Participation indicators

Participation in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services

Victoria
The Place To Be

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Foreword

This discussion paper is intended to assist in the development of the new consumer, carer and community participation policy in the Victorian health care system. It builds on the evidence reviewed and recommendations made in the *Consultation paper-Participation in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services* (the 'Consultation paper'), regarding the monitoring of participation (Department of Human Services, 2005).

The *Consultation paper* provides an overview on the use of performance indicators, and recommends a minimum set of participation performance indicators for the acute and sub-acute areas. These areas of the health service system were targeted to ensure their development, and to sit alongside what is already occurring in the other areas of the health service system. The minimum set of performance indicators is based on the development of a participation monitoring framework. The framework is a conceptual map for the core combination of activities necessary for successful and sustainable participation to occur within the health service system.

The systematic use of participation performance indicators in a health service system has not been achieved before. For this reason, it is recommended that a staged developmental approach for their introduction be undertaken. We welcome this initiative and the framing of the indicators within a quality improvement paradigm. A quality improvement approach to the development of participation indicators will facilitate learning about what works to improve our health services with consumers, carers and the community.

We commend this paper to you and look forward to working with you on the further development of indicators of participation. This, we are sure, will strongly contribute to a comprehensive evaluation and monitoring framework of participation across the Victorian health care service system.

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Executive Summary

This discussion paper is part of the development process of the *Participation in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services* (the 'Participation policy'). It builds on from the review and recommendations made in the *Consultation paper* and responds to objective 11 of the policy development process:

> *To develop a review and evaluation process of consumer, carer and community participation in Victorian health services including the development of key performance indicators of participation and those specific to community advisory committees* (Department of Human Services, 2005).

The *Consultation paper* researched current participation reporting requirements of acute and subacute health services and the use of performance indicators. It did not address the areas of mental health, aged care, primary care, public health and community health as development of indicators in these areas is being progressed by other processes. Similarly, it did not address the assessment of participation at the statewide level within the Department of Human Services. From this review, a minimum set of participation indicators is proposed, in conjunction with implementation recommendations. These recommendations, and the implementation of the minimum set of participation indicators, will be considered for incorporation into the participation policy.

The following table outlines the minimum participation indicator set.

Minimum participation indicator set: Victorian acute and subacute services

Recommended Standard	Indicator	Target or achievement
1. Governance		
1.1 The governing body is committed to consumer, carer and community participation.	Health service meets ACHS EQuIP standard 'The governing body is committed to consumer participation' (currently or its Standard 2.4) equivalent, to the level of 'MA' (Moderate Achievement).	The service reports its accreditation outcome and associated comments and recommendations to the department against this standard. If standard not met, summary of proposed action and their progress is reported annually to the Department of Human Services.
1.2 There is participation in higher level decision-making	There are consumers, carers, or community members on key governance and clinical governance structures	There are consumers, carers, or community members on the service's human research and ethics committee and the quality committee.
		There is ongoing support and networking of consumers involved in these committees
	A community advisory committee has been established in accordance with the *Health Services Act 1988* Section 239.*	Yes/No
	A community advisory committee has been established in accordance with the non-statutory guidelines.*	Yes/No
2. Accountability		
2.1 The service reports openly to its communities on quality and safety, and the participation in its processes.	The quality of care report outlines quality and safety performance and systems in the key care areas that address the health care needs of the service's communities, consumers and carer populations.	The report documents how it has met the 'minimum reporting requirements' ** The report indicates at least process and impact evaluation findings in meeting 'minimum reporting requirements' on participation activities. **
	A community participation plan has been developed and is being reported against annually to the Department of Human Services.*	Yes/No
3. Health care and treatment		
3.1 There is consumer and, where appropriate, carer participation in clinical care.	Consumer participation in decision making about their care and treatment is assessed on the Victorian Patient Satisfaction Monitor's Consumer' Participation sub-index. ***	The Victorian Patient Satisfaction Monitor Consumer Participation Sub-Index, and the Information Sub-Index improve over time.
	Appropriate information is available to enable all consumers and carers where appropriate to choose to share in decision-making about their care.	Health services can demonstrate that their processes for developing consumer and carer information for treatment and care options meet the Well-written health information: a guide check list (Currie et al, 2000).

* Only those services required under the Health Services Act 1988 to have community advisory committees need to meet these indicators.

** 'Minimum reporting requirements' refers to those requirements outlined in the Quality of care reports – guidelines and reporting requirements, located at www.health.vic.gov.au/consumer/reports.htm .

*** As part of the Department of Human Service's development of the participation policy an investigation into a reliable, valid and logical sub-index of consumer participation from existing experience-based questions on the Victorian Patient Satisfaction Monitor was investigated. The outcome being the identification of such an index that can be made available to health services.

Implementation recommendations

Recommendation 1

The Department of Human Services develops an overall plan for the introduction of the minimum set of participation indicators.

Recommendation 2

The Department of Human Services conducts a series of workshops with all stakeholders, including consumers, carers and community members, to: clarify expectations, listen to feedback and support health services in their development of the suggested staged implementation approach.

Recommendation 3

Apply the lessons learned from the implementation of the Victorian Patient Satisfaction Monitor, and other indicator implementations, to support the introduction of the indicators.

Recommendation 4

Each Victorian health service develops an implementation plan for introducing new indicators for participation to address the most common limitations and risks.

Recommendation 5

Health services develop an evaluation strategy of performance indicators to inform longer-term development of indicators, practice and monitoring.

Recommendation 6

The reporting requirements on participation to the department, as set out annually in the *Victoria – public hospitals and mental health services: policy and funding guidelines* (Department of Human Services, 2004), be updated in relation to the use and reporting on participation indicators.

Recommendation 7

Health services report annually, in their quality of care report, against their participation indicators.

Recommendation 8

The Department of Human Services reviews in 2007-08 the use of participation indicators and development of a more comprehensive set of indicators.

Recommendation 9

The Department of Human Services evaluates their participation activities to provide information about effectiveness and impacts, to inform practice and monitoring.

1 Introduction

1 Introduction	2 Why and how indicators should be used	3 Current context	4 Participation monitoring framework	5 Minimum participation indicator set	6 Second stage of indicator development	7 Implementation recommendations

This discussion paper on performance indicators for participation is aimed at Victorian public health services and is intended to assist in answering the question:

> *How can a public health service assess and report on its performance in involving consumers, carers and the community in health care delivery, planning, development and improving quality and safety?*

It is part of the development process of the *Participation policy* being developed by the department as outlined in the *Consultation paper* to the policy (Department of Human Services, 2005). Specifically, it builds on the 'participation evaluation and monitoring framework' outlined in this paper, and progresses the development of key performance indicators for participation.

The objectives of this paper are to:

- provide broad information about the use of indicators including definitions, benefits and limitations
- propose an overall participation monitoring framework
- develop participation indicators that can be used in acute and subacute health services in Victoria.

The paper assumes some knowledge of participation in health services. For a fuller explanation of the case for participation in health services, and its principles and frameworks, please read the *Consultation paper*.

2 Why and how indicators should be used

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The literature on performance indicators in participation was reviewed, but did not identify any existing frameworks for participation performance indicators. There was a wide range of material on the use of indicators more generally. The search strategy is detailed in Appendix 1.

In the previous decades there was an international trend towards public sector accountability and the measurement of performance of government agencies. However, performance indicators can be used for a variety of purposes (they have no value as stand-alone measures), and clarifying their purpose is a crucial step in their development and use. They should be closely related to the policies, goals and objectives of the organisation or system, rather than to what data is available (Wait, 2004).

Typically performance indicators are used to respond to three tasks:

- to measure progress towards a defined target - *quality and safety improvement*
- to offer a point for comparison to previous performance - *accreditation*
- to evaluate, assess or judge - *evaluation* (Primary Health Care Research and Information Service, 2004).

In Australia, performance indicators are most commonly used within a service improvement focus, policy development and for accountability (Primary Health Care Research and Information Service, 2004). They should identify the critical areas and articulate an activity, a process or outcome that has a significant impact on the quality of the work at hand (Performance Indicators in Community Health Project Working Group, 2002). An overview of what an indicator is and how it can be used is provided in Appendix 2. Health services may like to adapt this and use when explaining what an indicator is to their consumer, carer and community representatives.

