

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



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and the Department of Human Services**

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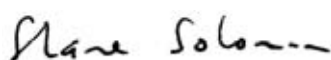
Foreword

Consumer, carer, and community participation in the Victorian health care system is recognised as a strong enabling strategy to create an effective health care system for Victoria. There have been concerted efforts to ensure participation across the system in acute, sub-acute, mental health, primary and community health services. This consultation paper and its recommendations provide an opportunity to draw together these individual efforts into a system-wide strategic policy.

Recommendations are made regarding definitions and outlining what is meant by participation. These recommendations have synthesised existing definitions used across the various sectors within the Victorian health care system. The definitions aim to inform understanding and to facilitate communication across the health care system by clarifying the meaning of consumer, carer and community participation.

The paper documents the evidence that participation improves or contributes to the improvement of health care delivery, planning and policy development. It acknowledges there are barriers to participation and highlights ways to overcome these barriers and where to find the resources to achieve participation. It recognises that the adoption of a participation evaluation and monitoring framework will enhance our understanding of the direct contribution of participation to individual health care outcomes, and the effectiveness and efficiency of our health care system.

We commend the recommendations to you and invite you to become involved in the consultation process for reviewing the recommendations and developing the participation policy.



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Acknowledgements

The development of the recommendations in this paper was based on an extensive review of the literature and resources in the field of participation. The dedication of the Policy Reference Committee in guiding the review process and the development of the policy has greatly contributed to the quality of the recommendations. The committee's willingness and ability to work together in this process is an excellent example of participation. The Department of Human Services gratefully acknowledges their time and contribution.

Please see Appendix 4 for a list of the Policy Reference Committee members.

Executive summary

The decision to develop a consumer, carer, and community participation policy for Victoria arose from a belief in the value of participation in the development of the Victorian health care system. Participation enables a health service to be part of the community and the community to identify its health needs and to work together to better meet those needs.

The aim is that the policy will guide participation across four levels:

- the Department of Human Services level
- the health service organisational level
- the department/ward/program within the health service level
- the individual consumer or patient level.

This consultation paper provides a review of the literature, existing policy documents, electronic information and other resources. The review's purpose was to develop a series of recommendations for consultation with stakeholders across the four levels. Feedback from the consultation about the recommendations will form the basis of the policy. The Policy Reference Committee has approved the recommendations. The committee comprises consumers, carers, community members, health service providers, Department of Human Services representatives, and representatives from non-government organisations and research groups.

Recommendation 1

We need a consumer, carer and community participation policy because participation is valued as:

- an important democratic right
- a mechanism to ensure accountability
- an aid to improve health outcomes and the quality of health care.

Recommendation 2

The policy must define participation and provide direction for the acute and sub-acute sectors of the health care system with clear links to the primary and mental health sectors in Victoria.

Recommendation 3

For the purposes of the policy, it is recommended that 'consumer', 'carer' and 'community' be defined by the Primary Care Partnership definition, but that the Consumer Focus Collaboration definition of diversity be incorporated such that:

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, sexual orientations, health and illness conditions.^{1,2}

Carers are families and friends providing unpaid care to consumers.²

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.²

Recommendation 4

The use of the term ‘consumer representative’ is to be used only in specific situations where representation is required or requested. It is recommended the policy adopt the definition used by the Consumers Health Forum of Australia which says ‘a consumer representative is someone nominated by and accountable to an organisation of consumers’.³

Recommendation 5

The policy should adopt the following definition and description of participation:

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 views, scrutiny of motive and an ability to listen and appreciate others’ views and ideas. Through involvement decisions are made that may accommodate a range of perspectives.

Within a health care system different types of participation can occur across service delivery, planning and policymaking. The following types and precursors of participation outline this discontinuous interaction model of participation: control, delegation, partnership, consultation and information.

Recommendation 6

The policy will be congruent with the Department of Human Services’ mission and values.

Recommendation 7

The recommended principles of participation are trust, openness, equal opportunity, advocacy and support, responsiveness, shared ownership, dissemination and evaluation.

Recommendation 8

The policy should identify that participation can add to and improve program design, clinical guidelines and psychosocial indicators of health, reduce health service use, and inform health care decision making.

Recommendation 9

Evaluation of participation activities should be undertaken to increase our understanding of the effects of participation, specifically concerning health outcomes and economic effectiveness of participation.

Recommendation 10

Evaluation in the area of consumer informatics and the changes this brings to the relationship between consumers and carers and the health professional, as well as the impact on health outcomes and costs, is a priority.

Recommendation 11

Evidence of participation activity in Victoria needs to be documented throughout the policy development consultations and this information included in the policy.

Recommendation 12

The enabling factors and key web sites should be promoted as part of the policy.

Recommendation 13

The identified barriers to participation should be addressed as part of the policy.

Recommendation 14

The participation evaluation and monitoring framework should be adopted in the policy and promoted across the health care system.

1 Introduction

The decision to develop 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 policy* (the ‘participation policy’) arose from the Victorian Government’s commitment to involving people in decision making about health care services and the recognition that a coordinating and unifying policy of participation is required. The strong commitment for participation expressed by health service providers, consumer organisations and the community supports this.

The commitment to participation in health development and care stems from the belief that consumer, carer and community participation enables a health service to be part of the community and the community to identify its health needs and work together to better meet those needs.

Participation in health is an essential principle of health development, community capacity building and the development of social capital.⁴ In particular, it is an enabling strategy for working with and meeting the health needs of those community members who are most socially and economically disadvantaged.^{5,6}

In Victoria there is a clear focus on developing the health care system to meet the growing needs of all Victorians.^{5,7} To use participation as an enabling strategy in the ongoing development of the Victorian health care system therefore requires a system-wide policy. The identified gap in participation policy in Victoria is in the acute and sub-acute sectors. Therefore, the proposed policy will link with existing participation policies in primary and mental health to ensure a system-wide framework.

The purpose of the following review of policy, literature and electronic information and resources is to provide a series of recommendations on which the policy is to be developed in consultation with stakeholders. Stakeholders include consumers, carers, community members, health service providers, and the Department of Human Services. The Policy Reference Committee has approved all recommendations. The committee comprises consumers, carers, community members, health service providers, Department of Human Services representatives and representatives from non-government organisations and research groups.

2 Review process

The review was based on the key terms ‘consumer participation’, ‘community/citizen participation’, ‘patient involvement’, ‘public involvement and patient-centred care’. The review searched the following databases: PubMed, Medline, MEDITEXT, APAIS Health, Health and Society and RURAL. The literature search focused on Australian articles from 1980 onwards and was restricted to publications in English. Articles reviewed in the evidence section were limited to the time period January 1998 to December 2004 and were accessed primarily through PubMed. This time period was restricted because the previous years were covered by the Consumer Focus Collaboration’s review, *The evidence supporting consumer participation in health care* and a systematic review by Crawford et al.^{6,8} In addition, all Australian state and territory government web sites were searched for health policies that included *participation*, particularly Victorian policies.

Similarly, key overseas web sites about health policy and *participation* were searched, beginning with links from the <<http://www.health.vic.gov.au/consumer/>> web site. An extensive range of articles and reports was identified and the review was then limited to those reports relating to the proposed policy, including:⁷

- the importance of participation in health care and planning
- the Victorian policy context
- definitions of key terms
- values and principles
- evidence of participation at the levels of:
 - the Department of Human Services
 - hospital/service organisation
 - ward/department
 - individual consumer/patient
- enablers and resources for participation
- barriers to participation
- evaluation and monitoring of participation.

1 The aim and objectives of developing the policy are outlined in Appendix 5. Note that objective 10 – to establish minimum guidelines for community participation plans – has been met through a separate consultation and development process. Similarly, the identification of performance indicators as outlined in objective 11 is being researched in a separate process.

3 Importance of participation

3.1 Democratic right

The belief in participation as a democratic right is frequently cited as a reason why participation is valued.⁹⁻¹¹ Across western democracies there have been what Hindess labels a ‘democratic deficit’, a need to pull citizens (consumers) back into the political mainstream as well as a belief that participation improves decision-making.¹² For example, in the State Government’s *Growing Victoria together* policy document, one of the key challenges listed is ‘improving confidence and participation in democratic decision-making’.⁵ Health Canada, in more than 1,998 consultations, identified a general disconnection between citizens and their government which led to the development of its policy document, *Public involvement: framework and guidelines*.¹³ However, Pickard et al. found in their investigation of the involvement of consumers in clinical governance activities within primary care groups and trusts in the United Kingdom, a lack of clarity about the role of consumers in these committees. This suggests that participation should not be regarded as an end in itself, but derive from the questions under consideration.⁹

3.2 Accountability

Participation is also viewed as an important accountability mechanism. This is illustrated in the United Kingdoms' Department of Health's *Patient and public involvement (PPI): the new arrangements* legislation and policies, which were put in place in 2002. These were in part developed as a response to the Bristol Royal Infirmary Inquiry report and aim to achieve a patient-centred National Health Service.¹⁴⁻¹⁶ Similarly, Queensland Health's *Smart state: health 2020 directions statement* aims 'to develop strong partnerships between individuals, communities, health services and the Queensland Government to improve health and ensure a responsive community and client-centred health system'.¹⁷ In Victoria, accountability is articulated in the establishment of legislative changes about consumer participation on health service boards, in the establishment of community advisory committees, and in reporting to the community on quality and safety.¹⁸⁻²⁰

3.3 Quality improvement and health outcomes

A third theme that emerges from the literature is that participation is considered important in improving the quality and safety of health care.²¹ This position is supported by the inclusion of participation within accreditation structures and quality frameworks.^{22, 23} Reviews of health systems also recommend the inclusion of participation to improve the quality of health care as itemised in the recommendations made by the Western Australian Health Reform Committee and in South Australia's steps towards reforming its health services system.^{24, 25} The Western Australia work was supported by research undertaken as part of the Health Consumers' Council of Western Australia's consultation report to the Health Reform Committee.²⁶

Evidence supporting the view participation improves health outcomes is cited in a number of reviews, including one conducted by the Consumer Focus Collaboration.⁶ This evidence is discussed in Section 7 of this consultation paper.

Recommendation 1

We need a consumer, carer and community participation policy because participation is valued as:

- an important democratic right
- a mechanism to ensure accountability
- an aid to improve health outcomes and the quality of health care.

