



RECOMMENDED SUITE OF CONSUMER, CARER AND
COMMUNITY PARTICIPATION STANDARDS FOR
VICTORIAN PUBLIC HEALTH SERVICES

FINAL REPORT

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The Project Reference Group is a subcommittee of the Department of Human Services (DHS) Participation Advisory Committee, advising on the implementation of the policy *Doing with us not for us*.

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In 2005, as part of the development of the *Doing it with us not for us* consumer, carer and community participation policy in the health service system, research was undertaken to inform the development of a minimum set of participation performance indicators (Department of Human Services [DHS], 2006a). This research, undertaken by Health Issues Centre on behalf of the Department of Human Services, recommended a minimum set of consumer, carer and community participation performance indicators, which were later adopted into the policy with some modification (DHS, 2006b). The minimum set of participation indicators were constrained by two key factors. First, they related to the acute and subacute health service sectors/areas only and did not include mental health, aged care, and community health care. Second, they concentrated on processes not outputs or outcomes.

To address these limitations DHS contracted Health Issues Centre to develop, with stakeholders, a comprehensive suite of standards and indicators that accommodate a range of measurement tools and reporting mechanisms. This document presents the resulting suite of recommended consumer, carer and community participation standards and associated indicators. A number of sub-measures are included to guide health services in achieving the relevant standard. Health Issues Centre developed this suite of standards in collaboration with the project Reference Group. The Reference Group is a subcommittee of the DHS Participation Advisory Committee formed to provide advice on implementing the *Doing it with us not for us* policy. The Statewide Quality Branch of the department funded the project.

This comprehensive suite of consumer, carer and community participation standards for Victorian public health services is recommended to DHS for implementation as part of the strategic direction of *Doing it with us not for us* for 2010–2013.

DEVELOPMENT PROCESS

The project included a literature search, the mapping of existing indicators and standards, and a Consensus Workshop. The workshop involved consumers, carers and community members and staff from mental health, aged care, acute and subacute, community health, and child and adolescent health.

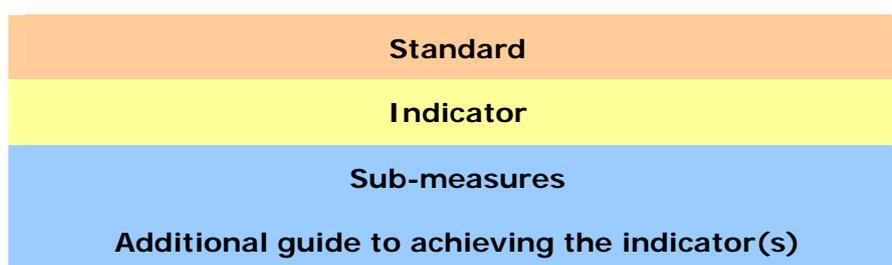
The recommended standards are a synthesis of:

- ▶ Current performance indicators/standards already in use in one or more areas of the Australian health system
- ▶ Best practice as revealed through the literature
- ▶ Agreement reached at the Consensus Workshop
- ▶ Analysis undertaken by the project Reference Group and Health Issues Centre.

The detailed report of findings from the mapping of relevant consumer, carer and community participation standards/indicators and key literature about standards/indicators is found in the accompanying document, *Findings from literature search and mapping exercise*.

Twenty-one (21) draft standards/indicators emerged from the mapping exercise and literature search undertaken by Health Issues Centre at the beginning of the project. These standards/indicators were presented at the Consensus Workshop. Through a participatory methodology consisting of a number of voting and small group discussions, participants at the Consensus Workshop provided feedback on the suite of draft standards/indicators. The Reference Group at the workshop then processed this information and a suite of nine revised standards/indicators was presented for participants' final vote at the end of the day.

In collaboration with the Reference Group, the standards/indicators that gained most votes (50 to 46 votes of a total of 56 participants) were then analysed and integrated further to arrive at the recommended suite of five standards with associated indicators and measures. The standards have been structured to include a pool of measures comprising:



Note the standards, indicators and sub-measures emerged from existing indicators/standards, the literature and work produced by the Reference Group. The sources of information for each standard and indicator and sub-measure are included in the tables below as a list of references.

Indicators in the tables below are applicable across all health areas unless otherwise specified. Some indicators are based on responses to consumer satisfaction or experience surveys, such as the Victorian Patient Satisfaction Monitor (VPSM), the (former) Primary Health Care Consumer Opinion Survey (PHCCOS) and other surveys developed by health services. Where possible these surveys have been specified.

Target, terminology, data sources, reporting and recommendations for implementation have been included to facilitate implementation of the standards and their indicators across health areas. Reporting requirements were minimised. For example, DHS advises Community Participation Plans (CPP),¹ developed by scheduled public health services,² could include or be amalgamated with the service's Cultural Responsiveness Plan.³ In a non-scheduled health service, the equivalent plan or section of a health services' strategic or business plan should encapsulate the objectives of these plans.

The recommended suite aims to improve and extend participation performance. It builds upon consumer, carer and community participation standards/indicators that are legislated or are already requirements for health services in Victoria or at the federal level. For example, standards which state that services should have a complaints system, should inform consumers of their rights and responsibilities, should seek informed consent or should inform consumers when services change or are no longer available, are not included. This exclusion does not negate their importance but acknowledges systems are already in place to meet these requirements, avoids duplicate reporting and encourages services to extend participation beyond these existing core requirements.

¹ Department of Human Services. 2006f. *How to develop a community participation plan*. Rural and Regional Health and Aged Care Services Division. Melbourne. Viewed 9 June 2009 at <http://www.health.vic.gov.au/consumer/pubs/howto.htm>

² Five regional health services (Ballarat Health Services, Barwon Health, Bendigo Health Care Group, Goulburn Valley Health and Latrobe Regional Hospital) and 13 metropolitan health services (Austin Health, Bayside Health [Alfred Health], Eastern Health, Melbourne Health, Northern Health, Peninsula Health, Peter MacCallum Cancer Centre, Royal Children's Hospital, Royal Women's Hospital, Southern Health, Dental Health Services Victoria, Royal Victorian Eye and Ear Hospital and Western Health) plus St Vincent's Health, which choose to participate in this process.

³ Cultural Responsiveness Plans were preceded by Health Service Cultural Diversity Plans (DHS, 2006c)

SUMMARY OF STANDARDS

These are the five recommended standards for consumer, carer and community participation in Victorian public health services.

Note: Appendix 1 contains a list of the remaining standards (from the original 21 standards) that were presented at the Consensus Workshop. Each is annotated to describe how it has been integrated into the five standards below.

Standards for consumer, carer and community participation in Victorian public health services

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

In developing the standards and indicators, the following terms apply. This is to ensure consistency of meaning across the different areas of health provided within Victorian public health services.

Definitions

Standards are general statements against which organisations can audit their performance. The Australian Council on Healthcare Standards (ACHS) defines standards as “a statement of the level of performance to be achieved”.

Indicators are numerical measures, with a numerator and a denominator. They help an organisation to track its progress and may help it compare itself with other like organisations as a way of improving what it does.