Most literature on performance indicators is found in the field of quality improvement. Several health departments (in New South Wales, Queensland and Victoria) have sets of indicators that have reporting on consumer participation embedded in their quality processes. The two main national accreditation bodies, the Quality Improvement Council (QIC) and the Australian Council on Healthcare Standards (ACHS), have consumer participation standards and indicators in their tools, as does the National Standards for Mental Health Services.

The differences in focus and application between indicators for accountability and for quality improvement can be seen in Table 1.

Table 1 Differences between accountability and quality improvement indicators

	Indicators for Accountability and assurance	**Indicators to stimulate improvement**
Purpose	Verification	Promoting continual improvement
Emphasis	Measurement oriented	Change oriented
Rationale	External Accountability	Promote change and improve care quality
Culture	Comparisons	Learn from differences

Source: (Wait, 2004)

Participation and indicators

Consumer, carer and community participation comprises a broad range of activities, many of which are describe in *Improving health services through consumer participation: a resource guide for organizations* (Consumer Focus Collaboration, 2000). Participation encourages consideration and debate through processes that allow people to be involved in decision making about their health care and that of the community. It necessitates the communication of your view, scrutiny of motive and an ability to listen and appreciate other's views and ideas. Through involvement, decisions are made that may accommodate a range of perspectives (Department of Human Services, 2005). Participation has a variety of purposes, and occurs in a diverse range of contexts. Measuring the success of participation needs to take these factors into account.

From an effectiveness and quality perspective, participation is a means to improving care and ensuring it is appropriate to the needs and culture of the individual and, where appropriate, their carers (Department of Human Services, 2005). A participation indicator should measure activity that reflects meaningful progress towards this goal.

Performance indicators can measure a myriad of activities. These are described variously as useful to monitor:

- inputs (effort)
- outputs (effects or results)
- changes
- processes (how and why a result was achieved),
- successes or achievements of programs or organisations.

Indicators allow comparisons between services, against standards, or within the same agency over time. Given the early stages of monitoring participation in Victorian health services, a focus on comparisons would be more useful at a later stage of benchmarking.

When developing and selecting indicators, the following criteria from the National Health Performance Committee should be considered. The indicator should:

- be worth measuring
- be measurable for diverse populations
- be understood by people who need to act
- be relevant to policy and practice
- reflect results of actions when measured over time (Performance Indicators in Community Health Project Working Group, 2002).

In addition Wait proposes that the following questions should be asked:

- Does the measure actually measure what it is intended to measure? (Core validity.)
- Is the information needed for the measure relatively simple to collect in the timeframe required? (Wait, 2004).

An overview of common measurement issues in the use of indicators is provided in Appendix 3.

Summary

From this review it is concluded that:

- participation indicators should reflect quality improvement over accountability, and be clearly linked to policy and program aims, objectives and their relevant context
- indicators should be used to identify the key areas for participation, based on policy aims and objectives
- the indicator set chosen by services should cover process and impacts, and build toward covering outcome
- indicators should be introduced and implemented with a full awareness of the potential benefits and possible limitations.

3 Current context

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Victorian participation context

There are over 100 health services in Victoria, many of which operate on multiple campuses. These services are diverse in their size, services, governance, and levels of participation. Many rural services, and some metropolitan services, also operate integrated care centres and community health services. All these services have been influenced by a number of departmental policies and guidelines, which include many of the principles of participation as outlined in the *Consultation paper*. In this context, participation varies across all services.

Some small rural services, and many community health services, have a strong history of involving their communities, carers and consumers. This includes representation on the board; although only in the stand-alone community health services are some board members elected by members (mainly consumers). Other, larger metropolitan services have developed their participation capacity considerably in recent years, most notably through the input of community advisory committees. Other services, both rural and metropolitan, have been slower to embrace a participation approach.

The introduction of indicators will present quite different challenges to this spectrum of organisations. The framework and reporting process should therefore respect this and allow for the variety of stages and contexts of different services.

Victorian monitoring and reporting context

There is already a range of requirements and reporting formats that include a focus on participation for Victorian health services. These include:

- the objectives of the *Health Services Act, 1988 (Parliment of Victoria)*
- standards set for accreditation by the Evaluation and Quality Program (EQuIP) (Australian Council on Healthcare Standards, 2005)
- the Victorian Patient Satisfaction Monitor
- guidelines set for the quality of care reports (Department of Human Servies, 2004)
- guidelines for community advisory committees and their community participation plans (Department of Human Servies, 2000; 2005).

Those that relate to participation are itemised in Appendix 4 and need to be considered as potential indicators.

Quality improvement frameworks and measures

Several existing quality improvement frameworks and measures include components relating to participation in Australia. These include:

- Victorian Quality Council's safety and quality improvement framework (Victorian Quality Council, 2003)
- the framework outlined under EQuIP (Australian Council on Heathcare Standaards, 2005)
- Health and Community Services Standards (Quality Improvement Council, 2004)
- Victorian Standards for Disability Services (Department of Human Service–Diasbility Services, 1999)
- NSWHealth Framework for Managing Quality of Care (New South Wales Health, 1999)
- National Standards for Mental Health Services (Commonwealth of Australia Mental Health Branch, 1996)
- Framework for Performance Assessment in Primary Health Care (Sibthorpe, 2004).

These frameworks are reviewed in Appendix 5 with respect to their ability to be used in the development of a participation monitoring framework and indicators.

4 Participation monitoring framework

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The monitoring framework

The proposed monitoring framework is a conceptual map of the activities necessary for successful and sustainable participation to occur within the health service system. The framework highlights the key domains where experience and evidence show that action is required to maximise both the extent and the value of participation in an organisation. It builds upon the evaluation and monitoring framework outlined in the *Consultation paper* and the work reviewed in Section 3 of this paper. The framework also organises the domains into three of the four levels proposed in the *Consultation paper*: individual level, program /department level, health service organisational, and Department of Human Services level (Department of Human Services, 2005). It does not outline a potential set of indicators at the fourth level (Department of Human Services), but leaves this for future work.

1. **Individual:** how could we assess how well a health service facilitates individual health care decision-making? This would include shared decision-making, use of decision aids, involvement in current and advanced care planning, self-care, and information development.
2. **Ward/program/department:** how could we assess how well a health service involves consumers, carers and community members in improving services at the ward/program/department level?
3. **Organisational:** how could we assess how well a health service involves the consumers, carers and its community in organisational planning and development?

In order to focus the scope of this paper further, consideration of the individual level has been restricted to issues of information and decision making. That is, clinical indicators for quality improvement are not the focus of this paper. Similarly, indicators for primary health, mental health and aged care are not included, because these are or have been developed through separate processes.

Domains

The domains of an indicator clarify the scope of activity that the indicator will monitor. The participation monitoring framework presented below in Table 2 outlines a set of key domains where the literature and experience suggest activity is required to ensure effective participation within an organisation. Thus they include not only direct participatory activities, but also the building of capacity to undertake and sustain such activity.

The domains are closely related to the enablers and barriers that are described in the *Consultation paper*. These relationships are identified in respect to the factors that need to be considered in achieving each of the domains, as outlined in Appendix 6. The domains were also informed from an analysis of: the literature reviews conducted by the department in its policy development process and by the Health Issues Centre for this paper; from the work of the Consumer Focus Collaboration; and from the development of the self assessment tool by the National Resource Centre in Consumer Participation in Health.

The domains are also reflected in some of the current quality and safety frameworks and current requirements and reporting formats, as set out in Section 3 of this paper. In order to focus the scope of this paper, consideration of involvement at the individual care level has been restricted to issues of information and decision-making.