4 Victorian policy context

Participation is highlighted in a number of key Victorian policy documents. *Growing Victoria together* (2001) notes Victoria has a 'proud tradition of community participation'.⁵ *Directions for your health system: Metropolitan Health Strategy* (2003) lists participation as an enabling factor and it is a key item in the vision statement of the *Primary Care Partnerships strategic directions 2004–2006*.^{27,28} Mental health guidelines on consumer participation have been in place for some time and carer participation guidelines were recently produced.²⁹ All these policies articulate the importance of participation as a way of improving health care services in Victoria.

Other relevant Victorian policies and plans include:

- *Departmental plan 2004–05: Department of Human Services*³⁰
- *Community advisory committee guidelines: non-statutory guidelines for metropolitan health services*¹⁸
- *Inquiry on the roles of community advisory committees of metropolitan health services*³¹
- *Cultural diversity guide: Multicultural Strategy*³²
- *Community health services – creating a healthier Victoria*³³
- *Victorian Women's Health and Wellbeing Strategy: policy statement and implementation framework 2002–2006*³⁴
- *Department of Human Services Aboriginal services plan, January 2004*³⁵
- *Partnership agreement: Department of Human Services/health, housing and community sector*³⁶
- *Guidelines for Department of Human Services advisory committees*³⁷
- *Department for Victorian Communities corporate plan 2003–2006*³⁸.

A review of the above policies highlights the need for a participation policy that is applicable to all public health services and provides guidance on further directions and expectations. The policy needs to establish links between the acute, sub-acute, community health, primary and mental health areas of the health care system.

Similarly, a review of other Australian health policies specifically about participation or in which participation is of significant importance highlights the need for Victoria to develop a policy that unifies participation across the health system. Notably, most Australian states and territories included consumer or community participation as a priority area, strategic direction or theme, or as part of their vision statement. At a national level, the Australian Council for Safety and Quality in Health Care supports this emphasis by consistently requiring participation in programs and guidelines approved through their processes. Key policies reviewed are outlined in Table 7, Appendix 1.

Recommendation 2

The policy must define participation and provide direction for the acute and sub-acute sectors of the health care system with clear links to the primary and mental health sectors in Victoria.

5 Definitions

The terms ‘consumer’, ‘carer’ and ‘community’ in association with ‘participation’ in health care delivery, policy and planning need to be clearly defined because their meanings differ according to the area of the health care system in which the term is being used. For example, ‘consumer’ can mean the individual receiving care; alternatively, this individual might be known as the ‘patient’, ‘client’ or ‘customer’. The term ‘consumer’ can also be extended to include the individual’s family or friend as well as some health care staff. The latter occurs when ‘consumer’ is closely identified with the term ‘customer’. The need to clarify the terms was a recommendation in the Victorian report, *Consumer and Community Participation Self-Assessment Project, acute services 2002–03*.³⁹

The review does not include a discussion on why the term ‘customer’ is not recommended because Draper has clearly outlined this.¹⁰ The review is centred on clarifying terminology across the Victorian health sectors to facilitate communication between acute and sub-acute and primary and mental health.

5.1 Consumer/carers/community/representative

There is a clear preference within the participation literature to use the term ‘consumer’ to define the patient or potential patient and not to include any health care staff in the definition. For example, the Consumer Focus Collaboration definition states:

*Consumer refers to people who either directly or indirectly make use of health services. Consumers are as diverse as the full range of people living in contemporary Australian society. Any definition of consumer must incorporate women and men, people from diverse cultural experiences, class positions and social circumstances, sexual orientations, health and illness conditions.*¹

The term ‘patient’ was found to be commonly used in the acute sector but, as Draper identifies, ‘patient’ does not define the relationship between the health professional and the person receiving care where ‘participation’ is wanting to be encouraged and valued.^{39,10} Research undertaken by the Australian Nursing Federation and the Royal College of Nursing Australia supports this position.⁴⁰ For example, patient means:

*Noun 1. one who is under medical or surgical treatment. 2. a person or thing that undergoes action (opposed to agent)...4. enduring pain, trouble, affliction, hardship, etc. with fortitude, calmness, or quiet submission.*⁴¹

This definition does not imply participation, empowerment or involvement in decision making about one’s own health care and treatment and the development of the health care system. Hence, the use of the term ‘consumer’ conveys ‘the idea that consumers can and do make rational decisions based on having the appropriate information available to them’.¹⁰ However, it should be recognised that some people understand consumer to mean a purchaser of health services. This is not the intended meaning of consumer in the reviewed definitions, but has been raised in past projects in Victorian health services.³⁹

Further, ‘consumer’ is a term that is often used to represent a range of people and groups: the individual using health care services, the family carer, the potential users of health services, consumer organisations and the broader community.¹⁰ Alternatively, some definitions of consumer differentiate between these groups. The Mental Health consumer participation policy confined the term ‘consumer’ to the people:

*with direct experience of mental illness or other severely disabling psychiatric conditions, who have used or are currently using public mental health services’.*²⁹

Similarly, the Department of Human Services Primary Care Partnership advice states:

*consumers are defined as people who are current or potential users of health services and carers are families and friends providing unpaid care to consumers. Communities are defined as groups of citizens who have interests in the development of an accessible, effective and efficient health services that best meet their needs [sic].*²

In contrast to the Primary Care Partnership definition of ‘carer’, this term is sometimes used to identify paid staff in health services. Carers Victoria, however, supports the Primary Care Partnership definition. Carers Victoria defines carers as those who provide unpaid care and support to ‘family members or friends who have a chronic or acute condition, mental illness, disability, or who are frail aged’.⁴²

The use of ‘community’ in the Primary Care Partnership definition does not include a geographical reference, which is another common way to define ‘community’. Nonetheless, the Consumer Focus Collaboration states ‘a characteristic of the term community is interactions between people’, which is implied in the Primary Care Partnership definition.^{27, 1}

Another term that is sometimes used is ‘consumer representative’. This term refers to somebody who has a constituency they represent and who feeds back information to that constituency. They represent the consumer view and participate in decision making processes on behalf of consumers.^{1, 43-45}

Recommendation 3

For the purposes of the policy, it is recommended that ‘consumer’, ‘carer’ and ‘community’ be defined by the Primary Care Partnership definition, but that the Consumer Focus Collaboration definition of diversity be incorporated such that:

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, sexual orientations, health and illness conditions.^{1, 2}

Carers are families and friends providing unpaid care to consumers.²

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.²

Recommendation 4

The use of the term ‘consumer representative’ is to be used only in specific situations where representation is required or requested. It is recommended the policy adopt the definition used by the Consumers Health Forum of Australia definition which says ‘a consumer representative is someone nominated by and accountable to an organisation of consumers.’³

5.2 Participation

The terms ‘consumer participation’ and ‘community participation’ in the reviewed documents have their origins in public policy, development theory, and public health.⁴ In the public policy sector ‘participation is the expectation that citizens have a voice in policy choices’.⁴⁶ Thus, an interactive process is implied, but the boundaries of the process are frequently left implicit.

*Participation invites reflection and debate. It requires the public expression of opinion, and scrutiny of motive. It enables us not just to express a point of view, but to hear contrary ideas and arguments. Through interaction, consensus or accommodation are possible.*⁴⁶

A similar definition has been proposed in the community health area, in Baum, Fry and Lenni.⁴⁷ Participation has also been characterised using a number of typologies as outlined in Bishop and Davis⁴⁶:

- a continuum or ladder, most notably by Arnstien (1969, 1971) and Pateman (1970)
- a continuum with a matrix through linking participation strategies to the policy problem by Thomas (1990, 1993)
- a continuum of management techniques by Shand and Arnberg (1996) not only looking at the policy problem, but also within the service delivery arena
- discontinuous interaction, breaking away from the continuum models and moving to a descriptive as opposed to normative schema, proposed by Bishop and Davis (2002).

Within health, another approach to participation is Entwistle’s synthesis of three key theoretical views of participation or consumer involvement.¹⁰ They are ‘ethical’, ‘rights-based’, and ‘consequentialist’ or ‘evidence-based’. A fourth approach, partnerships or co-production, is attributed to consumer organisations and Donobedian.¹⁰

In defining and conceptualising participation for the purpose of the policy, this consultation paper proposes the adaptation of the Bishop and Davis discontinuous interaction approach.⁴⁶ This marks a move away from a normative assessment of the types of participation; however, the categories proposed by Shand and Arnberg and the incorporation of the individual consumer level of participation are included in this adaptation.⁴⁶ Research by Wensing et al. on differentiating between patient-centred communication and shared decision making informed the individual consumer level of participation additions, as did the review on patient-centred care by Bauman et al.^{48,49} The proposed typology is outlined in Table 1.

Table 1 Participation types in a health care system*

Participation type	Objective	Key instruments	Limitations
Information (Precursor to participation)	<ul style="list-style-type: none"> • To support participation • To convey facts • To educate 	<ul style="list-style-type: none"> • Surveys • Focus groups • Public information campaigns • Health consultation (pre-admission, hospital admission, discharge, outpatient clinic or at community health centre and rehabilitation setting) 	<ul style="list-style-type: none"> • Information flow is one-way and is not viewed as meaningful participation. • Medical terminology and hospital procedures might not be well conveyed or understood. • There is a lack of education in patient-centred communication for health providers.
Consultation	<ul style="list-style-type: none"> • To gauge reaction to a proposal/care plan/treatment plan and invite feedback • Consultation is only participation when information gathered can influence subsequent policy, care and treatment choices. 	<ul style="list-style-type: none"> • Key contacts • Surveys • Interest group meetings; focus groups • Public meetings • Discussion papers • Public hearings • Consumer (patient) and carer (family) meetings • Health consultation 	<ul style="list-style-type: none"> • There can be a delay between consultation and any outcomes at the community level. • Communities feel betrayed if they do not like the decision. • It is expensive and time-consuming for complex decisions at the community level. • There can be a lack of time or opportunity for consultation in some acute health care situations. • There is a lack of education in patient-centred communication for health providers.
Partnership	<ul style="list-style-type: none"> • To involve consumers, carers and representatives in aspects of government or health service organisational decision making • To involve consumers, carers and representatives in health care or treatment decision making 	<ul style="list-style-type: none"> • Advisory boards • Community advisory committees • Policy community forum • Public inquiries • Shared decision making • Patient-centred care 	<ul style="list-style-type: none"> • There can be the issue of who can speak for a community. • There can be bias towards established interest groups. • There can be legitimacy issues with those excluded from the process. • Time that health service providers are accessible to consumer and carers can be limited. • It requires training in shared decision making or patient-centred care.

