review how your organisation currently undertakes planning and implementation of quality improvement activities and identify the level of consumer and/or carer involvement. This could involve: <ul style="list-style-type: none"> <li>– making a list of your quality improvement activities and identifying the level of consumer involvement</li> <li>– talking to members of the workforce who are involved in safety and quality improvement to find out how they work with consumers and/or carers</li> <li>– looking at your policies or processes to identify whether there is currently a requirement for consumer involvement in quality improvement approaches.</li> </ul> </li> <li>• <i>If consumers and/or carers are not actively involved in the implementation of quality improvement approaches</i> — you should develop or adapt processes and structures which include this as a requirement. Strategies to involve consumers in quality improvements may include: <ul style="list-style-type: none"> <li>– inviting consumers and/or carers onto steering committees for the planning, implementation and evaluation of quality improvement activities. See <a href="#">Getting started: involving consumers on committees (Aus)</a>,<sup>44</sup> <a href="#">Consumer participation on committees (Aus)</a><sup>45</sup> or <a href="#">Improving health services through consumer participation (Aus)</a><sup>28</sup> for information about involving consumers and/or carers in committees</li> <li>– inviting consumers and/or carers to be part of the project team for the planning and evaluation of a quality improvement project</li> <li>– talking with consumers and/or carers in waiting rooms or at informal meetings about quality improvement priorities, approaches and opportunities for improving services</li> <li>– establishing consumer advisory groups to help identify, develop and define quality improvement approaches. See the <a href="#">Guide for developing a community-based patient safety advisory council (US)</a><sup>47</sup> for information on establishing an advisory group</li> <li>– displaying information within your organisation about quality improvement approaches and inviting feedback on projects</li> <li>– conducting surveys of consumers and/or carers throughout the development and implementation of quality improvement approaches to identify and resolve issues and shape changes. Information on undertaking surveys can be found in <a href="#">Improving health services through consumer participation (Aus)</a><sup>28</sup> and <a href="#">The participation toolkit (UK)</a><sup>49</sup></li> <li>– meeting with community and consumer organisations to identify opportunities for quality improvement, and to help plan, implement and evaluate quality improvement activities</li> <li>– holding a workshop with staff and consumers and/or carers to discuss opportunities for improvement and/or to develop improvement approaches. See <a href="#">The participation toolkit (UK)</a><sup>49</sup> and <a href="#">The engagement toolkit (Aus)</a><sup>50</sup> for information on planning workshops.</li> </ul> </li> </ul> <p>See <a href="#">Patient-centered care improvement guide (US)</a><sup>88</sup> for more partnership and quality improvement strategies.</p>



Actions required	Implementation strategies
<b>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</b> (continued)	
(continued)  <b>2.8.2</b> Consumers and/or carers participate in the planning and implementation of quality improvements	<ul style="list-style-type: none"> <li>You should document how you have included consumers and/or carers in your organisation's quality improvement activities and provide feedback to consumers, carers and the community about the impact that this involvement has had. For example, describe changes which have occurred in response to consumer and/or carer feedback through local newsletters, media or your organisations web sites, display posters or information sheets within your organisation about how consumers have informed quality in your organisation or provide updates on the impact of consumer partnerships at organisational, community or consumer meetings and events.</li> </ul> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>record of review of processes and structures to identify level of consumer and/or carer involvement in quality improvement activities</li> <li>project plans, consultation plans, communication plans or reports on quality improvement activities which detail consumer and/or carer involvement</li> <li>membership of groups tasked with steering and advising on quality improvement activities include consumers and/or carers</li> <li>agenda items, minutes and other records of meetings demonstrate involvement of consumers and/or carers in quality improvement activities</li> <li>consumer and/or carer feedback on their involvement in quality improvement activities.</li> </ul> <p><b>Considerations:</b></p> <p>Your organisation may not need to establish new processes or strategies for involving consumers in the planning and implementation of quality improvements.</p> <p>When looking at ways of involving consumers think about your current processes and structures for planning and implementing quality improvements, and identify whether they can be used or modified to address this action.</p> <p>The systems that are needed to meet this action also apply for other actions in this standard, including Items 2.2 and 2.9.</p> <p>You may wish to contact your state-based safety and quality organisation to seek advice on how to engage with consumers and carers in planning and implementation of quality improvements. A list of state-based organisations can be found at Appendix A.</p> <p><b>Additional resources:</b></p> <p><i>Health literacy environment of hospitals and health centers (US)</i><sup>70</sup></p> <p><i>Consumer and community engagement and patient involvement and participation in health service planning, delivery and evaluation (Aus)</i><sup>92</sup></p> <p><i>Community participation in local health and sustainable development: Approaches and techniques (Eur)</i><sup>93</sup></p>