Table 2: Participation monitoring framework for health services

Level	**Key domain of activity**
Individual care	*Provision of condition-specific information* (evidence based where possible)
	Shared decision-making in care
	Consumer-focused care with appropriate carer involvement
Ward/department/ program	*Consumer and carer participation in planning and evaluation of service delivery*
	Monitoring, evaluation and reporting of consumer participation (including its scope and effectiveness)
Organisational	*Organisational Commitment* (such as leadership, supportive policies, active promotion of concept, budgets allocated, specified staff roles, and other resources)
	Staff capacity (ensuring sufficient skills, expertise, training provision)
	Participation in decision-making structures through formal, informal, ongoing and ad hoc or strategic involvement (for example, in planning via committees and feedback mechanisms, surveys, focus groups)
	Capacity of consumer, carer and community members (through providing support and training and development of relationships with community organisations)
	Monitoring and evaluation, and public reporting

5 Minimum participation indicator set

Staged process

The proposed participation monitoring framework in Section 4 presents the goal: *a framework for a service with a mature participation approach and experience*. It is unlikely that all of the services in Victoria are undertaking activity and collecting data on all the domains outlined in the framework. However, many would be active in most of the domains, and a few would be active and collecting data in all. This is supported by an analysis of current reporting requirements and potential indicators against the participation monitoring framework as set out in Appendix 7.

Importantly the analysis shows two things. First, it confirms the significance of the domains in the framework. Second, it suggests that the current reporting requirements and associated data collection provide a reasonable starting point or baseline for a staged introduction of participation indicators in Victoria.

This staged process relates to the acute and subacute areas of the health system as these were identified as a priority area for the development of the participation policy.

First stage: minimum participation indicator set

The recommended minimum participation indicator set is outlined below in Table 3, and accommodates how services are required to currently report on participation to the Department of Human Services, as outlined in Appendix 7. The indicators chosen also reflect the listed criteria and conclusions drawn in Section 2 on why and how indicators should be used. Given current reporting requirements, accountability is an element in the indicator set, but quality improvement indicators have also been selected to emphasise the value placed on using indicators to improve services.

A further rationale based on Section 2 was to choose a minimum number of indicators, so that they identify the critical participation areas. A minimum set of participation indicators makes collecting the information manageable, and allows services to easily monitor their progress over time. Some health services may see value in starting to share their data, and in comparing and learning from each other’s experiences. Where data is being published, for example from the Victorian Patient Satisfaction Monitor and quality of care reports, this information can be accessed publicly.

As demonstrated in Appendix 7, the current reporting requirements link closely to the participation and monitoring framework, and hence should relate closely to the final participation policy. This is important, as a strong lesson from the literature is that performance indicators should be tightly related to the policies, goals and objectives of the organisation or system, rather than to what data is available (Wait, 2004). This close link should continue to be fostered in later stages of indicator development.

Table 3 Minimum participation indicator set: Victorian acute and subacute services

Recommended Standard	Indicator	Target or achievement
1. Governance		
1.1 The governing body is committed to consumer, carer and community participation.	Health service meets ACHS EQuIP standard 'The governing body is committed to consumer participation' (currently Standard 2.4) or its equivalent, to the level of 'MA' (Moderate Achievement).	The service reports its accreditation outcome and associated comments and recommendations to the department against this standard. If standard not met, summary of proposed action and their progress is reported annually to the Department of Human Services.
1.2 There is participation in higher level decision-making	There are consumers, carers, or community members on key governance and clinical governance structures	There are consumers, carers, or community members on the service's human research and ethics committee and the quality committee. There is ongoing support and networking of consumers involved in these committees
	A community advisory committee has been established in accordance with the *Health Services Act 1988* Section 239.*	Yes/No
	A community advisory committee has been established in accordance with the non-statutory guidelines.*	Yes/No
2. Accountability		
2.1 The service reports openly to its communities on quality and safety, and the participation in its processes.	The quality of care report outlines quality and safety performance and systems in the key care areas that address the health care needs of the service's communities, consumers and carer populations.	The report documents how it has met the 'minimum reporting requirements' ** The report indicates at least process and impact evaluation findings in meeting 'minimum reporting requirements' on participation activities. **
	A community participation plan has been developed and is being reported against annually to the Department of Human Services.*	Yes/No
3. Health care and treatment		
3.1 There is consumer and, where appropriate, carer participation in clinical care.	Consumer participation in decision making about their care and treatment is assessed on the Victorian Patient Satisfaction Monitor's Consumer' Participation sub-index. ***	The Victorian Patient Satisfaction Monitor Consumer Participation Sub-Index, and the Information Sub-Index improve over time.
	Appropriate information is available to enable all consumers and carers where appropriate to choose to share in decision-making about their care.	Health services can demonstrate that their processes for developing consumer and carer information for treatment and care options meet the Well-written health information: a guide check list (Currie et al., 2000).

* Only those services required under the *Health Services Act 1988* to have community advisory committees need to meet these indicators.

** 'Minimum reporting requirements' refers to those requirements outlined in the *Quality of care reports – guidelines and reporting requirements*, located at www.health.vic.gov.au/consumer/reports.htm .

*** As part of the Department of Human Service's development of the participation policy, an investigation into a reliable, valid and logical sub-index of consumer participation from existing experience-based questions on the Victorian Patient Satisfaction Monitor was investigated. The outcome being the identification of such an index that can be made available to health services.

The limitations include that the formatting of the indicators can be refined, and the data collection standards should be improved. A further limitation is that the set focuses on process, which corresponds to the development of participation in acute and subacute health services. Future indicator sets should focus on the impacts and outcomes of participation. A detailed analysis of each of the indicators and their limitations is provided in Appendix 8.

Using the indicators

The indicators developed will be reported to each health service's board, to allow organisations to:

- monitor their performance against internal goals
- identify areas for improvement
- assess implementation of strategies to address areas of perceived weakness.

The indicators will be reported to the Department of Human Services, and will allow:

- analysis of trend data to show how services are performing over time
- comparison across health services
- highlighting of specific needs for support, including training and targeted assistance.

Importantly, indicators should be introduced and implemented with a full awareness of the potential risks in their use. Hence it is recommended that an internal implementation plan should be developed to address the most common of these limitations, as outlined in Appendix 3.

6 Second stage of indicator development

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Second stage: acute and subacute

The minimum set of participation indicators has been developed primarily based on current reporting requirements. This may mean that the set does not necessarily reflect all the areas of activity that current evidence and experience show as key components for participation in health services.

A more comprehensive set of indicators, which reflects all the elements of the participation monitoring framework, needs to be developed over time to facilitate improvement. This will comprise the second stage of the proposed process, where services can explore other indicators to illuminate practice within their own contexts. It is recommended that Stage 1 be reviewed two years after implementation, and the findings be used to develop a more comprehensive set of indicators.

Potential ways forward

In extending the minimum set of indicators, there are several paths forward. First, health services might wish to highlight certain activities they are undertaking that are not captured in the minimum set.

Second, services might wish to identify existing gaps in the current set more rigorously. These gaps might be suggested by areas where either:

- the literature reports that area as highly significant, such as in capacity building, and thus important for services to be undertaking some action
- useful indicators developed by other services that make sense to your organisation
- local experience suggests action is critical and should be monitored (community advisory committees could be useful in identifying such examples).

Last, the criteria reviewed in selecting indicators and the framework in Sections 2 and 3 should be used to select additional indicators.

A list of possible indicators and further potential measures are provided below, in Table 4 and 5 respectively. It is recommended that the department and health services use these potential measures to begin developing a more comprehensive set of indicators.

Possible consumer participation performance indicators

Table 4 Potential indicators: Victorian acute and subacute services

Recommended Standard	Indicator	Target or achievement
1. Governance		
1.1 The governing body is committed to consumer participation.	Health service meets ACHS EQuIP standard 'The governing body is committed to consumer participation' to the level of 'EA' (extensive achievement).	The service reports its accreditation outcome and associated comments and recommendations to the Department of Human Services against this standard. If the standard is not met, a summary of proposed actions and their progress is reported annually.
1.2 There is participation in higher level decision making.	Non-legislated services have developed mechanisms for consumer participation.	Services have developed a context-relevant consumer, carer and community advisory mechanism and a plan for their participation activities.
	Partnerships are established between consumer, carer, or community groups and the services.	Number and description of type of partnerships.
2. Accountability		
2.1 The service reports openly to its communities on quality and safety, and the consumer participation in its processes.	The service is actively monitoring and evaluating its participation activites.	Data are regularly collected on participation at the organisational level.
		A program of audits or participation is in operation.
		Project or program evaluations (processes and impacts) of specific initiatives or services measuring participation benefit.
	Legislated services are committed to achieving the goals in their community participation plan.	The majority of objectives (including both processes and impacts) in the community participation plan have been met.
		There are an increasing number of impact goals being met over time.
	Legislated services are committed to improving service delivery to identifiably hard to engage communities and consumers.	Data are collected routinely. Relevant goals are set for identified hard-to-engage communities and consumer groups.
		There is measurable improvement against those goals.
	There is participation in consumer health information development.	At least 80% of reviewed information meets the *Well-written health information: a guide* check list items (Currie et al., 2000).
	There is participation in policy development.	Consumers are involved and consulted about policy developments at program and organisational level.
	There is participation in quality improvement.	Consumers are involved and consulted about a range of quality improvement initiatives.