Participation type	Objective	Key instruments	Limitations
Delegation	<ul style="list-style-type: none"> To hand control to a board of community representatives within a specified framework To ensure policy options are formulated at arms length from partisan politics 	<ul style="list-style-type: none"> Public enquiries Impact assessment studies Health service boards 	<ul style="list-style-type: none"> It can be intimidating in its formality. There can be a high chance of excluding the most socially disadvantaged.
Control	<ul style="list-style-type: none"> To hand control of an issue to the electorate To hand control to the consumer of health care 	<ul style="list-style-type: none"> Referenda Community-elected board of management Advance care planning 	<ul style="list-style-type: none"> It can be costly, time-consuming and often divisive. It might discourage deliberation of the issue. Processes to respect choices might not be in place or known to the provider.

**Based on the work of Bishop and Davis (2002) and Shand and Arnberg (1996), as outlined in Bishop and Davis (2002).⁴⁶ Inclusion of patient-centred care and shared decision making informed by the work of Wensing et al. (2002) and Bauman et al. (2003).^{48, 49}*

Shand and Arnberg’s conceptualisation is recommended because it is within a service delivery context, but does not exclude a policy context that is consistent with the role of the Department of Human Services. This is in contrast to Bishop and Davis’s categories which focus on public policy development; however, their category of ‘delegation’ as it relates to public policy has been included. The addition of participation at the consumer level in health care ensures all the levels of the policy (Department of Human Services, hospital/service organisation, ward/department, and individual consumer/patient) are articulated. For further reading on patient-centred communication and shared decision making, see the references in Wensing et al.⁴⁸

There are a number of alternative typologies of participation which have not been commented on in this review. For a discussion of some of these, see Thompson et al.⁵⁰

Recommendation 5

The policy should adopt the following definition and description of participation:

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 views, scrutiny of motive and an ability to listen and appreciate others’ views and ideas. Through involvement decisions are made that may accommodate a range of perspectives.

Within a health care system different types of participation can occur across service delivery, planning and policy making. The following types and precursors of participation outline this discontinuous interaction model of participation: control, delegation, partnership, consultation and information.

6 Values and principles

This section identifies the values that should guide the policy and what the underlying principles of participation should be for the proposed policy.

6.1 Values

In Victoria, the Department of Human Services is responsible for administering health care funding and for ensuring public accountability of services provided with that funding. The proposed policy must therefore be congruent with the Department of Human Services' mission and values.

The Department of Human Services has as its mission to 'enhance and protect the health and wellbeing of all Victorians, emphasising vulnerable groups and those most in need'.⁵¹ Its values are:

Client focus	We work towards improving the health and wellbeing of our clients and community.
Professional integrity	We treat all people with dignity and respect.
Quality	We always strive to do our best and improve the way we do things.
Collaborative relationships	We work together to achieve better results.
Responsibility	We commit to the actions we take to achieve the best possible outcomes for our clients and community. ⁵¹

Recommendation 6

The policy will be congruent with the Department of Human Services' mission and values.

6.2 Principles

Several organisations have proposed principles of participation, including the International Association for Public Participation, the Consumer Focus Collaboration, and Health Canada. These organisations' principles of participation are outlined in Appendix 2 and consideration of these sets of principles and the Department of Human Services' values informed the following proposed set of principles as outlined in Table 2.

Table 2 Principles of participation

Principle	Operation
1. Trust	Participation works best where there is mutual agreement of the processes and assessment of the issues under consideration as developed through productive working relationships.
2. Openness	Participation must be built from the ground up and this can only be ensured if all participants are open to considering the ideas of consumers, carers and the community and are willing to accept change.
3. Equal opportunity	At the earliest possible time, involve all those who will be affected by the decisions, inform them of the decision making process and ensure they have access to the information and the means to participate.
4. Advocacy & support	Participation must be supported from the top and resourced so that participation is meaningful for the consumer, carer and community member.
5. Responsiveness	The capacity to undertake participation requires skilled organisations and benefits from multiple strategies and resources.
6. Shared ownership	All involved share ownership of the process and decisions and are responsible for monitoring and evaluating the impact and outcomes. How the responsibility is distributed should be defined as part of the participation arrangement.
7. Dissemination	The decisions made, and how consumers, carers or community members' participation influenced those decisions, should be communicated to all those involved and affected by the decisions.
8. Evaluation	Lessons learnt from the participation process should be identified and communicated as widely as possible.

Putting these principles into operation is the key to enabling participation within an organisation. Draper's (1997) collection of examples and the Consumer Focus Collaboration publications support this idea.^{1, 10} In addition, research undertaken into citizen involvement in health care investigating the National Health Service in England found similar priorities regarding how to take forward the involvement agenda.⁵⁰

Recommendation 7

The recommended principles of participation are trust, openness, equal opportunity, advocacy and support, responsiveness, shared ownership, dissemination and evaluation.

7 Evidence of participation

As indicated, the articles reviewed in the evidence section were limited to English publications published between January 1998 to December 2004 and were accessed primarily through the Clinician's Health Channel, Department of Human Services. Time constraints made it necessary to further limit the review to full text articles and there was some searching by hand. Key words used in the review of evidence were 'participation AND consumer' and 'patient education'. The time period was restricted because the previous years were covered by the Consumer Focus Collaboration's report, *The evidence supporting consumer participation in health care review*⁶ and by the *Systematic review of involving patients in the planning and development of health care* by Crawford et al.⁸ Crawford et al. excluded, among other research, participation focusing on 'the role of doctors and patients in determining individual treatment choices'. This research is important to the development of the proposed policy and was included in the review. Databases searched include PubMed, Ovid Medline, PreMedline and CINAHL and Informit AMI.

7.1 Criteria

The review included papers that focused on hospital-based care and cases where the need for hospitalisation was reduced. For example, studies demonstrating that self-management contributed to reducing the need for hospitalisation were included. Studies on participation in determining individual treatment choices were included, as were literature reviews and papers on participation in research which described the implications for changes in practices and health outcome benefits for consumers, carers or the community. Studies specifically focusing on primary care and mental health were excluded to ensure a focus on the identified policy gap areas of acute and subacute. Titles and abstracts of the papers were reviewed if they met the above criteria and were then read and analysed against the framework described in Section 7.2.

7.2 Analysis

The published evidence of participation was assessed using a framework based on:

- proposed types and precursors of participation as outlined in Section 5.2
- the research design (qualitative or quantitative; randomised control trial, review, survey or questionnaire, case study, action research, focus group, structured/unstructured interview, or economic evaluation)⁵²⁻⁵⁴
- whether the evaluation focused on the determinants of process, impact or outcome
- the review work done by Crawford et al.⁸

Process evaluation verifies whether or not a program was delivered as intended, including to the degree intended, and is usually concerned with questions of efficacy and availability.⁵⁵ For example, have public health services developed community advisory committees in accordance with the legislation and the non-statutory guidelines?

Impact evaluation determines if the immediate outcomes of a program were achieved and often relies on data that are indicators of long term outcome aims. For example, staff were identified as communicating more effectively with culturally and linguistically diverse consumers following a training program on using translating and interpreting services.

Outcome evaluation determines if a program's longer term aims (often over two to three years) were achieved and relies on the availability of end result data. Judgements are made as to 'the extent to which and the ways in which outcomes are caused by the program'.⁵⁵ For example, consumers were found to use medications and education strategies effectively two years after group education at a community health centre following introduction of a new education program based on shared decision making.

The analysis is itemised in Table 8, Appendix 3 and this should be read in conjunction with the systematic review of reports by Crawford et al. (Table 9, Appendix 3) and the Consumer Focus Collaboration's evidence report.^{6, 8}

7.3 Findings

The published evidence is beginning to grow across the levels (government department, hospital/service organisation, ward/department, and individual care). This is important because historically there has been a lack of evaluation studies on participation. However, there are many missed opportunities and a policy direction that promotes the evaluation of participation needs to include publication and promotion. This finding is explored further in Section 10, which looks at a participation evaluation and monitoring framework.

As the evidence reviewed went across the four levels of the policy, no one specific level was identified as a priority. There were few randomised controlled trials and a predominance of qualitative and descriptive statistical analysis. Attention to the quality of the design and analysis was not possible in this review, but it is an area that needs to be considered. In addition, there were few evaluations that focused on the outcome level (most evaluations were categorised as process evaluation) or economic impact, and participation and evaluation need to be increased in the developing field of health informatics.

Overall, findings supported participation and, where comparisons were made, demonstrated that participation frequently added different information from that provided by government, researchers and health service providers. Participation was seen to improve or contribute to:

- guidelines that had previously been developed by expert bodies
- psychosocial indicators of health
- how and when information is provided
- the evidence base for choice of education strategies or programs for consumers and carers
- the reduction in the use of follow-up and emergency services
- design of clinical trials in relation to ethically challenging studies.

Summaries of the findings of specific studies are outlined in Tables 8 and 9, Appendix 3.

It is also important to note there were a number of studies that did not meet the analysis criteria primarily because the effect of the consumer education component of the study was not assessed as an independent factor. For example, in the randomised control trial conducted by Young et al., education of the patients was a component of the intervention, but no analysis of that component's contribution to the outcome was made.⁵⁶ The researchers did note further studies should investigate component parts of the intervention.

Recommendation 8

The policy should identify that participation can add to and improve program design, clinical guidelines and psychosocial indicators of health, reduce health service use, and inform health care decision making.

Recommendation 9

Evaluation of participation activities should be undertaken to increase our understanding of the effects of participation, specifically concerning health outcomes and economic effectiveness of participation.

Recommendation 10

Evaluation in the area of consumer informatics and the changes this brings to the relationship between consumers and carers and the health professional, as well as the impact on health outcomes and costs, is a priority.

7.4 Victorian participation activity

Multiple participation activities are occurring within the Victorian health care system. These need to be documented, monitored and, where possible, evaluated and the learnings shared.