Actions required	Implementation strategies
<b>2.9 Consumers and/or carers participating in the evaluation of patient feedback data and development of action plans</b>	
<b>2.9.1</b> Consumers and/or carers participate in the evaluation of patient feedback data	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Implement a process for involving consumers and/or carers in the evaluation of patient feedback data</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should review your organisation's current processes for evaluating patient feedback and identify the level of consumer and/or carer involvement. This could involve looking at the way your organisation reviews patient experience survey information, information received through feedback boxes, complaints or compliments or information from other feedback mechanisms. You may need to consider who receives the raw data, which groups or committees are involved in the evaluation of the data, how it is collated and reported on, and how it is considered and used as a basis for informing change and quality improvement activities.</li> <li>• <i>If your organisation does not actively involve consumers in the evaluation of patient feedback data</i> — you should develop or adapt processes which actively involve consumers and/or carers in the evaluation of patient feedback data. This may involve:             <ul style="list-style-type: none"> <li>– inviting consumers and/or carers onto committees or groups tasked with evaluating patient feedback data. See <a href="#">Getting started: involving consumers on committees (Aus)</a>,<sup>44</sup> <a href="#">Consumer participation on committees (Aus)</a><sup>45</sup> or <a href="#">Improving health services through consumer participation (Aus)</a><sup>28</sup> for information on involving consumers and/or carers in committees</li> <li>– providing patient feedback data to individual consumers and/or carers for comment including identification of, and suggestions to address, key issues</li> <li>– displaying patient feedback data in your organisation and requesting comments and suggestions for improvements through an anonymous feedback box</li> <li>– providing patient feedback data to consumer groups and/or community groups for comment including identification of, and suggestions to address, key issues</li> <li>– engaging consumers and/or carers to evaluate patient feedback through workshops or focus groups. See <a href="#">The participation toolkit (UK)</a><sup>49</sup> and <a href="#">The engagement toolkit (Aus)</a><sup>50</sup> for information on planning workshops.</li> </ul> </li> <li>• You should document how you have included consumers and/or carers in your organisation's processes for evaluating patient feedback data. This could be through diary notes, reports, and newsletters.</li> </ul> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>• membership of groups tasked with evaluating patient feedback include consumers and/or carers</li> <li>• agenda items, minutes and other meeting records describe discussion of patient feedback involving consumers and/or carers</li> <li>• reports describing patient feedback include information on the level of consumer and/or carer involvement in the review and analysis of the feedback data</li> <li>• reports or statements from consumers and/or carers describing their involvement in the evaluation of patient feedback.</li> </ul>