Table 4 Potential indicators: Victorian acute and subacute services (continued)

Recommended Standard	Indicator	Target or achievement
2. Accountability (continued)		
	There is ongoing program of evealuation within service.	There are a number of evaluations of programs each year, including an evaluation of the consumer participation component.
3. Health care and treatment		
3.1 There is consumer and, where appropriate, carer participation in clinical care.	The service is actively facilitating involvement by consumers and carers in decision making about their care and treatment	Appropriate and reliable decision aids are being provided in a supportive environment to consumers and, where appropriate, carers.

Table 5 Potential measures of participation

Individual care level – key domains of activity	
Provision of condition-specific information, evidence based where possible.	• Consumers and carers receive regular, updated, appropriate and culturally sensible information about services. • Consumers are provided with evidence-based information about conditions and treatment options. • Consumers and carers receive information about rights and responsibilities, and Australian Council on Safety and Quality in Health Care's '10 tips' or the equivalent.
Shared decision-making in care.	• Consumers and carers participate actively in decision making about individual care and rehabilitation and care planning. • Consumers with chronic conditions are provided with referrals to self-management programs, self-help groups and so on. • Services have informed consent processes.
Consumer-focused care with appropriate carer involvement.	• Consumers and carers benefit from open communication with services. • Consumers and carers provide feedback and lodge complaints.
Other	• Participation in delivery of services.
Ward/program/department level – key domains of activity	
Consumer and carer participation in planning and evaluation of service delivery.	• There is participation in development of new health programs (policy decisions, design). • There is participation in the development and provision of health information.
Monitoring, evaluation and reporting of consumer participation, including its scope and effectiveness.	• Programs have mechanisms for feedback. • Programs have complaint management systems. • There is participation in monitoring and evaluation of programs.

Table 5 Potential measures of participation (continued)

Organisational level – key domains of activity	
Organisational Commitment (leadership, supportive policies, active promotion of concept, budgets allocated, specified staff roles, and other resources).	• Services have philosophical framework or value system supporting consumer and community participation. • Services have written consumer and community participation policies. • Participation principles are embedded in services' documentation, culture and actions. • Services identify and address barriers to participation. • Services have financial and physical resources for consumer, carer and community participation.
Staff capacity (ensuring sufficient skills, expertise, training provision).	• There is participation in training of staff.
Participation in decision making structures at organisational level, through formal, informal, ongoing and ad hoc or strategic involvement.	• Services work in collaboration with consumer representative bodies, advocacy groups and communities of interest. • There is participation in the management of services (boards, committees), including ethics and research. • There is participation in major service planning (policy decisions, design). • There is participation in quality processes. • Mechanisms exist for engaging marginalised groups. • Consumers are involved in analysis and reporting of adverse events.
Capacity of consumer carer and community members involved.	• Services address needs of culturally and linguistically diverse communities, indigenous and other diverse communities.
Monitoring and evaluation, and public reporting.	• Services monitor and evaluate consumer participation strategies. • Services have variety of accessible mechanisms for feedback. • Services have complaint management systems. • There is participation in monitoring and evaluation of services.

7 Implementation recommendations

The following recommendations are made to facilitate the implementation of the minimum set of indicators and the further development of consumer, carer and community participation indicators.

Recommendation 1

The Department of Human Services develops an overall plan for the introduction of the minimum set of participation indicators.

Recommendation 2

The Department of Human Services conducts a series of workshops with all stakeholders, including consumers, carers and community members, to: clarify expectations, listen to feedback and support health services in their development of the suggested staged implementation approach.

Recommendation 3

Apply the lessons learned from the implementation of the Victorian Patient Satisfaction Monitor, and other indicator implementations, to support the introduction of the indicators.

Recommendation 4

Each Victorian health service develops an implementation plan for introducing new indicators for participation to address the most common limitations and risks.

Recommendation 5

Health services develop an evaluation strategy of performance indicators to inform longer-term development of indicators, practice and monitoring.

Recommendation 6

The reporting requirements on participation to the department, as set out annually in the *Victoria – public hospitals and mental health services: policy and funding guidelines (Department of Human Services, 2004)*, be updated in relation to the use and reporting on participation indicators.

Recommendation 7

Health services report annually, in their quality of care report, against their participation indicators.

Recommendation 8

The Department of Human Services reviews in 2007-08 the use of participation indicators and development of a more comprehensive set of indicators.

Recommendation 9

The Department of Human Services evaluates their participation activities to provide information about effectiveness and impacts, to inform practice and monitoring.

Appendix 1 Literature search strategy

The aim of this literature review is to identify published and unpublished literature and practice examples of participation indicators. These will include measures that can be used to assess how well health services and policy makers are engaging consumers in improving service delivery, planning, and policy development and program evaluation at the state level.

Search Strategy

The search strategy has been focused through discussion with the Reference Group. Concepts identified are emerging as follows.

Concept 1	Concept 2	Concept 3	Concept 4
(consumer engage* or patient engage* or patient participat* or consumer participat* or community engage* or consumer centred care or community particip*)	(Performance indicator* or Performance measure* or Evaluation Or Feedback)	Plan* or Health policy develop* or Health program	Health service or Hospital or Acute or subacute

We will use Boolean operators AND and OR and NOT to adjust the results of recall and precision.

We will use a 'building block' approach to searching by adding new keywords to concepts already identified.

Searching the Scientific Literature

For primary literature, we will search relevant databases, printed indexes and abstracts.

For secondary literature, we will search academic and research library catalogues and the catalogues of special library collections.

We will also search the National libraries in Australia, United Kingdom, New Zealand and the USA.

The World Wide Web

Advanced search options and specific strategies will be used to scan the Internet. A preliminary search was performed using the search engines listed below with some success. Terms used were 'health information development consumer participation'. This retrieved 'community participation'.

Search engine	
Google	www.google.com.au
Alta Vista	www.altavista.com
Excite	www.excite.com
HotBot	www.hotbot.com
Ask Jeeves (from Hotbot)	www.hotbot.com
Lycos	www.lycos.com
Yahoo	www.yahoo.com

We will explore the use of metasearch services such as MetaCrawler (www.metacrawler.com) and Dogpile (www.dogpile.com).

Citation Searching

We will commence citation searching by identifying key references currently in our library collections. We will also search for citations during our subject searching. We will look for older references by scanning bibliographies and recent references by searching SciSearch/Science Citation Index; ScienceDirect and Google Scholar.

Searching for 'Grey' literature

We will consult with culturally and linguistically diverse and Aboriginal and Torres Strait Islander groups for unpublished and hard to find literature. We have also included relevant questions in the consultation strategy. For example, whether the person being interviewed is aware of any literature, or source of information, or person we should contact, to help us identify *harder to find* literature.

Search Filters

The following sources of evidence based literature will be explored –

NHS Centre for Reviews and Dissemination
http://www.york.ac.uk/inst/crd/search.htm

Centre for Evidence Based Medicine, Oxford
http://cebm.jr2.ox.ac.uk/docs/searching.html

Insitute for Health Science Library, Oxford
http://wwwlib.jr2.ox.ac.uk/caspfew/filters/

PubMed Clinical Queries using research methodology filters
http://www.ncbi.nlm.nih.gov:80/entrez/query/static/clinical.html

New Zealand Health Technology Assessment Clearing House
http://nzhta.chmeds.ac.nz/nzhtainfo/protocol.htm

Cochrane Library (we will follow links to Cochrane databases)
http://www.latrobe.edu.au/cochrane/

Electronic databases with a health focus

The main online databases were searched and scanned for threads to other databases.