Recommendation 11

Evidence of participation activity in Victoria needs to be documented throughout the policy development consultations and this information included in the policy.

8 Enablers and resources

8.1 Enablers

The review identified multiple enabling factors for participation. A summary of these is presented here for the broad participant categories of staff member of an organisation (health service or government department), consumer, carer, and community member. For further information in this area, see the Information Series on the Participate in Health web site <<http://www.participateinhealth.org.au/>> and the Consumer Focus Collaboration report, *Improving health services through consumer participation: a resource guide for organisations*.¹

Table 3 Enablers of participation

Organisational staff members	Consumers, carers and community members
Communicate to all staff that support for participation from the top of the organisation is forthcoming and that the organisation has a willingness to accept change.	Consumers, carers and community members should be involved from the earliest possible time and be given adequate notice.
Promote to staff the organisational policies and structures that facilitate participation.	They should be involved in developing the processes and issues under consideration.
Provide staff with training and information on how to facilitate participation.	Ensure they understand the language and systems the organisation uses.
Work with each other to create trust and mutual understanding of the participation issue.	Check information is culturally and age appropriate.
Decide on lines of accountability and terms of reference.	Ensure they are not isolated. Use open and inclusive processes and identify key staff who can provide individual support.
At the earliest possible time, inform all staff who will be affected by the decisions and provide access to information.	Reimburse costs of participation and provide resources to allow participation.
Consider and provide resources for a range of strategies to facilitate the particular participation aim.	Do not overburden people. Remember there are other important components of their lives.
Identify from the beginning organisational mechanisms to incorporate the lessons learnt into daily practice or future planning and policy development.	Inform people of the outcomes of their participation.
Ensure staff are skilled in evaluating participation activities and can publish results.	

8.2 Resources

There are many resources for consumer, carer and community participation. The references to this paper list many of these resources. Table 4 outlines the main web sites for participation resources.

Table 4 Key web sites with participation resources

• **Consumers Health Forum of Australia:** <www.chf.org.au>

This is the leading national organisation providing a voice for all health consumers. It works to promote consumers' views in all areas of health care. It contains links, publications and resources and has a consumer representative program.

• **Cochrane Consumers and Communication Review Group:** <www.latrobe.edu.au/cochrance>

This group coordinates the preparation and production of systematic reviews of interventions that affect consumers' interactions with health care professionals, services and researchers. It gives free access to the Cochrane Library in Australia. Another web site with resources that is linked to a range of Cochrane collaboration groups is the Informed Health Online site at <www.informedhealthonline.org>. The site is produced by the Health Research and Education Foundation Ltd, which is a health promotion charity based in Melbourne, Australia.

• **Department of Human Services:** <www.health.vic.gov.au/consumer>

The department supports a range of initiatives that promote and support consumer involvement in decision making about their own treatment and care, in-service development and quality improvement, and health policy developments. It contains information on Victorian Quality of Care Report guidelines, Victorian community advisory committees, links to international web sites and to the department's other web sites and those of Victorian hospitals, and has a range of participation publications, including *Communicating with consumers: good practice guide to providing information*.

• **Health Issues Centre:** <www.healthissuescentre.org.au>

The Health Issues Centre has gained a strong reputation around Australia for its public interest research and its analysis of the health system, particularly promoting awareness of consumer perspectives and needs. Its web site provides a consumer nominee program in Victoria, has links, a journal, library, policy analysis and publications. The Health Issues Centre maintains the National Resource Centre for Participation in Health's web site <www.participateinhealth.org.au>. This web site has many training resources and tools on participation, Consumer Focus Collaboration resources, and links.

• **Our Community:** <www.ourcommunity.com.au>

This is a one-stop gateway for practical resources, support and links between community networks and the general public, business and government. It builds capacity to strengthen the community in every Australian state and territory. Our Community holds an annual conference and has a calendar of events and a directory of non-profit community organisations.

• **Victorian Quality Council:** <www.health.vic.gov.au/qualitycouncil>

The Victorian Quality Council is responsible for fostering better quality health services in Victoria by working with stakeholders to develop useful tools and strategies to improve health service safety and quality. One of the Council's five key strategic areas is increasing the involvement of consumers in improving safety and quality of health care in Victoria. To assist health services to source consumers to collaborate on safety and quality improvement, the Council developed a guide, *Finding consumers and carers*, which is available on the web site. Further information on participation in relation to the quality and safety of health care can be found on the web site of the Australian Council for Safety and Quality in Health Care <www.safetyandquality.org>.

Recommendation 12

The enabling factors and key web sites should be promoted as part of the policy.

9 Barriers

The literature review identified the key barriers to participation. They are presented in Table 5. Barriers can be inherent to an organisational structure and systems, attitudinal, or arise from a lack of cultural and socioeconomic considerations.

Table 5 Barriers to participation

Organisational staff members	Consumers, carers and community members
A lack of overt support for participation from the top of the organisation	A lack of power concerning health and organisational knowledge
No provision of policies and structures on how participation can be achieved to staff	An unquestioning approach to receiving medical information, or receiving inadequate explanations
No staff skills in facilitating participation and no consideration that resources are necessary to achieve participation	No provision of support and resources for the individual consumer, carer or community member to participate
Strategies chosen by staff in isolation from consumers, carers and the community	No or poor feedback processes from consumer representatives to constituents
No resources for skills in evaluation. Lessons learnt are lost and not incorporated into the entire organisation	Escalation of poor health or caring role, preventing participation as previously established

Recommendation 13

The identified barriers to participation should be addressed as part of the policy.

10 A participation evaluation and monitoring framework

10.1 Evaluation

Evaluation involves collecting information (data), analysing the information, drawing conclusions and ascribing a value or judgement to the conclusion. It also involves considering the values and making recommendations. Therefore, evaluation is concerned with answering the questions of:

- efficacy/explanatory evaluation: can it work?
- effectiveness: does it work?
- availability: is it reaching those who need it?
- efficiency/economic evaluation: should the resources be spent on this program, procedure or service as compared with other things and, second, should they be spent in this way rather than some other way?^{52, 53}

Answering these evaluation questions involves a range of data types. It is often the availability of data that determines which questions can be answered and impacts on the value assigned to the conclusion. The importance of design, quality of the data or information, and choice of analysis methodology are key factors in building a knowledge base about how participation affects the health care system.^{53, 54}

Another way of conceptualising evaluation is the program evaluation model of process, impact and outcome evaluation outlined in Section 7.⁵⁵ The questions evaluation is concerned with answering can be incorporated into this model. The model is based on assessing the implementation and effects of the strategies employed, especially concerning the specific objectives of the program. This model is commonly used in health program evaluation and would be adaptable across the levels of the policy.

10.2 Monitoring

Monitoring ongoing performance is also important given the beliefs that are held about why participation is valued in relation to public accountability and the improvement of health outcomes. Current activities that involve monitoring participation are:

- external accreditation
- the Victorian Patient Satisfaction Monitor
- Quality of care reports
- annual reporting against community participation plans for legislatively designated public health services.

10.3 Proposed framework

Based on these evaluation models and existing monitoring activities, a Victorian framework for monitoring and evaluating participation activities across the levels of the proposed policy might include the following elements (Diagram 1 and Table 6). The suggested activities are not an exhaustive list and feedback from stakeholders will be sought to enhance the framework.

Diagram 1 Participation evaluation cycle

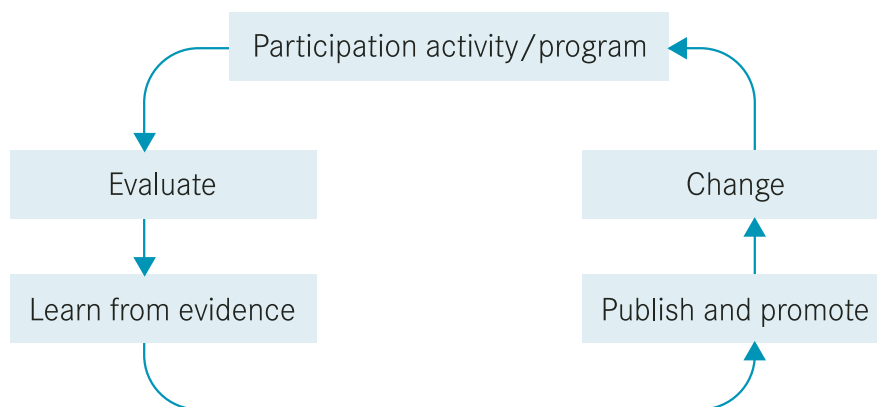


Table 6 Participation evaluation and monitoring activities

Policy level	Process	Impact	Outcome
Department of Human Services (appropriate areas)	<ul style="list-style-type: none"> • Meet Cabinet Handbook guidelines on appointments to committees.⁵⁷ • Meet Department of Human Service guidelines on advisory committees.³⁷ • Meet the <i>Partnership in practice: partnership agreement</i> guidelines.³⁶ 	<ul style="list-style-type: none"> • Relate result back to specific terms of reference, objectives, targets/indicators to evaluate participation at the policy and planning level. 	<ul style="list-style-type: none"> • Determine how effective participation has been in achieving its role as an enabler of departmental policy and programs.
Hospital/service organisation	<ul style="list-style-type: none"> • Achieve guidelines for community advisory committees. • Achieve guidelines for quality of care reports in relation to participation. • Meet Victorian Quality Council checklist for participation in safety and quality improvement.^{22, 58} 	<ul style="list-style-type: none"> • Evaluate if targets of the community participation plan have been achieved. • Meet external accreditation standards; for example, those about access. • Evaluate if specific participation activities, programs, and policies objectives have been met. 	<ul style="list-style-type: none"> • Evaluate achievement of community participation plan objectives and aim. • Evaluate collected evidence about meeting the long term goal of participation for a specific program or policy.
Ward/department	<ul style="list-style-type: none"> • Establish specific projects incorporating participation to evaluate efficacy, accessibility or efficiency of participation. • Have consumers and carers participate in development of clinical guidelines and evaluation of ward/unit/departmental processes. 	<ul style="list-style-type: none"> • Evaluate specific projects incorporating participation to evaluate effectiveness, or efficiency of participation. 	<ul style="list-style-type: none"> • Evaluate long-term participation goal/aim of project to identify effectiveness or efficiency of participation.
Individual consumer /patient	<ul style="list-style-type: none"> • Evaluate feedback strategies and information distribution processes. 	<ul style="list-style-type: none"> • Create a sub-index on participation within the Victorian Patient Satisfaction Monitor. • Evaluate feedback strategies and information distribution impact. • Evaluate the impact of consumer participation in decision making about care and treatment at pre-admission, during admission and post-admission. 	<ul style="list-style-type: none"> • Evaluate the effect of participation in decision making on readmission rates and primary care use.