Consumers are current or potential users of health services. This includes children, women and men, people living with a disability, people from diverse cultural and religious experiences, socioeconomic status and social circumstances, sexual orientations, and health and illness conditions (DHS, 2006:4).

Carers are families and friends providing unpaid care to consumers (DHS, 2006:4).

Communities are groups of people who have interests in the development of an accessible, effective and efficient health and aged care service that best meets their needs (DHS, 2006:4).

Participation occurs when consumers, carers and community members are meaningfully involved in decision-making about health policy and planning, care and treatment, and the wellbeing of themselves and the community. It is about having your say, thinking about why you believe in your views, and listening to the views and ideas of others. In working together, decisions may include a range of perspectives (DHS, 2006:4).

Diversity: the new set of recommended common standards presented here is underpinned by the overall principles about diversity upheld in *Doing it with us not for us*. That is, “consumers include children, women and men, people living with a disability, people from diverse cultural and religious experiences, socioeconomic status and social circumstances, sexual orientations, and health and illness conditions” (DHS 2006:4).

Victorian public health services: includes a hospital, health service (acute/subacute), community health service, mental health service and residential aged care service unless otherwise indicated.

STANDARD 1

The organisation demonstrates a commitment to consumer, carer and community participation appropriate to its diverse communities.

Rationale

Experience shows that consumer, carer and community participation will only be encouraged and facilitated by staff throughout a health service when there is sufficient organisational commitment to support them. This includes visible leadership, policies, processes, and concrete capacity building to enable participation to occur effectively and meaningfully. There is strong evidence from existing standards/indicators and the literature that such commitment by the organisation is a precondition for participation and that it engenders effective participation (see references below).

INDICATOR

Numerator: The number of specified actions implemented or in use

Denominator: The eight specified actions required

- 1.1 The organisation has a consumer, carer and community participation policy or adopts *Doing it with us not for us*.
- 1.2.1 The organisation has developed and is implementing a community participation plan, strategy or equivalent that addresses the five key areas of the DHS' *How to develop a community participation plan* guideline.
- OR**
- 1.2.2 The organisation contributes to development, implementation and monitoring of the Primary Care Partnership (PCP) Strategic Plan so that: a) the work of the partnerships reflects community needs, and b) consumers experience a better human services system.
- 1.3 The organisation uses a variety of approaches to record and report on consumer, carer and community participation to the wider community, including an annual Quality of Care Report.
- 1.4 The organisation has a Cultural Responsiveness Plan that meets the six minimum reporting requirements or its equivalent.⁴
- 1.5 The organisation has an Improving Care for Aboriginal and Torres Strait Islander Patients (ICAP) program, or its equivalent, and meets the four key result areas.⁵
- 1.6 The organisation has a Disability Action Plan as specified under the Disability Services Act.
- 1.7 The organisation has systems, processes and structures in place to *consult* and *involve* consumers, carers and community members.
- 1.8 The organisation builds the capacity of staff to support consumer, carer and community participation.

Target for all Victorian public health services: 75%

⁴ If no consumers self-identify as being from a CALD background or request an interpreter using a health service, the bundle of requirements may have to be modified for that service.

⁵ There are at least 15 small rural services that did not offer services to self-identified ATSI consumers in the 2007-08 period and the bundle of requirements may have to be modified for these services.

If all eight specified policies, systems and guidelines are applicable, implement a minimum of six.

OR if only seven specified policies, systems and guidelines are applicable (see footnotes 2 and 3), implement a minimum of five.

OR if only six specified policies, systems and guidelines are applicable, implement a minimum of four.

Terminology

Key terms as listed in 'Definition' box above.

Data sources:

Acute/subacute: Community Advisory Committees, VPSM, experience and satisfaction surveys.

Mental health: The elements of the measures such as priority actions from the *Caring Together – An action plan for carer involvement in Victorian public mental health services* (DHS 2006e) AND *Strengthening consumer participation in Victoria's public mental health services – Action Plan* (DHS 2009c) are incorporated in an overall consumer and carer participation plan. Consumer participation plans describe the nature and extent of consumer involvement in the delivery and evaluation of the plans.

Aged care: Public sector residential aged care services (PSRACS) resident and family satisfaction surveys.

Community Health:

Action 1.3: Results to questions 2.11 and 2.12 of Service Coordination Survey. These question numbers are relevant to the 2009 Survey. From time to time the Service Coordination Survey will be restructured, resulting in a different numeration. Up-to-date information on numeration of questions for use in this activity can be found at:

www.health.vic.gov.au/pcps/coordination/ppps.htm

Action 1.7: Results to Questions 2.1, 4.2, 4.8, 6.8, 6.11, 7.10 and 8.2 of Survey Coordination Survey. The numbers of the relevant questions in the Service Coordination Survey may vary from year to year when it is restructured. Relevant questions for use in this activity will be listed at:

www.health.vic.gov.au/pcps/coordination/ppps.htm

Reporting: Annually in the Quality of Care Report from 2010/2011.

Level at which indicator is applicable

- Individual care level
 - Program level
 - Organisational level
-

Recommendation for implementation

Victorian public health services: begin collecting data from 1 January 2010.

Except

Mental health: Clinical mental health services in the first instance from January 2010, followed by the PDRSS sector from 1 July 2010.

Community Health: The registration criteria set out in the Act are that the community health centre (CHC) has links with the local community to which it provides, or will provide, at least one community health service; demonstrated, for example, by:

- a member of the local community being a member of the applicant's board of directors; or
- a partnership between the applicant and another local agency; or
- having the capacity to meet the specific health needs of certain classes of persons living in the local community;

While items 1.4 and 1.5 are not specific requirements of CHCs, policy around Demand Management requires CHCs to prioritise access to ATSI communities, refugees, homeless persons and persons with complex needs⁶. Similarly, while 1.6 is not a mandated requirement on CHCs, certain CHCs have responded to their local community needs by developing a Disability Action Plan.

⁶ To outline the level at which these priority groups were engaged, agencies may prepare a report from their client management system stating the:

- Number of registered clients against each of these characteristics (from quarter to quarter, or year to year)
- Number of Community and Women's Health (CWH) occasions of service delivered to clients with these characteristics (noting that homelessness status is captured in Alcohol and Other Drug [AOD] episodes but not CWH activity).

SUB-MEASURES

Additional guide to achieving the indicator(s)

Sub-measures for #1.2.1 [*The organisation has developed and is implementing a community participation plan, strategy or equivalent that addresses the five key areas of the DHS' How to develop a community participation plan guideline*] could include:

- Consumers, carers and community members are involved in developing and monitoring the community participation plan.
- The participation plan/strategy or equivalent is evaluated annually with the participation of consumers, carers and community members.
- Consumers, carers or community members are involved in presenting the plan to the Board.