Actions required	Implementation strategies
<b>2.9 Consumers and/or carers participating in the evaluation of patient feedback data and development of action plans</b> (continued)	
<p>(continued)</p> <p><b>2.9.1</b> Consumers and/or carers participate in the evaluation of patient feedback data</p>	<p><b>Considerations:</b></p> <p>Your organisation may not need to establish new processes for involving consumers in the evaluation of patient feedback. When looking at ways of involving consumers think about your current processes for evaluating patient feedback and identify whether they can be used or modified for this purpose.</p> <p><b>Additional resources:</b></p> <p><i>A guide to using data for health care quality improvement (Aus)</i><sup>94</sup></p> <p><i>Consumer and community engagement and patient involvement and participation in health service planning, delivery and evaluation (Aus)</i><sup>92</sup></p>
<p><b>2.9.2</b> Consumers and/or carers participate in the implementation of quality activities relating to patient feedback data</p>	<p><b>Key task:</b></p> <ul style="list-style-type: none"> <li>• <b>Implement a process for involving consumers and/or carers in the implementation of quality activities identified through patient feedback data</b></li> </ul> <p><b>Suggested strategies:</b></p> <ul style="list-style-type: none"> <li>• You should review your organisation's current processes for involving consumers and/or carers in the implementation of quality activities which are identified through patient feedback. This could involve looking at the way your organisation plans and implements quality improvement approaches including identifying relevant policies or processes and looking at the level of consumer and/or carer involvement which is required.</li> <li>• <i>If your organisation does not actively involve consumers in the implementation of quality improvement activities</i> — you should develop or adapt quality improvement policies or processes, which require the involvement of consumers and/or carers in the implementation of quality improvement activities. This may include:             <ul style="list-style-type: none"> <li>– utilising consumer advisory committees to provide advice on the implementation of quality improvement activities. See the <i>Guide for developing a community-based patient safety advisory council (US)</i><sup>47</sup> for information on establishing an advisory group</li> <li>– involving consumers in steering groups established to guide implementation of quality improvement activities. Information on involving consumers and/or carers on committees can be found in <i>Getting started: involving consumers on committees (Aus)</i><sup>44</sup> or <i>Improving health services through consumer participation (Aus)</i><sup>28</sup></li> <li>– convening focus groups or workshops to shape the implementation of quality improvement activities. Further information on convening focus groups and workshops can be found in <i>The participation toolkit (UK)</i><sup>49</sup> and <i>The engagement toolkit (Aus)</i><sup>50</sup></li> <li>– working with consumer and/or community groups to contribute to the implementation of quality improvement activities</li> <li>– engaging with individual consumers and/or carers who were involved in the identification of issues to develop and implement solutions to quality issues.</li> </ul> </li> </ul> <p>See <i>The participation toolkit (UK)</i>,<sup>49</sup> <i>The engagement toolkit (Aus)</i><sup>50</sup> and Action 2.8.1 for more consumer and/or carer engagement strategies which can be applied to quality improvement processes.</p>

Actions required	Implementation strategies
<b>2.9 Consumers and/or carers participating in the evaluation of patient feedback data and development of action plans</b> <span style="float: right;">(continued)</span>	
<p>(continued)</p> <p><b>2.9.2</b> Consumers and/or carers participate in the implementation of quality activities relating to patient feedback data</p>	<ul style="list-style-type: none"> <li>You should document how you have included consumers and/or carers in your organisation's quality improvement activities. You should also provide feedback to consumers, carers and the community about the impact that this involvement has had. For example, describe changes which have occurred in response to consumer and/or carer feedback through local newsletters, media or your organisation's web sites, display posters or information sheets within your organisation about how consumers have informed quality in your organisation or provide updates on the impact of consumer partnerships at organisational, community or consumer meetings and events.</li> </ul> <p><b>Outputs of improvement processes may include:</b></p> <ul style="list-style-type: none"> <li>membership of groups tasked with implementation of quality activities identified through patient feedback include consumers and/or carers</li> <li>agenda papers, meeting minutes and/or reports of relevant committees that document involvement of consumers and/or carers in discussions about implementation of quality activities based on patient feedback</li> <li>documentation detailing processes for involving consumers and/or carers in implementation of quality activities developed in response to patient feedback</li> <li>action plan identifying future quality activities in response to patient feedback including detail of processes for involving consumers and/or carers</li> <li>reports of statements from consumers and/or carers describing their involvement in implementation of quality activities designed to respond to patient feedback.</li> </ul> <p><b>Considerations:</b></p> <p>Your organisation may not need to establish new policies and/or processes for involving consumers in the implementation of quality activities identified through patient feedback.</p> <p>When looking at ways of involving consumers think about your current processes for implementing quality improvements and identify whether they can be used or modified for this purpose.</p> <p>The systems that are needed to meet this action also apply for other actions in this standard, including Items 2.2 and 2.8.</p> <p>You may wish to contact your state-based safety and quality organisation to seek advice on how to engage with consumers and carers in implementation of quality activities identified through patient feedback. A list of state-based organisations can be found at Appendix A.</p> <p><b>Additional resources:</b></p> <p><i>Consumer and community engagement and patient involvement and participation in health service planning, delivery and evaluation (Aus)</i><sup>92</sup></p> <p><i>Making space for the consumer voice in quality and safety: A guide for community advisory committees in Victorian public health services (Aus)</i><sup>95</sup></p>

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# Appendix A: Key organisations

## Australian organisations for health consumers

Australian Institute for Patient and Family Centred Care  
[www.aipfcc.org.au](http://www.aipfcc.org.au)

Carers Australia  
[www.carersaustralia.com.au](http://www.carersaustralia.com.au)

Centre for Health Communication and Participation  
[www.latrobe.edu.au/chcp](http://www.latrobe.edu.au/chcp)