Performance indicators are not identified as part of the suggested evaluation activities in Table 9; however, some of the suggested activities could be proposed as indicators. The Department of Human Services has contracted the Health Issues Centre to research the development of participation indicators across the health care system. The Centre's research will be reported to the Policy Reference Committee and published separately to enhance consultation with stakeholders in this area.

Recommendation 14

The participation evaluation and monitoring framework should be adopted in the policy and promoted across the health care system.

11 Conclusion

Reviewing a range of information for this consultation paper has led to the development of a number of recommendations about formulating a participation policy. The review ensured the recommendations link into and are consistent with existing participation policies in the primary and mental health areas in Victoria. The comprehensiveness of the recommendations should also ensure the proposed policy establishes a guiding framework which includes evaluating and monitoring participation activities. The recommendations define participation and other terminology and identify the guiding principles of participation and the reasons participation is important to the ongoing development of the Victorian health care system. Key resources, enablers and barriers to participation have also been identified.

Time constraints limited the review, but it was closely monitored by and benefited from the advice of the Policy Reference Committee. Specific limitations of the review are that it was not possible to assign a quality rating to the research evidence and a second or third reviewer did not check the assessments.

The next stage in developing the policy is to consult with consumers, carers, community members and representatives, health service providers, and Department of Human Services staff about the proposed recommendations. From this consultation, a policy will be developed and confirmed with the stakeholders.

Appendix 1

State and territory policies and key documents

Table 7 National, state and territory policies and key documents on participation

Jurisdiction	Policy title
Australian Capital Territory	<i>Health action plan</i> ⁵⁹
Commonwealth Department of Human Services and Health	<i>The final report of the taskforce on quality in Australian health care</i> ⁶⁰
(Commonwealth) Australian Council for Safety and Quality in Health Care	Please refer to publications on the Council's web site: www.safetyandquality.org
New South Wales	<i>Strategic directions for health 2000–2005</i> ⁶¹
	<i>New South Wales Department of Health: guidelines to selecting consumer and community representatives</i> ⁶²
	<i>Working with consumers in New South Wales Health: guidelines for secretariat</i> ⁶³
Northern Territory	<i>Building healthier communities: a framework for health and community services 2004–2009</i> ⁶⁴
Queensland	<i>Consumer and community participation toolkit</i> ⁶⁵
	<i>Community engagement handbook</i> ²¹
South Australia	<i>First steps forward: South Australian health reform</i> ²⁴
	<i>SA Department of Human Services strategic directions 2003–2006</i> ⁶⁶
Tasmania	<i>Department of Health and Human Services corporate plan 2003–2006</i> ⁶⁷
Western Australia	<i>A healthy future for Western Australians</i> ²⁵

Appendix 2

Collected principles of participation

The International Association for Public Participation states on its web site the seven core values or principles of participation as follows:

- 1 The public should have a say in decisions about actions that affect their lives.
- 2 Public participation includes the promise that the public's contribution will influence the decision.
- 3 The public participation process communicates the interests and meets the process needs of all participants.
- 4 The public participation process seeks out and facilitates the involvement of those potentially affected.
- 5 The public participation process involves participants in defining how they participate.
- 6 The public participation process provides participants with the information they need to participate in a meaningful way.
- 7 The public participation process communicates to participants how their input affected the decision.⁶⁸

The Consumer Focus Collaboration devised eight key principles of participation based on the work of Lapis and Verity (2000):

- Principle 1:** Participation means partnership, means accepting uncertainty.
- Principle 2:** Deciding for effective consumer participation means deciding for organisational change.
- Principle 3:** Align your consumer involvement plans with organisational capacity. Involve staff in building that capacity.
- Principle 4:** Consumer participation must be supported from the top.
- Principle 5:** Consumer participation must be supported from the top down, but it is built from the bottom up.
- Principle 6:** It's all about relationships, so use and build people skills.
- Principle 7:** Consumer participation needs partnerships, partnerships need dialogue, dialogue needs trust. So build trust.
- Principle 8:** Multiple strategies work better.⁷

Similarly, Health Canada devised seven working principles of participation:

Equal opportunity for participation and receipt of information: As much as possible, all parties who express interest, who can contribute to a decision, or who are affected by the outcome should have an equal opportunity to influence decisions and receive equal access to information.

Mutual understanding: A clear, mutual understanding of the purpose of public involvement, and of the roles and expectations of all parties involved, should be established at the outset and revisited or redefined over time if necessary.

Early public involvement: The public should be involved early in defining the issues and possibly in the definition of public involvement processes and in providing input before decisions are made. When partnerships or joint decision-making processes are in place, accountabilities may be shared by government and other parties.

Outcomes are not predetermined: All those in a decision-making role need to be open to considering ideas and solutions brought forward by the public.

Shared responsibility and evaluation: Those who participate share responsibility for the success of the process, agree to participate in good faith and meet public participation objectives, and help evaluate the results of the process and related health outcomes.

Accountability: Accountability for final decisions, and for the public involvement process itself, should be seen to rest with government, unless a partnership or joint decision-making arrangement has been set up.

Decisions widely communicated: Decisions, including their rationale and the impact of public involvement in their development, should be communicated widely.

Evaluation of result, and of the public involvement process: The public should be involved in evaluating the success of the process, and in identifying lessons learned that will contribute to the success of future public involvement plans.¹³

Appendix 3

Review of published evidence

Table 8 Evidence of participation

Study	Nature of evidence	Participation type	Nature of service	Location and policy level	Findings
Andejeski et al. ⁶⁹	Survey and cross-sectional analysis (impact)	Partnership, breast cancer research	Scientific review panel	United States (government and organisation)	Support participation and recommend for other research programs
Ard and Natowicz ⁷⁰	Expert review (process)	Partnership, human and medical genetics	Government advisory committees	United States (government)	Low representation need to increase numbers
Bauman et al. ⁴⁹	Review of evidence and principles of patient-centred care	Partnership. One of the principles of patient-centred care is the formation of a partnership between clinician and patient.	General practitioners, asthma and diabetes studies	Australia (government, ward, individual)	Some evidence: increases patient satisfaction, engagement and task orientation, reduces anxiety and improves quality of life, and increases doctor satisfaction
Birchall et al. ⁷¹	Focus groups, qualitative multicentre study (process)	Partnership method worked with sensitive groups: bereaved carers and disfigured consumers.	Professional advisory process on national standards	United Kingdom (government, organisation, ward, individual)	Outcome of standards changed with consumer and carer participation
Carr ⁷²	Questionnaires and focus groups, qualitative analysis (process)	Partnerships. Participants views on involvement in processes	Development of national maternal and infant care guidelines	Australia (QLD) (government)	Barriers and enablers to participation identified and contrasted to provider view
Cassin ⁷³	Case study, assisted telephone interviews (impact)	Partnerships. Documents changes and enablers for partnership formation	Cardiac support group members creating change in hospital organisation	Australia (NSW) (organisation, ward, individual)	Trust and personal relationship establishment through avenue of partnership formation led to change from consumer input

Study	Nature of evidence	Participation type	Nature of service	Location and policy level	Findings
Clarke et al. ⁷⁴	Focus groups (process)	Consultation. Biographical approach to participate in own care	Aged care service, nursing care	United Kingdom (organisation, ward)	Promotes patient-centred care. Improved well-being of patients, carers and staff
Dolan et al. ⁷⁵	Pre- and post-participation focus group discussion (process)	Consultation. Evaluation of the effect of discussion on decision making by primary care consumers	Health priority setting	United Kingdom (government)	Health priority setting by consumers, carers and the community require a reflective process
Durey and Lockhart ⁷⁶	Semi-structured interviews, qualitative (process)	Consultation. Development of a new multipurpose service	Planning and development	Australia (rural and remote) (government)	Lack of representation, need guidelines on consultation for all
Gardner et al. ⁷⁷	Postal survey (impact)	Consultation. Parents of post-Neonatal Intensive Care Unit infants	Neonatal intensive care	Australia (ACT); (individual)	Support the selection and implementation of parent role and support programs
Green et al. ⁷⁸	Expert review. Comparison of web information to scientific quality information (process)	Information available for consumer access	15 web sites identified by three search engines on bone mineral density	Canada (international); (individual)	Scientific information not available using popular search engines. Consumers deflected from optimal treatment.
Guevara et al. ⁷⁹	Cochrane systematic review randomised controlled trials (impact and outcome)	Partnership towards control	Asthma education about children and young people	United States (international); (individual)	Improved lung function, self-efficacy, reduced emergency visits, absenteeism from school and days of restricted activity
Henderson et al.80	Questionnaire and follow-up telephone interview (impact)	Information impact	Discharge information for surgical patients	Australia (QLD); (ward, individual)	If information received less likely to access health service for follow-up. Questions of adequacy of information

Study	Nature of evidence	Participation type	Nature of service	Location and policy level	Findings
Horey et al. ⁸¹	Cochrane systematic review of randomised controlled trials (impact)	Information effectiveness. Perception of participation in decision making not measured	Caesarean birth information	Australia (international); (individual, ward)	No difference between groups on any outcomes measures. Further research recommended
Johnson and Bament ⁸²	Interviews and focus groups (process)	Consultation with consumers, community members and representatives	Preference about how to be involved in improving quality of hospital service	Australia (SA); (organisation, ward, individual)	Consumers and community members preferred 'passive' participation and representatives in 'active' methods. Use to prevent exclusion of participation of some groups
Kaplan and Brennan ⁸³	Qualitative review of structured consultation discussion (process)	Consultation conference with consumers/patients included as expert speakers	Conference session, 'Consumer informatics supporting patients as co-producers of quality'	United States; (government, organisation)	Research agenda prioritised with focus on supporting a provider consumer partnership
Kirk et al. ⁸⁴	Qualitative semi-structured interviews (process)	Consultation. Carers and consumers on satisfaction with information sharing and experiences of disclosure	Hospice. Themes of hope and prognosis and fully sharing with carer. With progression needs changed.	Australian (WA) and Canada; (individual, ward)	CALD did not diverge from carer and consumer sharing information. Stage of illness did diverge needs of carers and consumers
Koops and Lindley ⁸⁵	Quantitative and qualitative consultation, questionnaire, and focus group (process)	Consultation moving to partnership. Clinical trial development	Thrombolysis for acute ischaemic stroke	United Kingdom; (organisation)	Participation led to an ethically accepted trial in a difficult field and improved information to consumers and carers