Sub-measures for #1.3 [*The organisation uses a variety of approaches to record and report on consumer, carer and community participation to the wider community including an annual Quality of Care Report*] could include:

- Consumer, carer and community participation is reported in the annual report, Quality of Care report, and project reports and is acknowledged at formal organisation events and community forums.
- Consumer, carer and community participation is included in policies, the service's strategic plan, organisational charts, business plans and quality improvement plans.
- The organisation uses responses to and results for questions 2.11 and 2.12⁷ of the Service Coordination Survey to illustrate efforts it has made to ensuring that its contribution and that of its PCP addresses community needs and provides consumers with an experience of a better connected human services system.

Sub-measures for #1.7 [*The organisation has systems, processes and structures in place to consult and involve consumers, carers and community members*] could include:

- Roles for consumers, carers and community members engaged in the organisation are clearly defined and communicated to all staff and consumers, carers and community members involved.
- Consumers, carers and community members engaged in the organisation have access to information, orientation, minutes, downloading of documents, printing, photocopying, car parking, child care arrangements, support to attend conferences or workshops.
- Consumers, carers and community members are included in appraisals of relevant staff.
- Consumers, carers and community members are involved in the development of relevant position descriptions, and staff selection processes, and in the development and delivery of staff training.
- A policy on the payment and reimbursement of consumers, carers and community members exists.
- A staff position has been delegated authority for consumer, carer and community participation.
- The organisation uses responses to and results for questions 2.11, 4.2, 4.8, 6.8, 6.11, 7.10 and 8.2⁸ of the Service Coordination Survey to evaluate/improve its efforts and those of PCP partner organisations in delivering services in a coordinated way, which meets consumer/carer needs.

⁷ This numeration is used in the 2007 version of the Service Coordination Survey. The 2009 version of the Survey will be released in June 2009. Numeration of relevant questions will be posted at www.health.vic.gov.au/pcps/coordination/ppps.htm#survey

⁸ This numeration is used in the 2007 version of the Service Coordination Survey. The 2009 version of the Survey will be released in June 2009. Numeration of relevant questions will be posted at www.health.vic.gov.au/pcps/coordination/ppps.htm#survey

Sub-measures for #1.8 [*The organisation builds the capacity of staff to support consumer, carer and community participation*] could include:

- Information regarding professional development on patient-centredness, cultural competency and consultation methods is regularly identified and disseminated, and, when possible, made available in-house.
- If professional development on consumer, carer and community participation is available in-house, consumers, carers and community members are involved in the development and delivery of training and education programs.

References

Existing indicators/standard

- Department of Human Services, 2004a, *Standards for Psychiatric Disability Rehabilitation and Support Services(PDRSS)*
- Department of Human Services, 2005, *Homelessness Assistance Service Standards*
- Department of Human Services, 2006a, *Doing it with us and not for us*
- Department of Human Services, 2006c, *Health service cultural diversity plans*
- Department of Human Services, 2006e, *Caring together - An action plan for carer involvement in Victorian public mental health services*
- Primary Care Partnerships, Victoria, 2007, *Continuous Improvement Framework, A resource of the Victorian Service Coordination Practice Manual*
- Department of Human Services, 2008a *Draft inclusive practice guidelines for gay, lesbian, bisexual, transgender and intersex clients of Victorian DHS services*
- Department of Human Services, 2009c, *Strengthening consumer participation in Victoria's public mental health services. Action plan*

Literature

- Centre for Clinical Effectiveness, 2004
- National Resource Centre for Consumer Participation in Health, 2002 and 2003
- Abelson J et al., 2007
- Consumer Focus Collaboration, 2001
- Bagley P & Herron-Marx S, 2007
- National Health and Medical Research Council, 2004
- Health Issues Centre, 2008
- Abelson J et al., 2007
- Consumer Focus Collaboration, 2001
- Grimshaw L, 2003

For capacity building

Existing indicators/standards

- Department of Human Services, 2001, *Better Access to Services – A Policy & Operational Framework*
- Department of Human Services, 2005, *Homelessness Assistance Service Standards*
- Department of Human Services, 2006a, *Doing it with us and not for us.*
- Primary Care Partnerships Victoria, 2007, *Victorian Service Coordination Practice Manual*
- Department of Human Services, 2008c, *Towards a Demand Management Framework for Community Health Services.*
- Department of Human Services, 2009a, *Guidelines for applying to be a registered community health centre.*

Literature

- Coulter A, 2007b
- Coulter A, Parsons S, & Janet Askham, 2008
- Health Issues Centre, 2008
- Lewin SA, Skea ZC, Entwistle V, Zwarenstein M, & Dick J, 2001
- Reilly S, Venables D, Hughes J, Challis D, & Abendstern M, 2006
- Romios P, McBride T, & Mansourian J, 2007
- Siegel C et al., 2000
- VOICE, n.d

STANDARD 2

Consumers, and, where appropriate, carers are involved in informed decision-making about their treatment, care and wellbeing at all stages and with appropriate support.

Rationale

When consumers and carers are involved in decision-making, evidence from rigorous studies demonstrates that they achieve better health outcomes. For example, a Cochrane review shows that the use of decision aids for screening or treatment decisions improves people's knowledge of the options, creates accurate risk perceptions of their benefits and harms, reduces difficulty with decision-making, and increases participation in the process. Patient decision aids increase people's involvement and are more likely to lead to informed values-based decisions. They reduce the use of discretionary surgery without apparent adverse effects on health outcomes or satisfaction (O'Connor et al., 2003).

Evidence also exists to argue that people's involvement in decision-making should be facilitated by the provision of evidence-based, understandable and accessible information and support. Consumer involvement in the development of information can improve the clarity and relevance of materials, and can improve people's knowledge without increasing their anxiety about medical procedures (Nilsen et al., 2006).

INDICATOR FOR ACUTE/SUBACUTE

Numerator: The number of items positively rated on the 25 questions of the Overall Care Index on the VPSM

Denominator: The total number of items on the 25 questions of the Overall Care Index on the VPSM

INDICATOR FOR MATERNITY SERVICES

Numerator: The number of women who said they thought they were given an active say in making decisions about what happened during their labour and/or birth

Denominator: The total number of respondents to the Maternity Module's question 2 of the VPSM

INDICATOR FOR COMMUNITY HEALTH SERVICES

Numerator: The percentage of clients/carers satisfied or highly satisfied with their involvement in decisions about their care or treatment

Denominator: The total number of clients/carers who participated in consumer/carer surveys

INDICATOR FOR MENTAL HEALTH

Numerator: The number of achievements derived from the suite of evidence for engagement

Denominator: The four items in the suite of evidence as listed (in the terminology)

INDICATOR FOR RESIDENTIAL AGED CARE SERVICES (RACS)

Numerator: The number of residents/families/carers satisfied with their involvement in decision-making about their care or treatment

Denominator: The total number of residents/families/carers who participated in survey

Target for Acute/subacute:	75 (index)
Target for Maternity:	90%
Target for Community Health Centres:	90%
Target for Mental Health:	75%
Target for Residential Aged Care Services:	75%

Terminology:

Appropriate support: includes evidence-based and accessible information, access to staff/clinicians for advice or guidance, access to advocacy when required, evidence-based and accessible forms and documents to record the decision-making process and the final decision.