Cochrane Consumers and Communication Review Group  
[www.latrobe.edu.au/chcp/cochrane](http://www.latrobe.edu.au/chcp/cochrane)

Cochrane Consumer Network  
[www.cochrane.org/consumers](http://www.cochrane.org/consumers)

Consumers Health Forum of Australia  
[www.chf.org.au](http://www.chf.org.au)

Health Care Consumers' Association of the ACT  
[www.hcca.org.au](http://www.hcca.org.au)

Health Consumers Alliance of South Australia Inc.  
[www.hcasa.asn.au](http://www.hcasa.asn.au)

Health Consumers' Council (WA) Inc.  
[www.hconc.org.au](http://www.hconc.org.au)

Health Consumers NSW  
[www.hcnsw.org.au](http://www.hcnsw.org.au)

Health Consumers Queensland  
[www.health.qld.gov.au/hcq](http://www.health.qld.gov.au/hcq)

Health Consumers of Rural and Remote Australia Inc.  
[www.ruralhealth.org.au](http://www.ruralhealth.org.au)

Health Issues Centre Inc. (Victoria)  
[www.healthissuescentre.org.au](http://www.healthissuescentre.org.au)

## National, state and territory government organisations and programs

Australian Commission on Safety and Quality in Health Care  
[www.safetyandquality.gov.au](http://www.safetyandquality.gov.au)

Department of Health and Ageing  
[www.health.gov.au](http://www.health.gov.au)

## New South Wales

Health Care Complaints Commission  
[www.hccc.nsw.gov.au](http://www.hccc.nsw.gov.au)

NSW Health  
[www.health.nsw.gov.au](http://www.health.nsw.gov.au)

NSW Bureau of Health Information  
[www.bhi.nsw.gov.au](http://www.bhi.nsw.gov.au)

NSW Clinical Excellence Commission  
[www.cec.health.nsw.gov.au](http://www.cec.health.nsw.gov.au)

NSW Health – Essentials of Care program  
[www.health.nsw.gov.au/nursing/projects/eoc.asp](http://www.health.nsw.gov.au/nursing/projects/eoc.asp)

NSW Health – Patient and Carer Experience program  
[www.health.nsw.gov.au/performance/pcexperience.asp](http://www.health.nsw.gov.au/performance/pcexperience.asp)

NSW Health Patient Survey  
[www.health.nsw.gov.au/hospitals/patient\\_survey/index.asp](http://www.health.nsw.gov.au/hospitals/patient_survey/index.asp)

NSW Health – 'Take the Lead' project  
[www.health.nsw.gov.au/nursing/projects/take\\_the\\_lead.asp](http://www.health.nsw.gov.au/nursing/projects/take_the_lead.asp)

## Australian Capital Territory

ACT Health Services Commissioner  
[www.hrc.act.gov.au/content.php/content.view/id/6](http://www.hrc.act.gov.au/content.php/content.view/id/6)

ACT Health  
[www.health.act.gov.au](http://www.health.act.gov.au)

ACT Health – Access Improvement program  
[www.health.act.gov.au/c/health?a=da&did=11143891%20&pid=12886596-1](http://www.health.act.gov.au/c/health?a=da&did=11143891%20&pid=12886596-1)

ACT Health Healthcare Survey  
[www.health.act.gov.au/c/health?a=da&did=10101609&pid=1254-89026](http://www.health.act.gov.au/c/health?a=da&did=10101609&pid=1254-89026)

## Queensland

Health Quality and Complaints Commission  
[www.hqcc.qld.gov.au](http://www.hqcc.qld.gov.au)

Queensland Health  
[www.health.qld.gov.au](http://www.health.qld.gov.au)

Queensland Health – Healthcare Experience Improvement program  
[www.health.qld.gov.au/psq/hemt/webpages/patient\\_survey.asp](http://www.health.qld.gov.au/psq/hemt/webpages/patient_survey.asp)



**Queensland Health Patient Satisfaction Survey**  
[www.health.qld.gov.au/psq/hemt/webpages/patient\\_survey.asp](http://www.health.qld.gov.au/psq/hemt/webpages/patient_survey.asp)

**Queensland Health – Clinical Services Redesign program**  
[www.health.qld.gov.au/chi/CSRP/default.asp](http://www.health.qld.gov.au/chi/CSRP/default.asp)