Study	Nature of evidence	Participation type	Nature of service	Location and policy level	Findings
Oliver et al. ⁸⁶	Systematic Cochrane review	Information to partnership	Advice to parents from routine newborn blood spot screening service	United Kingdom (international); (government, organisation, ward, individual)	No controlled trial evidence. Need to evaluate the effects of interventions to support disclosure of carrier status to parents
Rankin et al. ⁸⁷	Telephone survey (process)	Consultation guideline development	Psychosocial care of women with breast cancer, national guidelines	Australia (NSW); (government)	Identified priority areas for clinicians to address in providing psychosocial care, and guidelines adequately reflected consumer opinions
Rasmussen et al. ⁸⁸	Qualitative semi-structured interviews (process)	Consultation and partnership	Type 1 diabetes and service delivery	Australia (VIC); (ward, individual)	Providers need to make services more accessible, and improve transition from teenager to young adult, pre pregnancy and obstetric care
Sampietro et al. ⁸⁹	Literature review, qualitative and quantitative analysis (process)	Consultation	Women's preferences in health care decision making	Spain; (government, organisation, individual)	Only 4 % of studies related to informing policy debate. Studies limited to white women from USA, UK and Canada
Timonen and Sihvonon ⁹⁰	Survey comparing nurses and patients; scaled reviews on bedside reporting	Identifying aim of reporting and enablers and barriers to participation	Four abdominal surgical and four orthopaedic wards	Finland; ward, individual	Patients did not participate in conversation reporting as much as nurses thought. Nurses need training in patient-centred communication

Study	Nature of evidence	Participation type	Nature of service	Location and policy level	Findings
Tracy et al. ⁹¹	Qualitative focus groups (process)	Consultation evaluating a patient decision aid	How much health care information are consumers willing to share?	Canada (individual)	Identified poor knowledge concerning use of personal health information. Cautious support for decision aid
Weingarten et al. ⁹²	Meta-analysis, patient education (impact)	Partnership. Effect of patient education on chronic illness control	Range of services study characteristics outlined at: < http://www.zynx.com/research/BMI_DM_2002/BMI_evidence_tables.pdf >	International; (individual, ward)	Highest percentage of programs producing significant results were for depression, asthma, and hypertension. Overall a small but significant improvement in disease control
Wellerd et al. ⁹³	Focus groups and observational qualitative analysis (process)	Partnership supporting consumer participation in health care delivery	Acute care at the bedside	Australia (VIC); (individual)	Practice and rhetoric did not match. Observed RN1s with Grade 1, 2 and 3 positions. Lack of basic relationship interaction and development observed
Wensing et al. ⁴⁸	Observational qualitative and quantitative analysis (process)	Partnership. Observation and assessment of patient-centred communication and shared decision making	General practitioners (evidence applicable to hospital setting)	Netherlands; (individual)	Distinguishing between the two and training in both methods in medical education is important to partnerships in care being instigated and developed

Study	Nature of evidence	Participation type	Nature of service	Location and policy level	Findings
Williams et al. ⁹⁴	Telephone survey (process)	Information, consultation and partnership. Audit of guidelines implementation by consumers	Women diagnosed with early breast cancer. Population-based cancer registries	Australia; (government, organisation, individual)	Support, information and care need to be improved to meet the guidelines on decision making, clinical trials, receiving breast reconstruction following mastectomy, evidence-based consumer guidelines and adequate support for families
Zernike and Henderson ⁹⁵	Control group comparison to intervention group. Pre- and post-assessment (impact)	Information to partnership.	Hypertension patient-centred education compared to ad hoc normal provision of information on ward	Hospital ward hypertension Australia (QLD); (individual, ward)	Role of nurses in acute care can include structured education. The benefits in increased knowledge are evident with indications for behaviour change
Ziebland et al. ⁹⁶	Qualitative analysis of narrative interviews (process)	Information. Use of internet information	Cancer patients' relationship with doctor	United Kingdom; (individual)	Covert questioning of doctor's information can maintain doctor/patient relationship if desired. Development of the competent consumer and arising question of negligent consumer

Table 9 Reports providing details of the effects of involving patients in planning and delivering health care⁸**

Study	Nature of evidence	Form of involvement	Nature of service	Location	Reported outcomes
Carlson and Rosenqvist	Retrospective review of records	Consultation meetings with 34 patients	Diabetes management in primary care	Sweden	Changes to organisation of care and information for patients
Milewa	Retrospective review of records	Five patient forums	Mental health	United Kingdom	Unspecified changes to organisation and delivery of services
Nutt	Retrospective review of records	Patient representation at 12 planning meetings	Primary care	United States	Broad range of suggestions for changes to services
Pilgrim and Waldron health	Action research	Patient group with 14 members	Mental health	United Kingdom	Extension of community mental team hours; funding of advocate; publication of service information for users
Sheppard	Action research qualitative methods	Meetings with patients at five general practitioners' practices	Primary care	United Kingdom	User involvement appreciated by patients and providers
Taylor	Action research	Range of consultation projects across all sectors and stakeholders	Learning disability	United Kingdom	Implementation of revised patient information; patients' input into substantial overhaul of services
Bowl	Telephone survey of 31 managers;	Patient forums	Mental health	United Kingdom	Patient dissatisfaction
Checkoway et al.	Survey of 154 service providers	Patient representation at meetings	General health	United States	Increased confidence of users who participate; changes to services provided
Hendessi	Survey of service providers	London-based patient groups and forums	Broad range	United Kingdom	Changes in policy, quality and methods of service delivery
NHSE	Survey of service providers	Mixed involvement initiatives	Range of settings	United Kingdom	Simplified procedures; provision of new services
Richardson and Bray	Postal survey	63 patient participation groups	Primary care	United Kingdom	Reorganisation of waiting rooms; development of new clinics; changes to opening times
Todd et al.	Interviews; qualitative analysis	Patient and carer representation on planning boards	Learning disability services	United Kingdom	User and carer dissatisfaction

Study	Nature of evidence	Form of involvement	Nature of service	Location	Reported outcomes
Atkinson and Farshi	Case study	Audit involving interviews with 32 service users	Community paediatric	United Kingdom	Changes to dissemination of information
Barnes	Case studies	Three user groups	Mental health	United Kingdom	Improved self-esteem
Barnes	Case study	User committee	Community care for physically disabled	United Kingdom	No changes implemented
Berger et al.	Case study	Consumer committee	HIV clinic	Australia	Patient-friendly services and support; improved self-esteem of patients
Broderick	Case study	Survey of 140 people by CHC	General health	United Kingdom	Reversal of plan to close hospital
Dixon et al.	Case study	Two patients employed as consumer advocates in assertive outreach team	Mental health	United States	Improved engagement with patients and staff awareness, but problems with boundaries
Elizabeth	Case studies	Three citizens' juries	General health	United Kingdom	Increase in participants' self-confidence and interest in local democracy
Gummer and Furney	Case study	Staff-patient forum: patients representing six groups	Mental health	United Kingdom	Improved design of new services; plan for advocacy; improved information, training and recruitment; culture shift; increased user self-esteem
Harris	Case study	Patient forum	Mental health	United Kingdom	Promotion of further user involvement
Harrison and Mort	Case studies	Health panels run by CHC	General health	United Kingdom	Little evidence of changes to services
Heginbotham	Case studies	Range of initiatives, including campaign by CHCs	Broad range	United Kingdom	Reversal of plan to close hospital
Kirk et al.	Case studies	Range of initiatives, including interviews with service users	Primary care	United Kingdom	Support for existing plans for expansion of services
Lord et al.	Case study with qualitative methods	Stakeholder meetings, including with service users	Mental health	Canada	Shift in service delivery towards individualised care; broader-based ownership and control
Millet	Case studies	Survey of 120 patients and three focus groups	Medical outpatients	United Kingdom	Development of information and shared care record book

Study	Nature of evidence	Form of involvement	Nature of service	Location	Reported outcomes
National Health Service executive	Case studies	Mixed methods (surveys, meetings)	General health	United Kingdom	Impact on strategies unclear; some service improvements, better communication with local residents
Pagett	Case study	Service users panel	Medical outpatients	United Kingdom	Revised patient information and appointment cards; improved disabled facilities
Pecarchik et al.	Case study	Health and welfare council	General health care	United States	Pressure from service users sped up changes to organisation of blood banks.
Poole	Case study	User-focused monitoring*	Neurological disorder	United Kingdom	Patients and staff found user involvement rewarding.
Sheahan	Case study	Survey of discharged patients	General hospital care	Australia	Development of information booklet
Silva	Case study	Client group to plan respite facility	Mental health	United States	Clients directed service design, became volunteer staff, and reduced dependency.
Smith	Case study	Ex-client representation at meetings; survey of current clients	Mental health	United States	Promotion of rehabilitation through enhanced self-worth, self-reliance
Summers and McKeown†	Case study	Mixed: focus groups; consultation; interviews; patient survey; CHC	Maternity services	United Kingdom	Strategy reflects call for more linkworkers; better catering; staff interest in user views stimulated
Summers and McKeown†	Case study	Mixed: focus groups; user forum; survey of voluntary organisations; CHC	Mental health	United Kingdom	Improved self-esteem for users; stimulated staff interest in user views
Tishler	Case study	Consumer board overseeing service providers	Mental health	United States	Training for staff on patient needs
Williams	Case study	Patient and staff interviews; survey	Outpatient services	United Kingdom	Improved waiting times, notes retrieval, patient information, and feedback to patients
Wistow and Barnes; (three studies)	Case study with qualitative methods	Survey; citizen advocacy; meetings	Community health and social care	United Kingdom	Improved access to services; enhanced self-esteem of users who participated; service provider more open to user involvement
Woods	Case study	Questionnaire survey	Surgical inpatient	United Kingdom	Revised admissions and discharge procedures and information; improved ancillary services; complementary medicine; liaison group established
Young	Case study	Lay board of directors controlling a primary care clinic	Primary care	Canada	Dissatisfaction among service providers

* A form of quality assessment by service users. † Two separate case studies in one report.