Evidence-based: Current best evidence is up-to-date information from relevant, valid research about the effects of different forms of health care, the potential for harm from exposure to particular agents, the accuracy of diagnostic tests, and the predictive power of prognostic factors.⁹

Cochrane: Cochrane reviews produce combined results of the world's best medical research studies and Cochrane reviews are recognised as the gold standard in evidence-based health care.¹⁰

Mental health

Engagement: Evidence of engagement is detailed below:

- Use of 'advance statements'
- Completion of the consumer self-rated measure
- Consumers' co-signatory on individual service plans, treatment and care plans or recovery plans
- Evidence of consumer held records.

Treatment and care: these terms are generally used within clinical environments.

Rehabilitation and support: these terms are generally used within the psychiatric disability rehabilitation and support services (PDRSS).

Data sources:

Acute/Subacute (including Maternity): VPSM six-monthly.

Mental health: Evidence of engagement is included in the consumer and carer participation plan and the appropriate scope and targets are determined by the mental health services in collaboration with the department. The file audit holds the data.

Aged care: Public sector residential aged care services (PSRACS) resident, carer and family satisfaction surveys.

Community Health: Consumer/carers surveys undertaken by agency as a requirement of accreditation.

Reporting: Annually in the Quality of Care Report from 2010/2011.

Level at which indicator is applicable:

- Individual care level
- Program level
- Organisational level

⁹ Cochrane Collaboration. 2009. Evidence-based medicine and health care. Viewed 8 April 2009 at <http://www.cochrane.org/docs/ebm.htm>

¹⁰ Cochrane reviews can be seen at <http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME>

Recommendation for implementation

Victorian public health services: begin collecting data from 1 January 2010.

Except

Mental health: Clinical mental health services in the first instance from January 2010 followed by the PDRSS sector from 1 July 2011.

SUB-MEASURES

Additional guide to achieving the indicator(s)

Victorian public health services:

- Systems are in place to enable consumers and carers/family to prepare written advance care plans. (Reference: Independent Health Care. National Minimum Standards Regulation [UK] and upcoming DHS policy for advance care planning).
- Consumers and carers are provided with the support they require to be able to make informed decisions about their treatment and care (including meeting the needs of consumers and carers with communication impairment, low literacy levels, and cultural needs where appropriate).
- Consumers and carers are provided with decision aids, question prompt sheets, coaching, contracts and consumers have access to personal medical records.

Mental Health:

- procedures are in place to enable advocacy for involuntary consumers (Lakeman R, 2008).

Community Health:

- In addition to results of satisfaction surveys, community health centres delivering Integrated Chronic Disease Management (ICDM) programs should consider using results of question on Intra-agency care planning in the Victorian Service Coordination Survey/ ICDM Survey to continually improve engagement with clients/carers. (N.B. This question ascertains whether care plans are written in *simple English* and whether there is evidence of *client acknowledgement*).
- Use the results of the Service Coordination Survey to evaluate whether consumers:
 - (a) Experience improved identification of their needs as soon as possible.
 - (b) Have timely access to the most appropriate services.
 - (c) Experience coordinated delivery of services and a continuum of care.
 - (d) Have confidence in the advice, support, treatment and care coordination they are receiving.
 - (e) Actively participate in the development of their care plans and in the delivery of their care.
 - (f) Have confidence in the way their health care information is collected and shared.
 - (g) Receive care and support delivered in an appropriate mode and setting.
 - (h) Receive care that proactively identifies, responds to and supports their needs over time.

References

Existing indicators/standards

- Australian Commission on Safety and Quality in Health Care, 2008, *Australian Charter of Health Care Rights*
- Commonwealth of Australia, 2002, *National Program Guidelines for the Home and Community Care (HACC)*
- Department of Health (UK), 2002, *Independent Health Care. National Minimum Standards Regulation*
- Department of Human Services, 2001, *Better Access to Services*
- Department of Human Services, 2004a, *Standards for Psychiatric Disability Rehabilitation and Support Services(PDRSS)*
- Department of Human Services, 2005a, *Homelessness Assistance Service Standards*
- Department of Human Services, 2006e, *Caring together - An action plan for carer involvement in Victorian public mental health services*
- Department of Human Services, 2007a, *Standards for Disability Services in Victoria*
- Department of Human Services, 2009c, *Strengthening consumer participation in Victoria's public mental health services - action plan*
- Minister for Community Services, 2005, *Standards for Community Service Organisations*
- Office of the Public Advocate (Queensland), 2008, *'In sickness and in health's and in health'. Addressing the health care needs of adults with a decision-making disability*
- Primary Care Partnerships Victoria, 2007, *Victorian Service Coordination Practice Manual*
- Primary Care Partnerships, Victoria, 2007, *Continuous Improvement Framework, A resource of the Victorian Service Coordination Practice Manual*
- Quality Improvement Council (QIC), 2004, *Health and Community Services Standards*
- UltraFeedback, 2008, *Victorian Patient Satisfaction Monitor*

Literature

- Coulter A, 2007a
- Coulter A, Parsons S, & Janet Askham, 2008
- Beach MC et al., 2005
- Bosch-Capblanch X, Abba K, Pictor M, & Garner P, 2007
- Kinnersley P et al., 2001
- O'Connor AM et al., 2003
- O'Connor AM & Stacey D, 2005
- Coulter A, 2007b
- Street RL Jr. & Gordon HS, 2006
- Wetzels R, Harmsen M, Van Weel C, Grol R, & M, 2007

Standard 3

Consumers, and, where appropriate, carers are provided with evidence-based, accessible information to support key decision-making along the continuum of care.

Rationale

Providing consumers and carers with information in ways that it is accessible to them ensures they are able to make informed decisions. There is strong evidence that consumers and carers benefit from receiving evidence-based and understandable information and that they should receive this information at key stages along the continuum of care (see references below).

INDICATOR

(all Victorian public health services)

Services rated "Yes" on at least 30 items of the *Checklist for Assessing Written Consumer Health Information*,¹¹, including at least five for section D.

Numerator: The number of new information resources produced, revised or adopted over last year which met at least 30 of the 40 items on the *Checklist for Assessing Written Consumer Health Information*, including at least five items from section D

Denominator: The total number of new information resources produced, revised or adopted in last year

INDICATOR FOR ACUTE/SUBACUTE

The rate of respondents to consumer and carer surveys who rate the information as being 'good' to 'excellent'.

Numerator: The number of respondents who rate the written information on how to manage your condition and recovery at home (Q. 16b) on the VPSM) given as being 'good' to 'excellent'

Denominator: The total number of respondents to Q 16b) on the VPSM

¹¹ Currie K, Spink J and Rajendran M, 2000. Well-Written Health Information: A Guide. Department of Human Services. Melbourne. Viewed 1 June 2009 at <http://www.health.vic.gov.au/consumer/downloads/dhs1074.pdf>

Target for all Victorian public Health Services:	85%
Target for Acute/Subacute:	75%

Terminology:

Accessible: Information that complies with the 40 criteria included in the Checklist for Assessing Written Consumer Health Information.