Medline
http://www.nlm.nih.gov/entrez/query.fcgi

Ovid
http://www.ovid.com

Sources to be used to identify full text journals on the Internet included:

- http://www.blackwell-synergy.com/Journals/journallist.asp
- http://www.medwebplus.com/cgi/mwp/mwpsearch
- http://clinical.uthscsa.edu/jnls.htm#primary
- http://www.blacksci.co.uk/PRODUCTS/JOURNALS/JNLTITLE.HTM
- http://pubs.ama.assn.org/
- http://www.blacksci.co.uk.online/
- http://www.munksgaarddirect.dk/usr/munksgaard/tidsskrifter.nsf/Alfanetisk?OpenView
- http://www.elsevier.co.jp/homepage/browse.htt
- http://www.scielo.br

Sources used to identify print journals not available on the Internet were:

Australian Journals Online
http://www.nla.gov.au/ajol/

Once journal titles were identified they were checked as to where they were indexed making sure that all titles considered relevant were indexed in databases being searched.

Documenting the search process

Electronic database searches

A copy of the search strategy for each database used was retained.
For example: MEDLINE on Ovid, searched January 1999, period 1990 to date.

Journal hand searches

A list of journal titles (where these are not available on the Internet) in alphabetical order including details of dates covered was retained. For example, Health Issues 1980 to date.

Conference proceedings

The format will be:
Health Promotion. 5th Flinders University National Conference on Health Promoting Services; 1994 Jul 25-28; Adelaide.

Proceedings published as part of a journal will be cited as:
Health promoting services; 1990, Sep 9, Adelaide, South Australia
(Health Issues. 1991 Supplement; 40).

Current awareness services

Example: Current Contents – Clinical Medicine, 1990 to date.

Unpublished literature

We maintained details about the database where information was identified plus contacts for information about unpublished studies.

Example:
Current Controlled Trials database. http://wwwcontrolled-trials.com/ searched 14/09/2000.

Other sources

We maintained a brief summary of other sources searched including Internet websites giving:

- Details of date searched
- Search terms used
- The URL

Specific features of the resources which might impact on the search such as 'only the titles were searchable' or 'sets could not be combined'.

Example:
Participate in Health website
http://www.participateinhealth.org.au
Searched 6/01/05 using the search terms 'health information provision'.

Appendix 2 What are performance indicators?

Why?

There is an old saying: 'If you can't measure it, you can't manage it'. A quick Google search offers some variants on this: 'If you can't measure it, it didn't happen', or, 'If you can't measure it, it's just your opinion!' In an area of joint endeavour where change is being sought or introduced, it is a useful maxim. Using the same measures gives all parties a common language and the same insights into progress.

How will we know over time whether a health service is introducing meaningful consumer, carer and community participation? How do we know if this is focused on a few areas within the service where staff are keen or part of their overall approach? Or whether it is creating the necessary changes to ensure it is effective and sustainable? Or when many organisations are all using it as an approach to improve service quality and how effectively services are using participation?

What are they?

There is a range of formal definitions of performance indicators, for example:

> *… a statistic or other unit of information which reflects, directly or indirectly, the extent to which an anticipated outcome is achieved or the quality of the process leading to that outcome (National Health Perfoemance Committee, 2002).*

Performance indicators are meant to be litmus tests of desired change. They are measures of activity that reflect meaningful progress against the goals that services have set themselves. For example, if a goal is to ensure optimal feedback from patients, a useful measure might be how many patient surveys or informal feedback meetings the service undertook.

At another level, we might want to measure how well the whole system is doing. That is, to what extent are we achieving the system goals, or at least putting the stepping-stones in place to get there?

Further, performance indicators are used to respond to three tasks:

- to measure progress towards a defined target (quality and safety improvement)
- to offer a point for comparison to previous performance (accreditation)
- to evaluate, assess or judge (evaluation).

In Australia, performance indicators are most commonly used for improving services and policy development as well as for accountability (Primary Health Care Research and Information Service, 2004). The use of indicators in Victorian health services in the next five years will be predominantly focused on:

- fostering the introduction of and improvement in effective consumer, carer and community participation approaches
- services learning from each other
- working to improve care.

Hence the quality focus seems an appropriate paradigm on which to develop consumer participation indicators.

How should we collect indicator information?

A system of routine data collection, preferably not onerous, which enables simple indicators to be determined and reported should be established. Purpose though will shape the choice of indicators.

How is it different from evaluation?

Evaluation is generally used to assess projects or programs against specific goals, and tends to be used in a strategic manner, rather than be systematically or routinely applied. It gives more rigorous and in-depth analyses of a programs' effect than reporting against what are generally relatively simple indicators. Evaluation is an essential tool in assessing how well new initiatives are being implemented, and in creating useful evidence to assess the impacts and outcomes once being implemented properly. However, continual and routine evaluations of activity on all fronts are impractical – it is expensive and time consuming. Indicators provide a way of monitoring key functions.

Choosing indicators – the value of frameworks

The package of indicators needs to be both broad and detailed enough to assist (and not confuse) decision making, but not create an unmanageable data collection and analysis process.

This implies selecting indicators for strategic reasons: which indicators mean the most and tell us the most? This is where a framework comes in useful. A framework should list the most important parts of a system (according to our values, policies and experience) and show how they are related. This can then guide where indicators are developed. In the case of consumer, carer and community participation, we know from the literature and experience that all change requires senior support, organisational policies and training of staff, consumers, carers and community members. These elements should appear in the framework, along with actual participatory activity at various levels.

Indicators are not a panacea, however, they must be founded on logical, reliable and valid data.

Appendix 3 Common measurement issues

There is a range of issues commonly identified in the literature about performance indicators. These include: reliability, validity, comparability and internal versus external use.

Relevance: the measure should address features of the health care system of importance to health professionals, policy makers and/or consumers, carers and the community.

Reliability or reproducibility: the measure should produce the same results when repeated in the same population setting.

Feasibility: the measure should make sense (face validity); correlate well with other measures of the same aspects of care (construct validity); and capture meaningful aspects of care (content validity) (Hurtado et al., 2001).

Possible negative effects and risks

A recent literature review showed the following list of risks of using performance indicators.

Risk	Description
Goal displacement	Diversion from what is important to what is measurable
Inappropriate use of comparisons	Undermines collaboration, staff moral and recruitment
Unintended changes in service provider behaviour	Manipulating data and avoiding hard cases to make data more positive
Impact on decision	Little evaluation of performance indicators to improve decision making
Focus on short term outcomes	Underestimating how long it takes to achieve significant improvements in outcomes
Resource and data issues	Poor data quality as a barrier to implement performance measurements

Source: (Jolley, 2003)

Indicators are clearly value based and reflect the dominant management styles and professional cultures within the organisation. However, the introduction of performance indicators may well produce changes in that culture. Some dysfunctional effect may result from applying performance indicators inappropriately, for example, creating fear instead of fostering quality improvement. When used to make judgements, they may be self-defeating, reduce morale and cause the failure of other quality enhancing activities that are not part of the performance management strategy (Sheldon, 1998).

This is of particular relevance to creating a framework for consumer, carer and community participation performance indicators. The timing of and process for the introduction of such a management strategy involving a new set of indicators will need to be considered carefully, in order to minimise their negative impact on activities and initiatives already in place.

The literature recommends exercising caution in using performance indicators. A review of performance indicators in Australian acute health services suggested that existing quality and outcome indicators are imperfect and that they will improve only through their application (Jolley, 2003). The international experience has shown that measuring and improving performance should be integrated or coordinated with other strategies of the service that try to promote quality.

Further, acting on the data from performance measurement requires skills in analysis and experienced people to work with staff to take action to improve performance. It has been suggested that there is a strong link between whether an indicator is believed to identify opportunities for improvement and whether an action is going to take place or be planned. An organisation is more likely to value indicators when it is committed to quality improvement and has the necessary resources and strategies to implement and disseminate the information throughout the organisation (Turpin et al., 1998). This suggests that services will need to complement the use of indicators with other signals that participation is important, and anticipate increased demand on the in-house resources to support greater and more sophisticated levels of participation. There are also a number of implementation issues including feasibility and data collection issues that services need to address.

Services need to be aware of all of the above in introducing participation indicators. Further, each service will have its own culture and systems, and be at a different level of progress in implementing participation into its overall approach. It is also clear the more the introduction of participation indicators can be integrated within existing systems, the easier it will be to undertake successfully.