** This table is the work of Crawford et al. and all references can be found in the original work: Crawford M, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, et al. Systematic review of involving patients in the planning and development of health care. *British Medical Journal* 2002;325(1263-doi:1136/bmj.325.7375.1263).

Appendix 4

Policy Reference Committee

The Participation in your health service system policy reference committee was established to facilitate the development of the proposed policy through expert advice and stakeholder input to the project officer throughout the policy development process.

Membership of the committee is for the duration of the policy development process. Committee membership commenced in July 2004 and is expected to end in June 2005.

The Department of Human Services sought committee members from key stakeholder groups and from among individuals so that consumers, carers and community members, the department, hospital executives, and professional and community groups were represented.

Membership

Chair: Dr Jenny Bartlett

Dr Jenny Bartlett is the Chief Clinical Advisor for the Department of Human Services and heads up the Office of Chief Clinical Advisor. This office is responsible for developing and implementing clinical quality and innovation programs for health services in Victoria. The program covers clinical improvement, clinical risk management, infection control, consumer policy and other aspects of consumer safety.

In addition she provides specialist clinical advice on all aspects of the division's activities, including advice to health services. She established the Victorian Quality Council and the Surgical Consultative Council as well as managing the Consultative Council on Anaesthetic Morbidity and Mortality. Management of the critical care and trauma programs for the state also sit within her portfolio.



Deputy Chair: Ms Helen Kurincic

Helen Kurincic became the Executive Director of Benetas (formerly Anglican Aged Care Services Group) in October 2000. Benetas offers an integrated network of residential and community aged care services to more than 1500 clients across 17 sites in Melbourne and employs 700 staff who are supported by several hundred volunteers. Helen first qualified as a registered nurse specialising in critical care. She went on to complete a Graduate Diploma in Women's Studies, a Master of Business Administration (specialising in accounting and finance) and a company director's course. Prior to working in a variety of leadership roles in aged care, Helen held consultancy, academic, counselling/advocacy and nursing positions.

She is actively involved in aged care policy and sector planning, representing the interests of the aged at many national and state forums. Helen is also on the Board of Melbourne Health Metropolitan Health Service (currently Chairperson Workforce Governance Committee and Acting Chair Community Advisory Committee) and the Board of the Victorian Association of Health & Extended Care. Helen was awarded the 2002 Telstra Victorian Business Woman of the Year. Helen was also a finalist in the national top five of the leading CEO for the advancement of women in the 2003 EOWA Annual Business Achievement Awards.



Mrs Judy Rynhart

I am married with five children and live on a farm at Elmore, which is half way between Bendigo and Echuca. My husband, Robert, and I farm hay and sheep.

I am a consumer representative on BreastScreen Victoria's Board of Management as well as being on the Victorian Consumer Advisory Committee for BreastScreen. I started on the BreastScreen Board about nine years ago and four years later became the Chair of this meeting and two years ago we started a consumer group at Bendigo which I also chair. The Elmore branch of the Country Women's Association plays a big part in my life and at present I am their president as well as regional chair for Red Cross.

I feel it is important to have consumers on committees as consumers bring a different point of view to the discussion around the table and it keeps the basic tone of the meeting honest.



Ms Dell Horey



I have been an active consumer representative in Australia for more than a decade, prompted by my experiences in maternity care. It seems obvious to me that people using health care services are in a good position to offer input into how health care can be improved and could better meet the needs of individuals.

My interest in perinatal research encouraged me to undertake a masters degree in clinical epidemiology. This was followed by studies towards a PhD looking at issues related to information given to women in pregnancy.

I am a member of the board of the Health Issues Centre and the Australasian coordinator of the consumer panel of the Cochrane Pregnancy and Childbirth Review Group. In this role I encourage women to comment on reviews of research in this area. I am also an editor with the Cochrane Consumers and Communication Review Group. I am also interested in health workforce issues and have participated in a range of working parties that have looked at specific aspects of the workforce.

Ms Carol Makhoul



My involvement on this reference committee stems from my interest in the development of a policy that is inclusive of, and reflects, the health needs and experiences of Victoria's culturally and linguistically diverse communities, and young people. Both culturally and linguistically diverse community members and youth have specific health needs and experiences in accessing and using health services, including barriers to full consumer participation, which need to be addressed.

My recent exposure to community health related needs and issues has come from telephone counselling, and a research project completed with Deakin University, Centre for Citizenship and Human Rights. The research sought to identify the needs of the Arabic-speaking community and gaps in service provision. A range of health needs and issues were raised by these members of the community, which are also relevant to other culturally and linguistically diverse communities.

My honours degree at the University of Melbourne sought to examine the accessibility and cultural sensitivity of domestic violence services to non-English speaking background women. Both these research projects have furthered my understanding of the need for culturally responsive services. Further, I am passionate about working with and empowering young people. I have pursued this through project development and research at the Victorian Arabic Social Services, mentoring with the Centre for Multicultural Youth Issues and, direct support through the Youth Referral and Independent Person Program.

Mr Robin Ould

Robin Ould is the Chief Executive Officer of the Asthma Foundation of Victoria, a position he has held since 1997. Robin has had considerable experience in both the corporate and not for profit sector in the fields of human resource management, training and strategic planning. With family experience of asthma, Robin is personally driven to ensure people with asthma have access to relevant, up to date education and information to better understand and manage their asthma.



Ms Jill Thompson

Jill is Policy Officer for the Victorian office of Council on the Ageing where she has been working for the past nine years. Prior to taking this position, Jill worked in aged care services in local government (Moorabbin) for eight years.

Council on the Ageing is an organisation which has represented the rights and interests of older people at both the state and federal level for over 50 years. We advocate to government and to service providers, on all the social and political factors, which affect their lives.

Mr Tony McBride

Tony is the Chief Executive Officer of the Health Issues Centre, a health consumer- focused policy and research organisation based in Melbourne. He is currently involved in policy advocacy around increased oral health services and Medicare, and in managing the wide range of Health Issues Centre's other research and practice change projects. He was a director of the National Resource Centre for Consumer Participation in Health until its recent closure. Tony has wide experience in a range of sectors: community health and community development in Melbourne and Docklands London; teaching and research in health promotion at Deakin University; managing health and community services for Brunswick and Moreland Councils; coordinating the statewide Healthy Localities Project at the Municipal Association of Victoria; and managing a range of population health funding programs for the Commonwealth Government. Tony was also Chairperson of the Centre for Development and Innovation in Health for many years.

Tony is very supportive of this initiative to develop a Department of Human Services consumer participation policy for health. The research (including recent Health Issues Centre research in Victoria) clearly shows strong policies are an essential component for creating change. Although there are other important factors that will drive increased levels and effectiveness of consumer participation in Victoria, clear departmental policies give a clear message about expectations, offer guidance about directions, and provide a valuable lever for champions at more local levels to utilise.



Mr Ian Pollerd

I began my working life as a Secondary School teacher. I taught economics, legal studies and accounting at a number of schools in metropolitan Melbourne.

Whilst teaching I added to my additional qualifications with a Bachelor of Education and Diploma in Criminology.

I had the opportunity to work as an analyst with the Police Complaints Authority before being appointed to a managerial position at the Baltara Reception Centre. I was then appointed to a number of managerial positions in the western metropolitan region of Melbourne – specialist children, family services, community programs, disability services, and aged care. I am currently manager of rural health policy projects in the rural and regional health services branch.

I have a great deal of experience in both policy and operations and believe that I can make a worthwhile contribution to the reference group. I am an advocate of community participation at all levels of decision-making.



Ms Beth Wilson

Beth Wilson has a Bachelor of Arts and a Bachelor of Laws from Monash University and a Graduate Diploma in Information Technology from the Royal Melbourne Institute of Technology and an Honorary Doctorate in Education from Royal Melbourne Institute of Technology University. She is currently the Health Services Commissioner (health ombudsman) in Victoria. The Commissioner receives and resolves complaints from consumers of health services about health service providers with a view to improving the quality of health services for all. Prior to becoming the Commissioner Beth was the President of the Mental Health Review Board. Her areas of special interest are in medico/legal issues especially ethical aspects, alternative disputes resolution in health care complaints and medical ethics.



Ms Lesley Thornton

Lesley is currently a Senior Project Officer with the Victorian Quality Council. A ministerial commitment was made to establish a new quality council in an announcement to the media in 2000. This followed a recommendation from the Health Services Policy Review Final Report that identified the need for such a body. Launched by the Minister for Health, the Hon John Thwaites MP in October 2001, the Victorian Quality Council is responsible for fostering better quality health services in Victoria by working with stakeholders to develop useful tools and strategies to improve health service safety and quality.

Mr Graeme Roberts

Graeme was born in Carlton in 1938 the eldest of seven children. He grew up in Footscray and attended Geelong Rd Primary School followed by Williamstown High School. Graeme joined the Government Aircraft Factories then Sir George Godfrey and Partners, makers of aircraft equipment in Airport West. He moved to Gippsland and joined the State Electricity Commission as a linesman assistant and went on to qualify firstly as a Linesman C Grade and then as a Linesman A Grade. Graeme enjoyed life in Gippsland playing cricket, squash and football in Moe. He later transferred to Essendon and married in 1964. They moved to Broadmeadows and later Epping where they raised their two children.

Graeme currently serves the Northern Hospital as a volunteer driver and is a serving member of the Austin Hospital's HARP Program reference group. He applied to join the Participation in your health service system policy reference committee as he feels that the health system and the hospital system in particular need a rethink on operational matters.



Ms Trish Karadimos

Hi, I'm Trish Karadimos a former carer of seven years of a mother with Lewy Bodies Disease (Dementia with Parkinsons). I'm also married, have two great kids, Jean-Louis and Andre. Previous to being a mum and carer, I had a varied work background from being a Chairman's secretary in a maternity hospital, to marketing and sales in fashion and furniture then going back to school at 32, in a mature aged capacity, of course, to do hospitality management. My path was planned for me and my journey really became meaningful when I had to care for mum. One becomes very resilient, strong-willed, tolerant and compassionate with this role. I lie, sometimes my tolerance failed me, but my journey has lead me to now do volunteer advocacy work on behalf of carers for Carers Victoria and volunteer work in public speaking for dementia awareness with Alzheimer's Victoria.

