

# Developing a strategy for consumer and carer participation in cancer service reform

Final project report

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## Foreword

The Victorian Government is committed to involving people in decision making about health care services and has developed the *Doing it with us not for us* participation policy (Department of Human Services 2006) to guide the process for consumer and carer participation in service delivery and planning. Consumer and carer participation is grounded in a number of key principles including trust, respect, equal opportunity, openness, responsiveness, shared ownership and accountability (ibid).

In 2005, the Clinical Services Working Group of the Ministerial Taskforce for Cancer commissioned the Health Issues Centre to develop options for an integrated strategy for consumer and carer participation in cancer service reforms, including involvement across Integrated Cancer Services and tumour streams.

This report, written by the Health Issues Centre, describes the project that was conducted over a seven month period in 2005. *A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services* has been developed to support the implementation of the project findings and is available at [www.health.vic.gov.au/cancer](http://www.health.vic.gov.au/cancer).

## Acknowledgements

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## Contents

Executive summary	1
Introduction	1
Cancer service reform	1
Strengthening the participation of consumers and carers	2
A guide to enhancing consumer and carer participation	3
1. Background	4
2. Project aims	5
3. Methodology	6
3.1 Establishment of the Project Advisory Group	6
3.2 Literature review	6
3.3 Survey to identify current consumer and carer participation	7
3.4 Stakeholder consultations	7
3.5 Cancer support group facilitator interviews	8
4. Literature review	9
4.1 Individual treatment level	9
4.2 Organisational level	9
5. Findings from the University of Stirling literature review	11
5.1 Who is involved	11
5.2 Levels of involvement	11
5.3 What is required for effective involvement	11
6. Key findings from consultations	12
6.1 Analysis of stakeholder consultations	12
6.2 Capacity of consumers and carers to participate in cancer reforms	16
6.3 Capacity of Integrated Cancer Services to support consumer and carer participation	18
7. Developing a guide to enhance consumer and carer participation	21
7.1 Aim of the guide	21
7.2 Context for the guide	21
8. References	22
Appendix 1: Literature review on consumer participation in Australian cancer services	23
Appendix 2: Project Advisory Group membership	44
Appendix 3: Location of focus groups	45

## Executive summary

### Introduction

This project represents the first strategic approach to involving consumers and carers as drivers in the quality improvement of cancer services in Victoria.

In Victoria, we know that cancer is the leading cause of death and disability, and we know that cancer has significant long-term impacts on individuals, families, workplaces and communities. Efforts to address cancer service improvement require the involvement of multiple stakeholders, including those who use the services.

For consumers and carers, this project represents a significant shift in thinking by the Victorian Government and cancer services. It acknowledges and values the input of people who have experienced the cancer journey, and makes a real contribution to legitimising the role of consumers and carers as key partners in the planning, delivery and reform of cancer services.

International and local support for consumer participation is increasing and evidence is mounting on the benefits of consumer and carer involvement in improving health services.

This project has advanced consumer participation knowledge by identifying priority actions and processes to support cancer services to engage consumers and carers. This project suggests that the involvement of consumers and carers should be part of the strategic framework for Integrated Cancer Services (ICS) and that key goals, objectives and outcomes can be planned.

A key output of this project was the development of *A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services*. This guide, the first of its kind, outlines a strategic model to support ICS to plan, implement and evaluate consumer and carer participation.

### Cancer service reform

The Victorian Government has developed a strategic approach to cancer reform, that includes setting up a Ministerial Taskforce for Cancer and implementing the *Fighting cancer* policy and *A cancer services framework for Victoria* (Cancer Services Framework).

A significant direction of the Cancer Services Framework is the establishment of ICS across Victoria to improve local level coordination of cancer services and to work in partnership with local stakeholders to implement the reforms. One of the priorities for ICS is to 'actively involve consumers and carers as partners in health care service planning and delivery' (Department of Human Services 2004).

As part of its work to implement the Cancer Services Framework, the Ministerial Taskforce for Cancer commissioned Health Issues Centre to develop a strategy for effective participation of consumers, carers and community members as partners in the Integrated Cancer Services. This significant piece of work aimed to capture the views of people who have experienced cancer and ensure that consumers and carers are a key component of the Victorian cancer reforms.