Appendix 4 Existing requirements for public health services

Health service organisational level

Health Services Act 1988 (Vic)

S 9 *The objectives of this Act are to make provision to ensure that*

(e) users of health services are provided with sufficient information in appropriate forms and languages to make informed decisions about health care.

(g) the users of health services are able to choose the type of health care most appropriate to their needs.

EQuIP Standard 2.4

the governing body is committed to consumer participation as a strategy to assist the improvement of quality and safe care and service.

Health Services Act -

S 65s *the functions of the board of the Public Health Service are to establish and maintain effective systems to ensure that the health services provided meet the needs of the communities served by the public health service and that the views of users and providers of health services are taken into account.*

S 65XB *In performing his or her functions the chief executive officer must have regard to (a) the needs and views of patients and other users of the health services…*

S 65za *The board of a public health service (a) must appoint at least one community advisory committee.*

Department guidelines on community participation plan (draft)

As a minimum guide the objectives of the Community Participation Plan should address the following areas:

- *The public health service has identified and assessed its strengths and limitations in consumer, carer and community participation, and how it plans to address the limitations.*
- *How participation will be used to improve service planning and development to meet the needs of your service's community.*
- *How service delivery to identifiably hard to engage communities will be enhanced through participation.*
- *How participation will be used to improve the safety and quality of treatment and care provided by your health service.*

Departmental guidelines on quality of care reports

In summary the minimum requirements are to:

- identify two 'core business' areas each year and provide in-depth discussion and analysis of quality approaches used

- describe progress on a number of mandatory areas since last report (for example: surgical postponements, clinical governance frameworks)
- report on key safety and quality indicators
- discuss continuity of care issues.

Ward/program/department level

EQuIP Standard 1.2

- *A comprehensive assessment by professionals identifies the clinical, non-clinical and social needs of consumers/patients as the basis for providing quality and safe care.*

EQuIP Standard 1.3

- *Consumer/patient needs for quality and safe care with desirable outcomes are addressed through the planning, delivery and evaluation of care.*

EQuIP Standard 4.1

- *Valid information sources support decision making and the identification of consumer/patient care outcomes.*

Departmental guidelines on Community Participation Plan (draft)

As a minimum guide the objectives of the community participation plan should address the following areas:

- *How the service will provide education and training to facilitate staff support of participation.*

Individual level

EQuIP Standard 1.1

- *Consumers/patients have access to health care appropriate to their needs.*

EQuIP Standard 1.4

- *consumer/patient and carer needs for ongoing care are addressed through the coordination of services and the provision of timely and useful information.*

Departmental Guidelines for Community Participation Plan

As a minimum guide the objectives of the Community Participation Plan should address the following areas:

- *Where enhancement of care can be facilitated through involving people in decision-making about their own care and treatment.*

Appendix 5 Review of quality improvement frameworks

Victorian Quality Council

The quality improvement framework developed by the Victorian Quality Council – *Better Quality, Better Health Care* – has five key strategic areas. One of these is 'increasing the involvement of consumers in improving safety and quality of health care in Victoria' (Victorian Quality Council, 2003).

It states that 'consumer participation should be facilitated at all levels of the organisation', and is included in each one of the dimensions of quality: safety, effectiveness, appropriateness, acceptability, access and efficiency. Although no 'indicators' as such are named, a consumer and community involvement checklist is provided as outlined below.

Victorian Quality Council: Checklist on consumer and community involvement in quality activities

	Processes established and working effectively	**Processes in place but need enhancement**	**Processes under development**	**No processes in place for this element**
a. consumer and community participation in improving safety and quality is an accepted part of the organisation's functioning	☐	☐	☐	☐
b. consumer and community feedback is regularly sought and is integrated into improvement activities	☐	☐	☐	☐
c. complaints are managed respectfully and effectively and the information fed into systems improvements	☐	☐	☐	☐
d. protocols are in place to enable consumers to participate in their care	☐	☐	☐	☐
e. consumers are made aware of the process for participating in their care	☐	☐	☐	☐
f. sufficient information and opportunity are provided for consumers to participate meaningfully in their care	☐	☐	☐	☐
g. health service staff are aware of, and trained in, protocols and procedures for enabling consumer participation in their care, including effective communication	☐	☐	☐	☐
h. consumers and community members are involved in consumer information development	☐	☐	☐	☐
i. consumers are invited to relate their health service experiences as part of the safety and quality improvement program	☐	☐	☐	☐
j. consumers and community members are invited to review and improve current services and assist in planning new ones	☐	☐	☐	☐

Australian Council on Healthcare Standards

The Australian Council on Healthcare Standards launched its fourth edition of the Evaluation and Quality Program (commonly known as EQuIP) in 2005. This edition includes the principle that consumers' needs and the need to obtain feedback from consumers to evaluate services be recognised. They also highlight the need for regular and transparent communication, knowledge and information to be available for consumers (Australian Council on Healthcare Standards, 2005).

The third standard in this edition is the 'Continuum of Care Function' and it promotes a consultative and collaborative approach to care that involves the consumer/patient and carer. This links with the 'Leadership and Management Function' standard which requires that 'the governing body is committed to consumer participation as a strategy to assist the improvement of quality, safe care and service' (Australian Council on Healthcare Standards, 2005).

The current participation standard in EQuIP is number 2.4. This is in the process of being reviewed by ACHS, and the Department of Human Services appreciates ACHS allowing it to reproduce the draft (as at 21 July 2005), below. Services will have access to the current version, but the new one gives a better indication of increasing levels of expectation in the sector, and is in line with the principles underlying this paper. The new standard is not yet finalised, and upon completion it is expected to be renamed EQuIP 1.2.

Draft new standard 1.2 The governing body is committed to consumer participation (equivalent to 2.4 in 2005 version)

Criteria	LA	SA	MA	EA	OA
1.2.1 *Input is sought from consumers, carers and the community* in planning, delivery and evaluation of the health service.	a. Management is committed to consumer participation. b. The organisation has a policy that promotes consumer participation. c. The organisation works with relevant consumers and consumer groups. d. Consumers are aware of the organisation's code of conduct.	a. Consumers are consulted about how they would like to participate and partnerships are then established between consumer/carer/community groups and the organisation. b. The organisation implements training programs for consumers. c. Data are collected on consumer/patient/carer participation in care. d. Consumers are involved in policy development and health services planning. e. There are mechanisms for involving consumers in an appropriate way within the organisation. f. Written guidelines on consumer participation are developed in partnership with consumers. g. Consumers sign confidentiality agreements when appointed to committees, and as appropriate.	a. Consumers are involved in the evaluation of care and service. b. Data on consumer participation are evaluated and improvements are made, as required. c. Consumers are involved in the evaluation of their participation. d. Consumers are involved to ensure issues are acted upon and improvements are made. e. Feedback is provided on consumer participation to the community and the organisation.	a. Consumers participate in the development and evaluation of models of care and the development of new models of care. (MA) b. Consumer participation is compared with other organisations and improvements are made, to ensure better practice. c. There is incentive for consumer participation. d. Staff are trained in how to implement and evaluate consumer participation strategies.	a. The organisation demonstrates leadership and innovation in involving consumers in the planning, delivery and evaluation of health services. b. Effective participation projects/models/services are identified as industry best practice.

Quality Improvement Council

The Australian Health and Community Services Standards: Health and Community Services Standards Core Module covers infrastructure and the relationship with services' communities of interest. It has two sections related to the relationship with the community served and the need for a consumer-focussed culture and most sections have a 'consumer principle'. For example, the section on planning, quality improvement and evaluation has a consumer principle that states: 'consumers have opportunities to contribute to service planning, identifying priorities, quality improvement and evaluation to ensure services and programs are appropriate, of high quality and effective'. The 'consumer principle' on consumer and community participation states that 'consumer and the community of interest are actively involved in debate and decisions about issues that affect their wellbeing' (Quality Improvement Council, 2004).