Continuum of care: includes screening, diagnosis and referral, determination of treatment and/or care, initial care and/or treatment, ongoing treatment and/or care, discharge planning, and end of life or palliative care.¹²

Data sources:

Victorian public health services: internal audit of new information resources.

Acute/subacute: VPSM

Aged care: Public sector residential aged care services (PSRACS) resident and family satisfaction surveys.

Reporting: Annually in the Quality of Care Report from 2010/2011.

Level at which indicator is applicable

- Individual care level
 - Program level
 - Organisational level
-

Recommendation for implementation

Victorian public health services: begin collecting data from 1 January 2010.

Except

Mental health: Clinical mental health services in the first instance from January 2010, followed by the PDRSS sector from 1 July 2010.

¹² Adapted from Department of Human Services. 2006g *Victorian Government Cancer Initiatives. Patient Management Frameworks*. Metropolitan health and Aged Care Services Division. Victorian Government Department of Human Services, Melbourne. Viewed 8 April 2009 at <http://www.health.vic.gov.au/cancer/pmfsnew.htm>

SUB-MEASURES

Additional guide to achieving the indicator(s)

- Consumers and carers receive information about cost, eligibility and waiting time.
- Where possible, information has been personalised.
- Community health centres and other agencies in Primary Care Partnership (PCP) may choose to use results of Service Coordination Survey for Question 4.8 as a basis for improving consumer and services information about health promotion at inter- and intra-organisational levels.

References

Existing indicators/standards

- Australian Commission on Safety and Quality in Health Care, 2008, *Australian Charter of Health Care Rights*
- Commonwealth of Australia, 2002, *National Program Guidelines for the Home and Community Care (HACC)*
- Department of Health (UK), 2002, *Independent Health Care. National Minimum Standards Regulation*
- Department of Human Services, 2004b, *Public Sector Residential Aged Care Quality of Care Performance Indicator Project Report*
- Department of Human Services, 2005a, *Homelessness Assistance Service Standards*
- Department of Human Services, 2006a, *Doing it with us and not for us*
- Department of Human Services, 2006b, *Performance Indicators and Standards for hospital breast services in Victoria*
- Department of Human Services, 2006c, *Health service cultural diversity plans*
- Department of Human Services, 2006e, *Caring together - An action plan for carer involvement in Victorian public mental health service*
- Department of Human Services, 2006g, *Patient management Frameworks*
- Department of Human Services, 2008a, *Draft inclusive practice guidelines for gay, lesbian, bisexual, transgender and intersex clients of Victorian DHS services*
- Department of Human Services, 2009c, *Strengthening consumer participation in Victoria's public mental health services - action plan*
- Keri Thomas and Department of Health England, 2005, *Gold Standards Framework. A Community Program for Palliative Care.*
- UltraFeedback, 2008, *Victorian Patient Satisfaction Monitor*
- WA Council for Safety and Quality in Health Care, 2006, *Patient first*

Literature

- Balding, C. 2006
- Coulter A, 2007b
- Coulter A, Parsons S, & Janet Askham, 2008
- Edwards AGK et al., 2006
- Grain, 2004
- Johnson A, Sandford J, & Tyndall J, 2003
- Lakeman R, 2008
- Nilsen ES, Myrhaug HT, Johansen M, Oliver S, & Oxman AD. 2006
- Reilly S, Venables D, Hughes J, Challis D, & Abendstern M, 2006
- Romios P et al., 2007
- Siegel C et al., 2000
- VOICE, n.a

STANDARD 4

STANDARD 4

Consumers, carers and community members are active participants in the planning, improvement, and evaluation of services and programs on an ongoing basis.

Rationale: Consumer, carer and community participation has been linked to quality improvement. Involving consumers, carers and community members as active participants in planning, improvement processes and evaluation of services ensures that organisations are responsive to the views, opinions and needs of the communities they serve. There is strong anecdotal and some evaluation evidence, as well as an implicit rationale behind a range of existing indicators/standards, to support this (see references below).

INDICATOR

Numerator: The number of dimensions or specified activities where consumers, carers and community members are active participants

Denominator: The six dimensions or specified activities

Six dimensions or specified activities are:

- 4.1 Strategic planning.
- 4.2 Service, program and community development.
- 4.3 Quality improvement activities.
- 4.4 Developing and monitoring feedback, complaints' and appeals' systems and in the review of complaints.
- 4.5 Ethics, quality, clinical and corporate governance committees.
- 4.6 Consumers, carers and community members are involved in the development of consumer health information.

Target for all Victorian public health services: 75%

Terminology:

Programs: includes, for example, health promotion and health education programs.

Reporting: Annually in the Quality of Care Report from 2010/2011.

Data sources:

Victorian public health services: Strategic Planning processes, quality improvement reports, complaints resolution mechanisms, development of the Quality of Care report and quality and safety committee reports/minutes.

Acute/Subacute scheduled public health services¹³: Community Participation Plans.

Mental health: Dimensions or specified activities of participation are to be included in the consumer and carer participation plan.

Aged care: Public sector residential aged care services (PSRACS) resident and family satisfaction surveys.

Community Health Centres: PCP Integrated Health Promotion Plan, including relevant performance measures.

Level at which indicator is applicable

- Individual care level
 - Program level
 - Organisational level
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Recommendation for implementation

Victorian public health services: begin collecting data from 1 January 2010.

Except

Mental health: Clinical mental health services in the first instance from January 2010, followed by the PDRSS sector from 1 July 2010.

¹³ Five regional health services ((Ballarat Health Services, Barwon Health, Bendigo Health Care Group, Goulburn Valley Health and Latrobe Regional Hospital) and 13 metropolitan health services (Austin Health, Bayside Health (Alfred Health), Eastern Health, Melbourne Health, Northern Health, Peninsula Health, Peter MacCallum Cancer Centre, Royal Children's Hospital, Royal Women's Hospital, Southern Health, Dental Health Services Victoria, Royal Victorian Eye and Ear Hospital and Western Health) plus St Vincent's Health who choose to participate in this process.

SUB-MEASURES

Additional guide to achieving the indicator(s)

- The organisation has systems in place to document and report the degree to which listening to consumers, carers and community members has affected change, including quality improvement activities.
- The organisation develops, implements and evaluates programs in partnership with consumer and community groups.
- Consumers, carers and community members are consulted about service development and quality improvement of service delivery on an ongoing basis.
- Consumer, carer and community needs are documented and the organisation responds accordingly.
- The organisation uses a range of appropriate methods for consulting with consumers, carers and community members.
- There are pathways for consumers, carers and community members to be involved in informing research agendas and identifying, commissioning and undertaking research.