## Victoria

**Health Services Commissioner**  
[www.health.vic.gov.au/hsc](http://www.health.vic.gov.au/hsc)

**Victorian Department of Health**  
[www.health.vic.gov.au](http://www.health.vic.gov.au)

**Victorian Department of Health – Improving the Patient Experience Program**  
[www.health.vic.gov.au/emergency/edaudit.htm](http://www.health.vic.gov.au/emergency/edaudit.htm)

**Victorian Department of Health  
Victorian Patient Satisfaction Monitor**  
[www.health.vic.gov.au/patsat](http://www.health.vic.gov.au/patsat)

**Victorian Quality Council**  
[www.health.vic.gov.au/qualitycouncil](http://www.health.vic.gov.au/qualitycouncil)

## Northern Territory

**Health and Community Services  
Complaints Commission**  
[www.hcsc.nt.gov.au](http://www.hcsc.nt.gov.au)

**Northern Territory Department  
of Health and Families**  
[www.health.nt.gov.au](http://www.health.nt.gov.au)

## South Australia

**Health and Community Services  
Complaints Commissioner**  
[www.hcsc.sa.gov.au](http://www.hcsc.sa.gov.au)

**SA Health**  
[www.sahealth.sa.gov.au](http://www.sahealth.sa.gov.au)

**SA Health Patient Evaluation  
of Health Services Survey**  
[www.health.sa.gov.au/pros/Default.aspx?PageContentMode=1&tabid=44](http://www.health.sa.gov.au/pros/Default.aspx?PageContentMode=1&tabid=44)

## Tasmania

**Health Complaints Commissioner Tasmania**  
[www.healthcomplaints.tas.gov.au](http://www.healthcomplaints.tas.gov.au)

**Department of Health and  
Human Services Tasmania**  
[www.dhhs.tas.gov.au](http://www.dhhs.tas.gov.au)

## Western Australia

**Western Australian Health and Disability  
Services Complaints Office**  
[www.hadsco.wa.gov.au/home](http://www.hadsco.wa.gov.au/home)

**WA Health**  
[www.health.wa.gov.au](http://www.health.wa.gov.au)

**WA Health Office of Safety and Quality in  
Healthcare and Patient First program**  
[www.safetyandquality.health.wa.gov.au/involving\\_patient/patient\\_1st.cfm](http://www.safetyandquality.health.wa.gov.au/involving_patient/patient_1st.cfm)

## International organisations

**Institute for Healthcare Improvement (US)**  
[www.ihl.org](http://www.ihl.org)

**Institute for Patient- and Family-Centred Care (US)**  
[www.ipfcc.org](http://www.ipfcc.org)

**The King's Fund (UK)**  
[www.kingsfund.org.uk](http://www.kingsfund.org.uk)

**Picker Institute (US)**  
[www.pickerinstitute.org](http://www.pickerinstitute.org)

**Picker Institute Europe**  
[www.pickereurope.org](http://www.pickereurope.org)

**Planetree (US)**  
[www.planetree.org](http://www.planetree.org)

## Appendix B: Links to resources

**A guide to using data for health care quality improvement (Aus)**<sup>94</sup>

[www.health.vic.gov.au/qualitycouncil/pub/improve/data\\_guide.htm](http://www.health.vic.gov.au/qualitycouncil/pub/improve/data_guide.htm)

**A toolkit for collecting and using patient stories for service improvement in WA Health**<sup>62</sup>

[www.health.wa.gov.au/hrit/docs/A\\_toolkit\\_for\\_collecting\\_and\\_using\\_patient\\_stories.pdf](http://www.health.wa.gov.au/hrit/docs/A_toolkit_for_collecting_and_using_patient_stories.pdf)

**A toolkit for redesign in health care (US)**<sup>79</sup>

[www.ahrq.gov/qual/toolkit/toolkit.pdf](http://www.ahrq.gov/qual/toolkit/toolkit.pdf)

**Accredited consumer representative training course (Aus)**<sup>56</sup>

[www.healthissuescentre.org.au/](http://www.healthissuescentre.org.au/)

**Advancing the practice of patient- and family- centered care in hospitals: How to get started (US)**<sup>31</sup>

[www.ipfcc.org/pdf/getting\\_started.pdf](http://www.ipfcc.org/pdf/getting_started.pdf)

**Advancing the practice of patient- and family-centred care in primary care and other ambulatory settings: How to get started (US)**<sup>32</sup>