Victorian standards for disability services

The Department of Human Service's Disability Services, *Victorian Standards for Disability Services, Self-Assessment System User's Guide* (2003) is a guide for services to complete self-assessments based on the *Victorian Standards for Disability Services* (1997). The self-assessment package contains three parts: consumer assessment, service delivery self-assessment and management self-assessment. In all three parts there are elements of consumer participation (Department of Human Services–Disability Services, 1999). The consumer assessment part is designed to gain consumer feedback about the quality of the service. In addition, consumers, advocates, family members, volunteers and interested members of the community are members of a quality team established to conduct the assessment.

Victorian mental health consumer and carer surveys

There is considerable consumer participation within the Victorian mental health system, including the employment of consumer advocates. A further example is that Victoria has led the way nationally in the development of statewide consumer & carer satisfaction and experience surveys in mental health services. The survey questions reflect consumer and carer identified priorities, needs and expectations of services, and are linked to the National Standards for Mental Health Services. The aim being to provide specific guidance for quality improvement and meaningful benchmarks for consumers, carers and service providers (Department of Human Services). Similarly, under the second National Mental Health Plan 1998-2003, the Department of Human Services received funding to further develop consumer and carer evaluation of Psychiatric Disability Rehabilitation and Support Services (PDRSS).

National standards for mental health services

The National Standards for Mental Health Services states in standard three that 'consumers and carer are involved in the planning, implementation and evaluation of the MHS [Mental Health Services]'. This standard is now being monitored at the Victorian state level and reported back to health services. They also include a discussion about outcome measurement and the importance of consumers being able to provide a self-rating on outcome (Commonwealth of Australia Mental Health Branch, 1996). This can be found at http://www.health.vic.gov.au/mentalhealth/outcomes/about.htm.

New South Wales Health

The NSWHealth framework for managing quality of care includes six dimensions: safety, effectiveness, appropriateness, consumer participation, efficiency and access. The principles assume that consumers have the right to participate in health care delivery and their input should have considerable benefits. It suggests that opportunities should be provided for consumers 'to participate collaboratively with health organisations and service providers in health service planning, delivery, monitoring and evaluation at all levels in a dynamic and responsive way. Consumer participation should enhance the level of acceptability of services which describes the degree to which a service meets or exceeds the expectations of informed consumers' (New South Wales Health, 1999).

Primary health care

The *Framework For Performance Assessment In Primary Health Care* has four components or levels:

- stewardship
- organisational structures and processes
- processes of care
- intermediate outcomes (Sibthorpe, 2004).

Appendix 6 Factors within the participation monitoring framework

KEY: EB = enabler and barrier (both identified in Consultation paper, based on literature search), SAT – National Resource Centre in Consumer Participation in Health Self-Assessment tool, CPP = Community participation Plan guidelines, V = Victorian Quality Council's Checklist

Table 6 Factors within the participation monitoring framework

Individual care	**Key factors to be addressed**	**Source**
Domain		
Provision of condition-specific information	• Provision of socially sensitive; culturally, age and disability appropriate information	E, V
	• Consumers made aware of process for participating in their care and treatment	
	• Consumers and where appropriate carers supported to understand and encouraged to question staff about their care and treatment	E
Shared decision-making or other involvement in care	• Enhancement of care facilitated through involving people in decision-making about their own care and treatment	CPP, V
	• Shared decision-making or other involvement in care allows for the possible deterioration of the consumers' health and consequent changes to the carers' role	B
Consumer-focused care	• As above	SAT
Ward/program/department	**Key factors to be addressed**	**Source**
Domain		
Participation in service delivery and planning	• Strategies not chosen in isolation from consumers, carers and the community	EB
	• Consumers, carers and the community involved as early as possible	
	• Support provided for participation resources	
	• Consumers, and where appropriate carers, invited to relate their experiences as part of the safety and quality program	V
	• Participatory process and support offered allows for the possible deterioration of the consumers' health and consequent changes to the carers' role	EB
Monitoring, evaluation and public reporting	• Consumer, carer and community feedback regularly sought	EB, V
	• Feedback findings to participants	EB
Organisational	**Key factors to be addressed**	**Source**
Domain		
Organisational commitment	• Support from top of organisation is clearly communicated and organisation willing to change where necessary	EB
	• Identification and assessment of organisation's strengths and limitations in consumer, carer and community participation, and plans to address the limitations	CPP
	• Policies and structures on how participation can be achieved are developed and promoted:	EB
	• how participation will be used to improve service planning and development to meet the needs of community, and the safety and quality of care	CPP
	• clarifying roles and lines of accountability	EB
	• involving of consumers as early as possible in processes and where appropriate carers	
	• supporting consumers and where appropriate carers to be involved	

Table 6 Factors within the participation monitoring framework (continued)

Organisational (continued)	Key factors to be addressed	Source
Domain		
	• Sufficient resources are allocated for range of strategies and supports to meet participation aims	EB
	• Understanding of service's community, carers and consumers and their needs	SAT
Staff capacity	• Training and information provided to build staff skills in facilitating participation	EB, CPP, V
	• Staff work together to create trust and mutual understanding re participation	EB
Participation in decision making structures at organisational level	• Issues to be tackled and strategies not chosen in isolation from consumers, carers and the community	EB, V
	• Consumers, carers and the community invited to review and improve current services and assist in planning new ones	
	• Plans on how service delivery to identifiably hard to engage communities will be enhanced through participation	CPP
Capacity of consumer, carers and community members involved	• Provided with information re organisational commitment to participation, and training about health system, organisation, and language (medical and organisational terms) used	EB, V
	• Support and resources provided for consumer to participate	B
	• Participatory process and support offered allows for the possible deterioration of the consumers' health and consequent changes to the carers' role	
Monitoring, evaluation and public reporting	• Staff trained in evaluation and dissemination	EB
	• Organisational mechanisms established to disseminate lessons to staff so they can incorporate into future work	
	• Feedback findings to participants	

Appendix 7

Table 7 Analysis of reporting requirements and indicators against the participation monitoring framework*

Note some clauses are repeated where applicable to more than one domain of the framework

Proposed framework	Current reporting requirement		How this might be demonstrated
Individual level domains	**Where required**	**Current potential participation indicators**	
Provision of condition-specific information, evidence based where possible	Health Services Act 1988 S9 (e)	• Users of health services are provided with sufficient information in appropriate forms and languages to make informed decisions about health care.	• Quality of care report. • Victorian Patient Satisfaction Monitor index.
	EQuIP 1.4	• Consumer/patient and carer needs for ongoing care are addressed through the coordination of services and the provision of timely and useful information.	
Shared decision making or other involvement in care	Health Services Act 1988 S9 (g)	• The users of health services are able to choose the type of health care most appropriate to their needs.	• Victorian Patient Satisfaction Monitor index. • Quality of care report.
	Community participation plan*	• Where enhancement of care can be facilitated through involving people in decision-making about their own care and treatment.	
	EQuIP 2.4	• Consumers are informed of their rights and responsibilities, the consent process and complaints mechanisms.	• EQuiP 2.4.2 met at MA (Moderate Achievement require collection of relevant outcome data, monitoring, evaluation and improvements of systems and outcomes resulting in developed systems being in place).
Consumer-focused care	See above	• See above	• Comparison of per cent of people who receive assistance from interpreters against per cent assessed as requiring it as for example reported in maternity service indicators.
Ward/Department/ Program level domains	**Where required**	**Current potential participation indicators**	
Participation in service delivery and planning	EQuIP 1.3	• Consumer/patient needs for quality and safe care with desirable outcomes are addressed through the planning, delivery and evaluation of care.	• At organisational level each year, consumers involved in a range of service improvement projects (at program/unit level), and in range of capacities.
	EQuIP 4.1	• Valid information sources support decision making and the identification of consumer/patient care outcomes.	
Monitoring, evaluation and public reporting	EQuIP 1.3	• Consumer/patient needs for quality and safe care with desirable outcomes are addressed through the planning, delivery and evaluation of care.	• At organisational level, number of evaluations (at ward level) where consumers involved, and in what capacity.