References

Existing indicators/standard

- Department of Human Services, 2005a, *Homelessness Assistance Service Standards*
- Department of Human Services, 2005b, *Improving care for Aboriginal and Torres Strait Islander Patients*
- Department of Human Services, 2005c, *Disability Action Plan 2005-2008*
- Department of Human Services, 2006a, *Doing it with us and not for us*
- Department of Human Services, 2006c, *Health service cultural diversity plans* Department of Human Services, 2006d, *Women's health - everyone's business Victorian Women's Health and Wellbeing Strategy: Stage Two 2006–2010*
- Department of Human Services, 2006e, *Caring together - An action plan for carer involvement in Victorian public mental health services*
- Department of Human Services, 2008a *Draft inclusive practice guidelines for gay, lesbian, bisexual, transgender and intersex clients of Victorian DHS services*
- Department of Human Services, 2008b *Integrated Health Promotion: A practice guide for service providers*
- Department of Human Services, 2009b, Primary Health Integrated Health Promotion Planning 2009-2012. Interim advice
- Department of Human Services, 2009c, *Strengthening consumer participation in Victoria's public mental health services - action plan*
- Quality Improvement Council (QIC), 2004, *Health and Community Services Standards*

Literature

- Beal G et al., 2007
- Consumer Focus Collaboration, 2001
- Consumers' Health Forum of Australia, 2004a
- Consumers' Health Forum of Australia, 2004b
- Erwin PC et al., 2006
- Health Issues Centre, 2008
- Nilsen ES, Myrhaug HT, Johansen M, Oliver S, & Oxman AD, 2006
- Northrop M, Pittam G, & Caan W, 2008
- Romios P et al., 2007
- Sheahan M, Little R, & Leggat S, 2007
- Siegel C et al., 2000
- Varney H, Connely M & Phillips, 2005
- VOICE, n.d.

For consultation

Existing indicators/standards

- Australian Council of Healthcare Standards, 2006, *Evaluation and Quality Improvement program (EQulP) 4*
- Department of Health (UK), 2002, *Independent Health Care. National Minimum Standards Regulation*
- Department of Human Services, 2004a, *Standards for Psychiatric Disability Rehabilitation and Support Services(PDRSS)*
- Department of Human Services, 2004b, *Public Sector Residential Aged Care Quality of Care Performance Indicator Project Report*
- Department of Human Services, 2005a, *Homelessness Assistance Service Standards*
- Department of Human Services, 2005b, *Improving care for Aboriginal and Torres Strait Islander Patients* Department of Human Services, 2006c, *Health service cultural diversity plans*
- Department of Human Services, 2006b, *Patient management Framework*
- Department of Human Services, 2006d, *Women's health - everyone's business Victorian Women's Health and Wellbeing Strategy: Stage Two 2006–2010*
- Department of Human Services, 2008b *Integrated Health Promotion: A practice guide for service providers*
- Quality Improvement Council (QIC), 2004, *Health and Community Services Standards*
- UltraFeedback, 2008, *Victorian Patient Satisfaction Monitor*

Literature

- Coulter A, 2007a
- Health Issues Centre, 2008
- Romios P et al., 2007
- Siegel C et al., 2000
- VOICE, n.d.

STANDARD 5

STANDARD 5

The organisation actively contributes to building the capacity of consumers, carers and community members to participate fully and effectively.

Rationale: There is evidence in existing standards and the literature of the value of supporting participating consumers, carers and community members through enhancing their knowledge and skills to participate effectively (see references below).

DESCRIPTIVE REPORTING

For all Victorian public health services

INDICATOR FOR MENTAL HEALTH

Numerator: The number of in-service training and orientation programs that demonstrate evidence of consumer and carer involvement in delivering orientation/in-service training

Denominator: The total number of orientation and in-service training programs conducted by the mental health service for its staff

Target for all Victorian public health services: N/A for descriptive reporting

Target for Mental Health: 75%

Terminology:

Key terms as listed in 'Definition' box above.

Data sources:

Victorian public health services: Quality of Care Report development process

Acute/Subacute scheduled public health services¹⁴: Community Participation Plans.

Mental health: A training register should be maintained by the mental health service with an indicator of consumer and carer delivering training. It is recommended that as far as practicable, elements of consumer and carer participation are integrated into the training curriculum. Consumer and carer participation plans are also a source of data.

Aged care: Public sector residential aged care services (PSRACS) resident and family satisfaction surveys.

Community health: Integrated Health Promotion Plan.

Reporting: Annually in the Quality of Care Report from 2010/2011.

Level at which indicator is applicable

- Individual care level
 - Program level
 - Organisational level
-

Recommendation for implementation

Victorian public health services: begin collecting data from 1 January 2010.

Except

Mental health: Clinical mental health services in the first instance from January 2010, followed by the PDRSS sector from 1 July 2010.

¹⁴ *ibid*

SUB-MEASURES

ADDITIONAL GUIDE TO ACHIEVING THE INDICATOR(S)

FOR THIS STANDARD, THE FOLLOWING ARE POTENTIAL ACTIVITIES THROUGH WHICH SERVICES COULD BE ENHANCING THE CAPACITY OF CONSUMERS, CARERS AND COMMUNITY MEMBERS TO PARTICIPATE.

- Training is provided to consumers, carers and community members engaged in organisation activities, and, when possible, the training is developed in-house.
- Information regarding training for consumers, carers and community members is regularly identified and disseminated.
- If training for consumers, carers and community members is developed in-house, consumers, carers and community members are involved in its development.
- The organisation actively engages in consumer, carer or community initiated or led activities/initiatives and these activities influence service planning and delivery.
- The organisation *is open to* and supports peer-support and self-help groups to enhance their capacity to support consumers, carers and community members.
- The organisation supports consumers, carers and community members to undertake their own advocacy work.
- The organisation supports consumer/carer-led initiatives on an ongoing basis.
- Consumers, carers and community members can identify that changes have taken place within the organisation's program because of their active participation.

References

Indicators/standards

Department of Human Services, 2005a, *Homelessness Assistance Service Standards*

Department of Human Services, 2006e, *Caring together - An action plan for carer involvement in Victorian public mental health services*

Department of Human Services, 2009c, *Strengthening consumer participation in Victoria's public mental health services - action plan*

Literature

Branfield et al., 2006

Coulter A, 2007b

Health Issues Centre, 2008

Holden DJ, Evans WD, Hinnant LW, & Messeri P, 2005

Romios P, McBride T, & Mansourian J, 2007

APPENDIX 1: LIST OF REMAINING STANDARDS/INDICATORS

Below is a list of remaining standards/indicators that were presented to the Consensus Workshop, annotated to describe how they have been integrated into the final five standards:

- The organisation has formal mechanisms in place to report and record consumer participation. [included in Standard 1]
- The organisation has an accessible and transparent complaints or appeals system that is reviewed regularly and is linked to quality improvement. [included in Standard 4]
- The organisation has allocated funding to support consumer participation. [included in Standard 1]
- The organisation provides ongoing professional development to staff to enhance their capacity to implement consumer participation. [included in Standard 1]
- Consumers, and, where appropriate, carers, are informed about the circumstances in which the service may no longer be provided or may need to change and the circumstances in which care and support will be reinstated. [Eliminated – considered service standard]
- Each consumer, and, where appropriate, carer, is informed and understands his or her rights and responsibilities and the available complaints and appeal processes. This information is provided on an ongoing basis. [Eliminated – considered service standard]
- Consumers, carers and community members are consulted about service development and quality improvement of service delivery on an ongoing basis. [included in Standard 4]
- Consumers provide informed consent for the use of their personal data for continuous quality improvement, research and evaluation purposes. [Eliminated – considered service standard]
- Consumers, carers and community members are involved in governance activities. [included in Standard 4]
- The organisation engages consumers, carers and community members in workforce planning, the development of staff position descriptions, and, where appropriate, staff selection panels. [Included in Standard 1]
- The organisation has systems in place to enable consumers and carers/family to prepare written advance care plans. [included in Standard 2]
- The organisation has procedures in place to enable advocacy for involuntary consumers. [included in Standard 2]
- The organisation undertakes initiatives with consumer groups and community organisations. [included in Standard 5]
- The organisation provides assistance to peer-support and self-help groups to enhance their capacity to support consumers, carers and community members. [included in Standard 5]
- Consumers, carers and community members are supported by health services to undertake their own advocacy work. [included in Standard 5]
- Consumers, carers and community members are involved in commissioning and undertaking research. [included in Standard 4]