My passion and belief in a health system that needs major change, restructuring, more respect for the disabled and the elderly, more understanding for the cultural and linguistically diverse and the many that cannot advocate for themselves has lead me to be a committee member as a carer representative in a reference group to create a policy for the importance of consumer participation in our health system. I have also been involved in other projects but my biggest highlight and my claim to fame was when I spoke at Government House for Carer's Week in 2002. That was a day in October that I was very humbled to be part of a very special group of people that dedicate their lives to helping their sick family members. It was also the day for my very first public speaking assignment. What a way to be launched into volunteer work!



Dr Tracey Batten



Dr Batten was appointed as the Chief Executive Officer for Eastern Health in January 2004. Eastern Health is the main provider of health services to patients who reside in the central east, outer east and Yarra Ranges regions of greater metropolitan Melbourne. With an annual turnover of \$400 million and approximately 6,900 staff, Eastern Health provides acute, mental health, aged care, rehabilitation and community health services across five main campuses: Angliss Hospital; Box Hill Hospital; Healesville and District Hospital; Maroondah Hospital and the Peter James Centre. Prior to 2004, Tracey was the Chief Executive Officer of Dental Health Services Victoria. Tracey has worked in health management roles for the past ten years including the Chief of Health Programs at the Inner & Eastern Health Care Network and Director of Clinical Services at St Vincent's Hospital. Tracey's qualifications include a Bachelor of Medicine and Surgery from the University of Melbourne, a Master of Health Administration from the University of New South Wales, Fellowship of the Royal Australasian College of Medical Administrators, and a Master of Business Administration from Harvard Business School.

Ms Debra Cerasa



Debra Cerasa is the Chief Nursing Officer at Latrobe Regional Hospital and is currently studying for her Doctorate of Business Administration. Debra is a senior health manager with more than 30 years experience in the health industry. Following general nurse training in Deniliquin, Debra returned to Melbourne where she gained clinical experience in general surgical, medical and operating theatre nursing, along with certificates in intensive care and midwifery.

Debra has a keen interest in quality management systems and has been involved in public education and nursing education in a number of Melbourne hospitals. She has also worked with the undergraduate and postgraduate paramedic programs of the Victorian Ambulance Service. Debra held an executive management position as Country Manager - Clinics and Training with International SOS, a privately owned international medical service company based in Indonesia, before being appointed to her current position in 2001.

Her interests in nursing are stimulated by innovation and new concepts in care delivery. Debra's commitment to the professionalism of nursing is evidenced by the many initiatives that she has introduced for the Latrobe Regional Hospital nurses, including the annual nurses forum, the quarterly nurses newsletter, the annual nurses International Conference Scholarship and the Hospital Professional Awards for nurses.

Ms Marija Joyce

Until December 2004 Marija was the Coordinator, Consumer Participation for the Royal Women's Hospital and acts as Resource Officer for the legislatively-based Community Advisory Committee on Women's Health. The ten community-based members of this committee are committed to enhancing links between women in the community and the Board, management and staff of the hospital.

The Community Advisory Committee on Women's Health has, over the last four years, played a significant role in planning for the redevelopment and building of a new hospital for women, due to open in 2008. This planning has included a series of community consultations detailing issues relevant to both the physical design and service provision of the new hospital, ensuring that the needs of the community are well reflected.

In her role, Marija also acted as a resource for staff in the hospital, advising them on the best ways to involve consumers in the planning and review of services. Prior to this role, Marija performed management and coordinating roles in the health and community sector for over 20 years. This included a focus on working with marginalised communities in a range of international development projects and counselling and group work for people, including adolescents, with long term illnesses such as cancer.

Due to leaving her position at the Royal Women's Hospital Marija resigned from the Policy Reference Committee in December 2004. Mr Phill Goulding of the Royal Children's Hospital filled her position on the committee.



Dr Sophie Hill

Dr. Sophie Hill is the Coordinating Editor of the Cochrane Consumers and Communication Review Group. The review group coordinates the production of systematic reviews of the effectiveness of interventions to improve people's interactions with the health system. She is the lead reviewer for a Cochrane review on interventions for informed decision making by consumers on end-of-life decision making, and a co-reviewer with a team examining interventions to prepare children and adolescents for hospital and treatment therein.

In her capacity as Senior Research Fellow in the School of Public Health at La Trobe University, she is the Manager of the PHERP Innovations Program, 'Promoting and facilitating evidence-based policy and practice in public health and health promotion: tertiary education', that has led to the establishment of a tertiary subject on evidence-based public health for public health professionals at La Trobe University. She is also the lead investigator for several projects, including the following in 2004:

- GPs' and consumers' views of the issues of format and communication of absolute risk for cardiovascular disease
- consumers' views of the risks, benefits and regulatory requirements of the professions of naturopathy and western herbal medicine
- an evidence-based approach to quality improvement on communication issues in three Victorian hospitals.

Sophie has extensive experience in working for health consumer organisations and government, researching people's experiences of health care and investigating ways to improve service delivery, including five years with Health Issues Centre. Sophie is a member of the National Health and Medical Research Council's Health Advisory Committee and co-edited *Technologies and Health: Critical Compromises* (OUP 2001).



Mr Paul Butler



Paul Butler is currently the Manager of Policy for the Primary and Community Health Branch of the Department of Human Services. In this role, Paul is responsible for future planning and directions for Victoria's Community and Women's Health Services, Public Dental Services and Primary Care Partnerships. Paul and his team have responsibility for promoting consumer, carer and community participation in Victoria's primary health care services. The branch has a Consumer, Carer and Community Advisory Group that provides advice to the Branch from a consumer perspective.

Prior to working for the department, Paul has worked in a range of jobs in Victoria's primary health care sector, most recently in a research and consultancy role at La Trobe University. Paul has written extensively about primary health care in Victoria and Australia and on the importance of consumer and community involvement.

Ms Robyn Humphries



Robyn Humphries has 25 years experience working in the public mental health sector in Melbourne. Her background is in social work, and in 2000 she achieved a Master of Business Leadership qualification. In 2002 she was appointed Manager of the Northern Area Mental Health Service, NorthWestern Mental Health. Robyn has a strong commitment to consumer and carer participation in the mental health service system, and is pleased to contribute to the development of consumer and carer participation strategies in the broader health services system.

Mr Graham Ludecke

Graham Ludecke, a retired senior banker, has a long association with the Sandringham and District Memorial Hospital (SDMH) on whose Board he served. He was made a life Governor of SDMH in 1981. He has a particular interest in service quality, community health and welfare and the continual improvement of family, local and global values.

He is currently a member of the Bayside Health, Community Advisory Committee (CAC) and was a member of the Southern Health Care Network CAC. Mr Ludecke has recently retired as a Director of Southern Family Life and is currently President of the Black Rock Sports Auxiliary, the main fund raising auxiliary for Sandringham and District Memorial Hospital, Board Secretary of the Banking and Finance Service Ombudsman and Committee Member of Australian Business in Europe. He was a director of the public company, Data Advantage Ltd and continues to be involved in local community activities.

Mr Ludecke welcomed the opportunity to be a member of the Participation in your health service system, Project Reference Committee and to contribute to the development of a policy that will encourage community participation in the health service and subsequently lead to improvements in the delivery of services.

He is particularly interested in exchanging best practice between the various Health Services and to give disadvantaged and under resourced groups a voice in the delivery of health services.



Mr Timothy Moore

Timothy is the Senior Policy Officer at the Victorian Aboriginal Community Controlled Health Organisation Incorporated. Victorian Aboriginal Community Controlled Health Organisation is the peak body that represents the Aboriginal Community Controlled Health Services in Victoria. It is the channel for communities to direct Aboriginal health policies, and co-ordinate national and statewide opinion and direction on Aboriginal health issues that affect member organisations. Victorian Aboriginal Community Controlled Health Organisation supports locally planned, statewide and national initiatives and works on behalf of members as requested.

Senior Project Officer: Ms Cath Harmer

Cath joined the Victorian Department of Human Services in 2004 to manage the Consumer Participation and Information Program in acute health. She has been greatly impressed by the activity between consumers and health service providers working together to improve the systems, particularly, the quality of health care. Prior to this Cath has spent over ten years working in the community sector for consumer managed organisations. She has been a support worker, consumer advocate, trainer, community development worker and gone on to manage direct care services in the community. Cath worked in the areas of youth homelessness, mental health, acquired brain injury and diabetes. She has also conducted research projects with a strong public health focus and has completed several courses including a Master of Public Health and the Victorian Public Health Officers Trainee Program.



Appendix 5: Policy development aim and objectives

Aim

The project aims to develop and promote the *Participation in your health system: Victorian consumers/patients, carers, and the community working together with their health service and the Department of Human Services* policy.

Objectives

1. To develop the policy in consultation with consumers, community members, carers, health service staff, health service boards and other stakeholders.
2. To identify why consumer, carer and community participation is important in the planning, delivery and outcomes of health care.
3. To identify the underlying values of participation for the Department of Human Services and Victorian health services, consumers, carers and community members.
4. To identify across the Department of Human Services where the policy will need to link into, including primary and mental health.
5. To define the terms consumer, patient, carer and community for the purposes of the policy and in working with the acute, and subacute health areas of the Department of Human Services.
6. To identify how best to support consumers, carers and community members to participate in decision making across the four key result areas:
 - i. the state (Department of Human Services) level
 - ii. the health service organisational level
 - iii. the ward/program within the health service level
 - iv. the individual consumer/patient level.
7. To identify and provide examples and benefits of consumer, carer, and community participation in health services across the four key result areas.
8. To identify key enablers/resources to link to the health services to increase consumer, carer and community participation.
9. To identify the barriers and minimise potential disadvantages resulting from consumer, carer and community participation in health services.
10. To identify the minimum requirements of a community participation plan for an acute health service.
11. 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.
12. To implement a promotional strategy of the policy to the health services, consumer and carer support groups, the community and within the Department.

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