[www.ipfcc.org/pdf/GettingStarted-AmbulatoryCare.pdf](http://www.ipfcc.org/pdf/GettingStarted-AmbulatoryCare.pdf)

**Advocacy, leadership and community participation (Aus)**<sup>58</sup>

[www.health.vic.gov.au/pcps/downloads/chps/nthctrlmetro\\_consumer.pdf](http://www.health.vic.gov.au/pcps/downloads/chps/nthctrlmetro_consumer.pdf)

**Audit tools for National Safety and Quality Health Service Standards (Aus)**<sup>36</sup>

[www.health.qld.gov.au/psq/safetyandquality/nsqhss-audit-tools.asp](http://www.health.qld.gov.au/psq/safetyandquality/nsqhss-audit-tools.asp)

**Case studies of consumer engagement in Australian health policy and related fields (Aus)**<sup>52</sup>

[www.healthissuescentre.org.au/documents/items/2009/06/280548-upload-00001.pdf](http://www.healthissuescentre.org.au/documents/items/2009/06/280548-upload-00001.pdf)

**Community participation in local health and sustainable development: Approaches and techniques (Eur)**<sup>93</sup>

[www.euro.who.int/\\_\\_data/assets/pdf\\_file/0013/101065/E78652.pdf](http://www.euro.who.int/__data/assets/pdf_file/0013/101065/E78652.pdf)

**Consumer and community engagement and patient involvement and participation in health service planning, delivery and evaluation (Aus)**<sup>92</sup>

[www.health.qld.gov.au/hcq/maca\\_eoi/HQC\\_Community\\_eng.pdf](http://www.health.qld.gov.au/hcq/maca_eoi/HQC_Community_eng.pdf)

**Consumer and community participation toolkit (Aus)**<sup>27</sup>

[www.healthissuescentre.org.au/documents/items/2008/08/226706-upload-00001.pdf](http://www.healthissuescentre.org.au/documents/items/2008/08/226706-upload-00001.pdf)

**Consumer participation and culturally and linguistically diverse communities (Aus)**<sup>54</sup>

[www.ceh.org.au/downloads/Consumer\\_Participation\\_and\\_CALD\\_Communities.pdf](http://www.ceh.org.au/downloads/Consumer_Participation_and_CALD_Communities.pdf)

**Consumer participation guide (Aus)**<sup>63</sup>

[www.canceraustralia.gov.au/publications-resources/cancer-australia-publications/consumer-participation-guide](http://www.canceraustralia.gov.au/publications-resources/cancer-australia-publications/consumer-participation-guide)

**Consumer participation in primary care – training modules A-D (Aus)**<sup>87</sup>

[www.healthissuescentre.org.au/subjects/list-library-subject.shtml?subject=44](http://www.healthissuescentre.org.au/subjects/list-library-subject.shtml?subject=44)

**Consumer participation on committees (Aus)**<sup>45</sup>

[www.healthissuescentre.org.au/documents/items/2008/09/231151-upload-00001.pdf](http://www.healthissuescentre.org.au/documents/items/2008/09/231151-upload-00001.pdf)

**Consumer representative checklist (Aus)**<sup>60</sup>

[docs.health.vic.gov.au/docs/doc/Consumer-checklist](http://docs.health.vic.gov.au/docs/doc/Consumer-checklist)

**Consumer representatives handbook (Aus)**<sup>46</sup>

[www.health.qld.gov.au/hcq/network\\_reps/cons\\_handbook.pdf](http://www.health.qld.gov.au/hcq/network_reps/cons_handbook.pdf)

**Consumer training and mentoring guide (Aus)**<sup>57</sup>

[www.healthissuescentre.org.au/documents/items/2011/02/364261-upload-00001.pdf](http://www.healthissuescentre.org.au/documents/items/2011/02/364261-upload-00001.pdf)

**Education and training for consumer participation in health care: Resource guide (Aus)**<sup>64</sup>

[www.healthissuescentre.org.au/documents/items/2008/08/226167-upload-00001.pdf](http://www.healthissuescentre.org.au/documents/items/2008/08/226167-upload-00001.pdf)

**Emergency surgery redesign: Toolkit for implementation in NSW hospitals (Aus)**<sup>81</sup>

[www.archi.net.au/documents/resources/hsd/surgery/emergency\\_surgery/emergency-surgery-toolkit.pdf](http://www.archi.net.au/documents/resources/hsd/surgery/emergency_surgery/emergency-surgery-toolkit.pdf)