REFERENCES

- Abelson J, Forest PG, Eyles J, Casebeer A, Martin E, & Mackean G. (2007). Examining the role of context in the implementation of a deliberative public participation experiment: Results from a Canadian comparative study. *Social Science & Medicine*, 64(10), 2115–2128.
- Australian Commission on Safety and Quality in Health Care. (2008) *Australian Charter of Health Care Rights*. The Australian Commission on Safety and Quality in Health Care. Sydney.
- Australian Council of Healthcare Standards. (2006). *Evaluation and Quality Improvement program (EQulP) 4*. Sydney.
- Balding C. (2006). *South Australian Safety and Quality Framework & Strategy 2007–2011*. Retrieved from <http://www.safetyandquality.sa.gov.au/Default.aspx?tabid=106>
- Bagley P. & Herron-Marx S. (2007). *A scoping exercise of patient and public involvement*. London: The National Centre for Involvement.
- Beach MC, Sugarman J, Johnson RL, Arbelaez JJ, Duggan PS, & Cooper LA. (2005). Do patients treated with dignity report higher satisfaction, adherence, and receipt of preventive care? *Annals of Family Medicine*, 3(4), 331–338.
- Beal G, Chan A, Chapman S, Edgar J, McInnis-Perry G, Osborne M, et al. (2007). Consumer input into standards revision: Changing practice. *Journal of Psychiatric & Mental Health Nursing*, 14(1), 13–20.
- Bosch-Capblanch X, Abba K, Pictor M, & Garner P. (2007). Contracts between patients and healthcare practitioners for improving patients' adherence to treatment, prevention and health promotion activities. *Cochrane Database of Systematic Reviews* (Issue 2. Art. No.: CD004808. DOI: 10.1002/14651858.CD004808.pub3.).
- Branfield F, Beresford P, Andrews EJ, Chambers P, Staddon P, Wise, G, et al. (2006). *Making user involvement work: Supporting service user networking and knowledge*. York: Joseph Rowntree Foundation.
- Centre for Clinical Effectiveness. (2004). *Consumer and community participation self-assessment project: Acute Services 2002–03*. Retrieved from www.health.vic.gov.au/consumer
- Commonwealth of Australia (2002) *National Program Guidelines for the Home and Community Care (HACC)*. Canberra.
- Consumer Focus Collaboration. (2001). *Consumer participation in accreditation. Resource guide*. Canberra.
- Consumers' Health Forum of Australia. (2004a). *Best practice principles for consumer participation in the development, trialling and implementation of HealthConnect*. Retrieved from http://www.chf.org.au/publications/all_search3.asp?id=477
- Consumers' Health Forum of Australia. (2004b). *Consumers' policy principles for accreditation of health services*.
- Coulter A. (2007a). *Literature on the effectiveness of strategies to improve patients' experience of cancer care*. Oxford.
- Coulter A. (2007b). *Informed and empowered individuals, families and communities: A whole systems approach*. Picker Institute.
- Coulter A, Parsons S, & Askham J. (2008). *Where are the patients in decision-making about their own care?* Copenhagen.
- Currie K, Spink J and Rajendran M, 2000. *Well-Written Health Information: A Guide*. Department of Human Services. Melbourne.
- Department of Health (UK), 2002, *Independent Health Care. National Minimum Standards Regulation*. The Stationary Office. London.
- Department of Human Services (2001). *Better Access to Services*. Metropolitan Health and Aged Care Services Division. Victorian Government Department of Human Services. Melbourne.
- Department of Human Services. (2004a). *Standards for Psychiatric Disability Rehabilitation and Support Services*. Metropolitan Health and Aged Care Services Division. Victorian Government Department of Human Services. Melbourne.
- Department of Human Services. (2004b). *Public Sector Residential Aged Care Quality of Care Performance Indicator Project Report*. Aged Care Branch. Victorian Government Department of Human Services. Melbourne.

- Department of Human Services, (2005a). *Homelessness Assistance Service Standards*. Victorian Government Department of Human Services. Melbourne.
- Department of Human Services. (2005b). *Improving care for Aboriginal and Torres Strait Islander Patients*. Victorian Government Department of Human Services. Melbourne
- Department of Human Services. (2005c). *Disability Action Plan 2005-2008*. Victorian Government Department of Human Services. Melbourne.
- Department of Human Services. (2006a). *Doing it with us and not for us. Participation in your health service system 2006–09: Victorian consumers, carers and the community working together with their health services and the Department of Human Services*. Rural and Regional Health and Aged Care Services Division, Victorian Government Department of Human Services. Melbourne.
- Department of Human Services (2006b) *Performance Indicators and Standards for hospital breast services in Victoria*. Victorian Government Department of Human Services. Melbourne.
- Department of Human Services, (2006c). *Health service cultural diversity plans*. Victorian Government Department of Human Services. Melbourne.
- Department of Human Services.(2006d). *Women's health - everyone's business. Victorian Women's Health and Wellbeing Strategy: Stage Two 2006–2010*. Victorian Government Department of Human Services. Melbourne.
- Department of Human Services (2006e) *Caring together - An action plan for carer involvement in Victorian public mental health services*. Mental Health Branch, Victorian Government Department of Human Services, Melbourne.
- Department of human Services (2006f) *How to develop a community participation plan*. Rural and Regional Health and Aged Care Services Division. Melbourne.
- Department of Human Services (2006g) *Victorian Government Cancer Initiatives. Patient Management Frameworks*. Metropolitan health and Aged Care Services Division. Victorian Government Department of Human Services, Melbourne.
- Department of Human Services (2007a) *Standards for Disability Services in Victoria*. Victorian Government Department of Human Services. Melbourne.
- Department of Human Services. (2008a). *Draft inclusive practice guidelines for gay, lesbian, bisexual, transgender and intersex clients of Victorian DHS services*. Victorian Government Department of Human Services. Melbourne. Unpublished.
- Department of Human Services. (2008b). *Integrated health promotion. A practice guide for service providers*. Primary and Community Health Branch in partnership with the Public Health Branch, Rural and Regional Health and Aged Care Services Division. Victorian Government Department of Human Services. Melbourne (updated from June 2003).
- Department of Human Services, 2008c, *Towards a Demand Management Framework for Community Health Services*. Rural and Regional Health and Aged Care Services Division, Victorian Government Department of Human Services. Melbourne.
- Department of Human Services, 2009a, *Guidelines for applying to be a registered community health centre*. Rural and Regional Health and Aged Care Services Division, Victorian Government Department of Human Services. Melbourne.
- Department of Human Services, 2009b, *Primary Health Integrated Health Promotion Planning 2009-2012*. Rural and Regional Health and Aged Care Services Division, Victorian Government Department of Human Services. Melbourne
- Department of Human Services, 2009c, *Strengthening consumer participation in Victoria's public mental health services. Action plan*. Portfolio Services and Strategic Projects, Victorian Government. Melbourne.
- Edwards AGK, Evans R, Dundon J, Haigh S, Hood K, & Elwyn GJ. (2006). Personalised risk communication for informed decision making about taking screening tests. *Cochrane Database of Systematic Reviews* (Issue 4. Art. No.: CD001865. DOI: 10.1002/14651858.CD001865.pub2.).
- Erwin PC, Hamilton CB, Welch S, & Hinds B. (2006). The Local Public Health System Assessment of MAPP/The National Public Health Performance Standards Local Tool: A community-based, public health practice and academic collaborative approach to implementation. *Journal of Public Health Management & Practice*, 12(6), 528–532.
- Grain H. (2004). Health informatics standards for health consumers: International developments. *The Australian Health Consumer* (Issue 1), 2.
- Grimshaw L. (2003). *Consumer participation in staff selection strategy*. Northern Area Mental Health Services. Melbourne.