Proposed framework	Current reporting requirement		How this might be demonstrated
Organisational level domains	**Where required**	**Current potential participation indicators**	
Organisational commitment	EQuIP 2.4	• The governing body is committed to consumer participation.	• Board and management policies. • Commitment promoted to staff, for example via guidelines, memos, newsletters. • Significant relationships or partnerships with key consumer, carer and community organisations.
	Quality of Care reports guidelines and minimum reporting requirements	• 'Health services are required to report on those key consumer care areas that reflect the health and care needs of their community and the consumer population they serve.'	• By meeting the presentation, distribution and minimum reporting requirements as outlined in the guidelines.
	Community participation plan*	• The public health service has identified and assessed its strengths and limitations in consumer, carer and community participation, and how it plans to address the limitations.	• Developed plan and reported against it annually.
Staff capacity	Community participation plan*	• How the service is providing education and training to facilitate staff support of participation.	• Per cent of targeted staff that have been trained in facilitating participation.
Participation in decision-making structures at organisational level	Health Services Act 1988 S65 (c)	• 'the functions of the board ... are .... to ensure that the health services provided meet the needs of the communities served by the public health service and that the views of users and providers of health services are taken into account'.	• Needs assessment undertaken to ascertain needs (about care and safety and quality) of communities served.
	Health Services Act 1988 S65 (xb)	• 'In performing his or her functions the chief executive officer must have regard to (a) the needs and views of patients and other users of the health services ...'.	• Description of how views of consumers, carers and community are taken into account in annual report and quality of care report.
	EQuIP 1.3	• Consumer/patient needs for quality and safe care with desirable outcomes are addressed through the planning, delivery and evaluation of care.	• EQuIP 1.3 met with consumer participation.

Proposed framework	Current reporting requirement		How this might be demonstrated
Organisational level domains (continued)	**Where required**	**Current potential participation indicators**	
	Community participation plan*	• How participation will be used to improve service planning and development to meet the needs of your service's community. • How participation will be used to improve the safety and quality of treatment and care provided by your health service. • How service delivery to identifiably hard-to-engage communities will be enhanced through participation	• Community Participation Plan produced and reported against annually, especially levels of participation.
	Health Services Act 1988 S 65 (za) *	• The board of a public health service (a) must appoint at least one community advisory committee.	
Capacity of consumer, carers and community members involved	Community participation plan (see above)*	• 'The public health service has identified and assessed its strengths and limitations in consumer, carer and community participation, and how it plans to address the limitations'.	• Developed plan and reported against it annually, in particular in addressing consumer capacity issues identified.
Monitoring, evaluation and public reporting of consumer participation	EQuIP 1.3	• 'Consumer/patient needs for quality and safe care with desirable outcomes are addressed through the planning, delivery and evaluation of care'.	• Standard met with consumer participation in such evaluation.
	EQuIP 4.1	• Valid information sources support decision making and the identification of consumer/patient care outcomes.	• Standard met with consumer participation in such evaluation. • Description of how consumer outcomes measured and reported.
	Quality of Care Report	• 'Identifies a distribution strategy to the community and a means of evaluating effectiveness of the strategy'.	• Report produced and distributed to community. • Report on evaluation of distribution strategy in following years report.

* Community participation plan guidelines only apply to those services under legislation that are required to establish a community advisory committee as listed under the *Health Services Act 1988,* Section 239.

Several of the reporting requirements/indicators are relevant to several elements of the framework, but would of course only need to be reported once.

Appendix 8

Table 8 Limitations of minimum indicator set

Chosen indicator (from Table 3)	Rationale for selection	Limitations
1.1 Health service meets ACHS EQuIP standard 'The governing body is committed to consumer participation' (currently Standard 2.4) or its equivalent, to the level of 'MA' (Moderate Achievement).	This is a quality improvement indicator matching the preferred approach to use of indicators. The current EQuIP standard 2.4 includes many desirable elements of effective consumer participation as described in the proposed framework in Table 2, and the proposed new version to be introduced in January 2007 is even more useful (Appendix 5). Most health services use EQuIP and hence have existing data collection processes.	Not all services use EQuIP. The Quality Improvement Council's indicators are framed slightly differently. Accreditation is carried out every four years with a mid-review at two years. Hence data will not be available every year.
1.2 There are consumers, carers, or community members on key governance and clinical governance structures.	The *Health Services Act 1988* requires a board to ensure views of users are taken into account. The community participation plan guidelines require services to identify how participation is going to improve both service planning and safety and quality. Most - if not all - research ethics committees already have consumer members.	Services that do not have to produce a community participation plan may not have reporting mechanisms to capture this data (although this would be simple to implement).
1.3 A Community advisory committee has been established in accordance with the *Health Services Act 1988* Section 239.	These committees are required under the *Health Services Act 1988* and thus the health services are accountable to put this participation structure in place. The committee's activities have to be reported on under Part 7 of the *Financial Management Act 1994*.	Not all health services are required to have a community advisory committee.
1.4 A Community advisory committee has been established in accordance with the non-statutory guidelines.	One of their primary roles is to ensure greater community participation in strategic thinking and decision making within the health services. Another key role is to advocate to the board on behalf of the community.	Varying amounts of support are provided to the committees, depending on the implementation of the committee at each health service.
2.1 The quality of care report outlines quality and safety performance and systems in the key consumer care areas that address the health and care needs of the service's communities and consumer population.	All services produce a quality of care report, and the current guidelines and minimum reporting requirements include key elements identified in the framework. For example, continuity of care needs to demonstrate how services respond to the needs of consumers and carers and all services have to report on progress on clinical governance.	These are not independent reports, but produced by the services themselves. However, services are required to involve their community in its development.

Chosen indicator (from Table 3)	Rationale for selection	Limitations
2.2 A community participation plan has been developed and is being reported against annually to the Department of Human Services.	As a minimum the objectives of each plan must report on: • The public health service has identified and assessed its strengths and limitations in consumer, carer and community participation, and how it plans to address the limitations. • How the service will provide education and training to facilitate staff support of participation. • How participation will be used to improve service planning and development to meet the needs of your service's community. • How service delivery to identifiably hard to engage communities will be enhanced through participation. • Where enhancement of care can be facilitated through involving people in decision-making about their own care and treatment. • How participation will be used to improve the safety and quality of treatment and care provided by your health service (Department of Human Services, 2005).	Only those services required under legislation to have a community advisory committee have to develop a plan and report on progress towards the plan.
3.1 Consumers participate in decision making about their care and treatment as assessed on the Victorian Patient Satisfaction Monitor's consumer participation sub-index.	This sub-index is based on the experience of the consumer in input into decision making about their care and treatment. It links directly back to the individual level and the key domain of activity 'Shared decision making in care' in the framework.	Not all consumers of health care services complete the monitor.
3.2 Appropriate information is available to enable all consumers, and carers where appropriate, to choose to share in decision making about their care.	The Health Services Act 1988 requires users to be 'provided with sufficient information in appropriate forms and languages to make informed decisions about health care'. Several items in EQuIP also require such information provision. The easiest way to assess whether the service has addressed this issue is to look at the policies and guidelines in place. It also has a quality improvement emphasis.	Having policies in place does not automatically mean that they are implemented effectively.

Definitions

In order to be consistent with the department participation policy being developed, the definitions in the Consultation paper have primarily been adopted.

Consumers are defined as people who are current or potential users of health services. This includes children, young people, women and men, people from diverse cultural backgrounds and experiences, class positions and social circumstances, (dis)abilities, sexual orientations, and health and illness conditions.

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

Communities are defined as groups of citizens who have interests in the development of an accessible, effective and efficient health service that best meets their needs.

Consumer, carer and community participation encourages consideration and debate through processes that allow people to be involved in decision-making about their health care and that of the community. It necessitates the communication of your view, scrutiny of motive and an ability to listen and appreciate other's views and ideas. Through involvement decisions are made that may accommodate a range of perspectives.

Note that here the term 'participation' is used to encompass consumer, carer and community participation unless otherwise specified.

Health service means a publicly funded organisation providing health care. This includes hospitals, rehabilitation centres, aged care services, community health centres and primary care services.

Performance measurement is a strategy that enables an organisation to systematically assess progress against defined goals and objectives. It measures how well current strategies, plans and processes are working and provides information to aid decision making and shape future action.

Performance indicator is variously defined. One common definition is:

> *… a statistic or other unit of information which reflects, directly or indirectly, the extent to which an anticipated outcome is achieved or the quality of the process leading to that outcome* (National Health Performance Committee, 2002).

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Participation indicators

Participation in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services

State Government
Victoria

Department of
Human Services