**Enabling the consumer role in clinical governance: A guide for health services (Aus)**<sup>29</sup>

[www.health.vic.gov.au/qualitycouncil/downloads/clingov\\_cons.pdf](http://www.health.vic.gov.au/qualitycouncil/downloads/clingov_cons.pdf)



**Establishing critical friends groups in general practice (UK)<sup>48</sup>**

[www.pdptoolkit.co.uk/files/adobe%20files/setting%20up%20cfg.pdf](http://www.pdptoolkit.co.uk/files/adobe%20files/setting%20up%20cfg.pdf)

**Evaluating health information with consumers (Aus)<sup>67</sup>**

[www.healthpromotion.cywhs.sa.gov.au/library/3.4\\_3\\_Evaluating\\_health\\_info.pdf](http://www.healthpromotion.cywhs.sa.gov.au/library/3.4_3_Evaluating_health_info.pdf)

**Feedback, participation and consumer diversity A literature review (Aus)<sup>55</sup>**

[www.healthissuescentre.org.au/documents/items/2008/08/226293-upload-00001.pdf](http://www.healthissuescentre.org.au/documents/items/2008/08/226293-upload-00001.pdf)

**Finding consumers and carers (Aus)<sup>35</sup>**

[www.health.vic.gov.au/qualitycouncil/downloads/consumer\\_dir.pdf](http://www.health.vic.gov.au/qualitycouncil/downloads/consumer_dir.pdf)

**Getting started: Involving consumers on committees (Aus)<sup>44</sup>**

[www.healthissuescentre.org.au/documents/items/2008/07/222372-upload-00001.pdf](http://www.healthissuescentre.org.au/documents/items/2008/07/222372-upload-00001.pdf)

**Guidance on the use of patient stories (UK)<sup>61</sup>**

[www.wales.nhs.uk/sites3/Documents/781/Microsoft%20Word%20-%20GUIDANCE%20ON%20THE%20USE%20OF%20PATIENT%20STORIES%20\\_Final.pdf](http://www.wales.nhs.uk/sites3/Documents/781/Microsoft%20Word%20-%20GUIDANCE%20ON%20THE%20USE%20OF%20PATIENT%20STORIES%20_Final.pdf)

**Guide for developing a community-based patient safety advisory council (US)<sup>47</sup>**

[www.ahrq.gov/qual/advisorycouncil/](http://www.ahrq.gov/qual/advisorycouncil/)

**Guidelines for consumer representatives (Aus)<sup>59</sup>**

[www.chf.org.au/pdfs/crr/crr-237-guidelines-consumer-reps.pdf](http://www.chf.org.au/pdfs/crr/crr-237-guidelines-consumer-reps.pdf)

**Health care providers' guide to engaging multicultural communities and consumers (Aus)<sup>53</sup>**

[www.health.qld.gov.au/multicultural/support\\_tools/com-engage-guide.pdf](http://www.health.qld.gov.au/multicultural/support_tools/com-engage-guide.pdf)

**Health literacy environment of hospitals and health centers (US)<sup>70</sup>**

[www.ncsall.net/?id=1163](http://www.ncsall.net/?id=1163)

**Health literacy universal precautions toolkit (US)<sup>65</sup>**

[www.ahrq.gov/qual/literacy/healthliteracytoolkit.pdf](http://www.ahrq.gov/qual/literacy/healthliteracytoolkit.pdf)

**Health service co-design toolkit (NZ)<sup>73</sup>**

[www.healthcodesign.org.nz/](http://www.healthcodesign.org.nz/)

**Hospital Care Quality Information from the Consumer Perspective – web site (US)<sup>96</sup>**

[www.hcahponline.org/home.aspx](http://www.hcahponline.org/home.aspx)

**How to present the evidence for consumers: preparation of consumer publications (Aus)<sup>69</sup>**

[www.nhmrc.gov.au/guidelines/publications/cp66](http://www.nhmrc.gov.au/guidelines/publications/cp66)

**Improving health services through consumer participation: A resource guide for organisations (Aus)<sup>28</sup>**

[www.healthissuescentre.org.au/documents/detail.chtml?filename\\_num=226531](http://www.healthissuescentre.org.au/documents/detail.chtml?filename_num=226531)

**In other words...can they understand? Testing patient education materials with intended readers (US)<sup>66</sup>**

[www.healthliteracy.com/article.asp?PageID=3811](http://www.healthliteracy.com/article.asp?PageID=3811)