- Health Issues Centre. (2008). *Content analysis of Health Issues Centre's advice to organisations undertaking consumer, carer and community participation*. Melbourne: Unpublished.
- Holden DJ, Evans WD, Hinnant LW, & Messeri P. (2005). Modeling psychological empowerment among youth involved in local tobacco control efforts. *Health Education & Behavior*, 32(2), 264–278.
- Johnson A, Sandford J, & Tyndall J. (2003). Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home. *Cochrane Database of Systematic Reviews* (Issue 4. Art. No.: CD003716. DOI: 10.1002/14651858.CD003716.).
- Kinnersley P, Edwards A, Hood K, Cadbury N, Ryan R, Prout H, et al. (2001). Interventions before consultations for helping patients address their information needs. *Cochrane Database of Systematic Reviews* (Issue 3. Art. No.: CD004565. DOI: 10.1002/14651858.CD004565.pub2.).
- Lakeman R. (2008). Family and carer participation in mental health care: Perspectives of consumers and carers in hospital and home care settings. *Journal of Psychiatric & Mental Health Nursing*, 15(3), 203–211.
- Lewin SA, Skea ZC, Entwistle V, Zwarenstein M, & Dick J. (2001). Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews* (Issue 4. Art. No.: CD003267. DOI: 10.1002/14651858.CD003267).
- Minister for Community Services (2005) *Standards for community service organisations. Children, Youth and Family Act 2005*. Melbourne.
- National Health and Medical Research Council. (2004). *A model framework for consumer and community participation in health and medical research*. Retrieved from <http://www.nhmrc.gov.au/publications/synopses/ files/r33.pdf>
- National Resource Centre for Consumer Participation in Health. (2002). *Primary care self-assessment tool for community and consumer participation, V1.0*. Melbourne.
- National Resource Centre for Consumer Participation in Health. (2003). *Organisational self-assessment and planning tool for consumer and community participation*. Melbourne.
- Nilsen ES, Myrhaug HT, Johansen M, Oliver S, & Oxman AD. (2006). Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews* (Issue 3. Art. No.: CD004563. DOI: 10.1002/14651858.CD004563.pub2.).
- Northrop M, Pittam G, & Caan W. (2008). The expectations of families and patterns of participation in a Trailblazer Sure Start. *Community Practitioner*, 81(2), 24–28.
- O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, et al. (2003). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* (Issue 1. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431).
- O'Connor AM, & Stacey D. (2005). *Should patient decision aids (PtDAs) be introduced in the health care system?* Copenhagen.
- Office of the Public Advocate, Queensland. (2008). *'In sickness and in health's and in health'. Addressing the health care needs of adults with a decision-making disability*. Department of Justice and Attorney General. Brisbane.
- Primary Care Partnerships Victoria, 2007, *Victorian Service Coordination Practice Manual*. Metropolitan Health and Aged Care Services Division. Victorian Government Department of Human Services. Melbourne.
- Primary Care Partnerships, Victoria, 2007, *Continuous Improvement Framework, A resource of the Victorian Service Coordination Practice Manual* Metropolitan Health and Aged Care Services Division. Victorian Government Department of Human Services. Melbourne
- Quality Improvement Council (QIC). (2004). *Health and Community Services Standards*. Quality Improvements Council Limited. Melbourne
- Reilly S, Venables D, Hughes J, Challis D, & Abendstern M. (2006). Standards of care in day hospitals and day centres: A comparison of services for older people with dementia. *International Journal of Geriatric Psychiatry*, 21(5), 460–468.
- Romios P, McBride T, & Mansourian J. (2007). *Consumer participation and culturally and linguistically diverse communities: A discussion paper*. Melbourne.
- Sheahan M, Little R, & Leggat S. (2007). Performance reporting for consumers: Issues for the Australian private hospital sector. *Australia and New Zealand Health Policy*, 4(5) This article is available from: <http://www.anzhealthpolicy.com/content/4/1/5>

- Siegel C, Davis-Chambers E, Haugland G, Bank R, Aponte C, & McCombs H. (2000). Performance measures of cultural competency in mental health organizations. *Administration and Policy in Mental Health, 28*(2), 91–106.
- Street RL Jr, & Gordon HS. (2006). The clinical context and patient participation in post-diagnostic consultations. *Patient Education & Counselling, 64*(1–3), 217–224.
- Thomas K and Department of Health England, 2005, *Gold Standards Framework. A Community Program for Palliative Care*. National health System. retrieved from <http://www.goldstandardsframework.nhs.uk/index.php>
- UltraFeedback. (2008). *Victorian patient satisfaction monitor Year 7 annual report 1 March 2007 to 29 February 2008*. Retrieved from http://www.health.vic.gov.au/patsat/annual_report_march07_feb08.pdf
- Varney H, Connely M & Phillips. (2005). Using consumer groups in an audit of Complaints. *Health Issues, 84*, 30–33.
- VOICE. (n.d). Developing a culturally competent organization. In Q. Government (Ed.), *Voice Resources - Topic Guide*.
- WA Council for Safety and Quality in Health Care. (2006). *Patient first*. Retrieved from http://www.safetyandquality.health.wa.gov.au/docs/patient_first_program/PatientFirstBooklet.pdf
- Wetzels R, Harmsen M, Van Weel C, Grol R, & M, W. (2007). Interventions for improving older patients' involvement in primary care episodes. *Cochrane Database of Systematic Reviews* (Issue 1. Art. No.: CD004273. DOI: 10.1002/14651858.CD004273.pub2.).