**Making space for the consumer voice in quality and safety: A guide for community advisory committees in Victorian public health services (Aus)<sup>95</sup>**

[www.healthissuescentre.org.au/documents/items/2008/04/204794-upload-00001.pdf](http://www.healthissuescentre.org.au/documents/items/2008/04/204794-upload-00001.pdf)

**National Health Service – Patient Experience Surveys web site (UK)<sup>84</sup>**

[www.nhssurveys.org/](http://www.nhssurveys.org/)

**Online training module: Guidelines for consumer representatives (Aus)<sup>34</sup>**

[www.ourhealth.org.au/consumer-rep-support/online-training-and-education](http://www.ourhealth.org.au/consumer-rep-support/online-training-and-education)

**Review of existing models of reporting to consumers on health service quality (Aus)<sup>90</sup>**

[www.healthissuescentre.org.au/documents/items/2008/08/226713-upload-00001.pdf](http://www.healthissuescentre.org.au/documents/items/2008/08/226713-upload-00001.pdf)

**Partnering with patients and families to enhance safety and quality: A mini toolkit (US)<sup>51</sup>**

[www.ipfcc.org/tools/Patient-Safety-Toolkit-04.pdf](http://www.ipfcc.org/tools/Patient-Safety-Toolkit-04.pdf)

**Partnering with patients, residents, and families: A resource for leaders of hospitals, ambulatory care settings and long-term care communities (US)<sup>33</sup>**

[www.ipfcc.org/resources/pinwheel/index.html](http://www.ipfcc.org/resources/pinwheel/index.html)

**Partnership self-assessment tool (US)<sup>42</sup>**

[partnershiptool.net/](http://partnershiptool.net/)

**Patient based care challenge (Aus)<sup>43</sup>**

[www.cec.health.nsw.gov.au/\\_documents/programs/partnering-with-patients/cec\\_patient\\_based\\_care\\_challenge\\_dl\\_brochure\\_web.pdf](http://www.cec.health.nsw.gov.au/_documents/programs/partnering-with-patients/cec_patient_based_care_challenge_dl_brochure_web.pdf)

## Appendix B: Links to resources

**Patient-centered care improvement guide (US)<sup>88</sup>**

[planetree.org/wp-content/uploads/2012/01/Patient-Centered-Care-Improvement-Guide-10-28-09-Final.pdf](http://planetree.org/wp-content/uploads/2012/01/Patient-Centered-Care-Improvement-Guide-10-28-09-Final.pdf)

**Project Management Docs web site (US)<sup>89</sup>**

[www.projectmanagementdocs.com/templates/communications-management-plan.html](http://www.projectmanagementdocs.com/templates/communications-management-plan.html)

**The engagement toolkit (Aus)<sup>50</sup>**

[www.dse.vic.gov.au/\\_\\_data/assets/pdf\\_file/0003/105825/Book\\_3\\_-\\_The\\_Engagement\\_Toolkit.pdf](http://www.dse.vic.gov.au/__data/assets/pdf_file/0003/105825/Book_3_-_The_Engagement_Toolkit.pdf)

**The King's Fund experience based design toolkit (UK)<sup>80</sup>**

[www.kingsfund.org.uk/ebcd/](http://www.kingsfund.org.uk/ebcd/)

**The participation toolkit (UK)<sup>49</sup>**

[www.scottishhealthcouncil.org/patient\\_\\_public\\_participation/participation\\_toolkit/the\\_participation\\_toolkit.aspx](http://www.scottishhealthcouncil.org/patient__public_participation/participation_toolkit/the_participation_toolkit.aspx)

**Well-written health information: A guide (Aus)<sup>68</sup>**

[www.health.vic.gov.au/consumer/downloads/dhs1074.pdf](http://www.health.vic.gov.au/consumer/downloads/dhs1074.pdf)

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## Notes

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**Australian Commission on Safety and Quality in Health Care**

Level 7, 1 Oxford Street, Darlinghurst NSW 2010  
GPO Box 5480, Sydney NSW 2001

Phone: (02) 9126 3600 (international +61 2 9126 3600)

Fax: (02) 9126 3613 (international + 61 2 9126 3613)

Email: [mail@safetyandquality.gov.au](mailto:mail@safetyandquality.gov.au)

**[www.safetyandquality.gov.au](http://www.safetyandquality.gov.au)**