## Strengthening the participation of consumers and carers

The project, which was implemented over seven months in 2005, had several stages including a literature review and a statewide consultation process. These stages aimed to scope current consumer participation activity, effective methods of engagement and advice on future strategies.

A review of the literature on consumer and carer participation in cancer services in Australia was undertaken. This literature review identified evidence-based strategies and tools for involving consumers and carers in decision making about their treatment and care. Tools such as decision aids, question prompt lists, recording and summaries of consultations, and written and verbal information at discharge, have strong Cochrane Review level evidence and their use should be considered and planned for by cancer services.

The literature review also identified interventions to promote participation of consumers and carers in quality improvement and service development activities. The review found that Victoria is leading the way in developing many of the recent policies for involving consumers and carers at the health service and statewide levels.

The statewide consultations sought the views of more than 150 people, including ICS directors and managers, members of the Ministerial Taskforce for Cancer, statewide organisations and peak bodies, clinicians, service providers, consumers and carers. These people shared their experiences and identified key mechanisms for involving consumers and carers in decision making. The consultations also captured opinions on existing levels of participation, capacity of consumers and carers to participate, capacity of cancer services to support participation, and perceived barriers and enablers to effective consumer and carer participation.

The consultations revealed that:

- consumer and carer participation is happening in Victoria's cancer services, but in a fragmented way
- consumers and carers want to have a greater say in their cancer treatment and care
- consumers and carers have valuable ideas to contribute to the quality improvement of cancer services and are keen to participate
- cancer services need to develop systems, structures and processes to support consumer participation
- consumer participation could happen at all levels of cancer services from the individual treatment level, to the ward and program level, to the organisational policy and planning level
- service providers need appropriate support to implement consumer and carer participation
- cancer services should develop a range of methods for engaging consumers and carers and these should be developed in partnership with consumers and carers and based on previous work relationships and local knowledge.

The consultations also suggested that for participation to be effectively implemented, managers of cancer services need to recognise the benefits of participation and plan strategically for it to occur. Plans should be developed to ensure the involvement of local stakeholders, such as general practitioners (GPs), community health service staff and cancer support groups.

Statewide cancer agencies and consumer / carer groups also advocated for a strong role in supporting ICS to plan for and implement consumer and carer participation.

## **A guide to enhancing consumer and carer participation**

A key output of this project has been the development of *A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services*. This guide builds upon the findings from the literature review, consultations and Health Issues Centre's own consumer participation experience and materials.

The guide assists ICS to strategically plan for consumer and carer participation as part of their overall quality improvement approach. The guide aims to respond to the needs and capacities of service providers, consumers and carers to meaningfully participate in cancer services reform. The guide includes practical methods, case studies and references to support planning for consumer and carer participation.

## 1. Background

Cancer is the leading cause of death in Victoria, representing 29 per cent of all deaths in 2002 (Department of Human Services 2005a). To respond to the high prevalence of cancer in Victoria and the perceived fragmentation of the cancer service system, the Victorian Government developed a vision for cancer service improvement that outlined a commitment to the restructure, coordination, integration and development of cancer services and research (Department of Human Services 2005a). This approach has included implementing the *Fighting cancer* policy (Australian Labor Party 2002) and *A cancer services framework for Victoria* (Collaboration for Cancer Outcomes Research and Evaluation 2003) and establishing a Ministerial Taskforce for Cancer to provide advice and leadership in the implementation of the cancer reforms.

Two significant directions of the Cancer Services Framework are the establishment of ICS in metropolitan and regional Victoria, and the development of service delivery and improvement through a tumour streams model. The Cancer Services Framework encourages ICS to develop collaborative partnerships with a wide range of stakeholders to implement the reforms. This includes the active involvement of consumers and carers as 'partners in health care service planning and delivery' (Department of Human Services 2004).

The conceptual background for consumer participation is found within the principles of primary health care as defined by the World Health Organization (WHO) in the 1970s (World Health Organization 2003). In Australia, the 1993 National Health Strategy established that consumer participation in health implies that:

- all citizens have a democratic right to participate in their own health care and the organisations that provide care
- participation produces better health outcomes and improves the quality of health
- most people would like to have information about their own health and the processes involved in the delivery of health services (National Health Strategy 1993).

As part of its work to implement the Cancer Services Framework, the Ministerial Taskforce for Cancer commissioned Health Issues Centre to develop a strategy for effective participation of consumers, carers and community members as partners in cancer services. This project aimed to ensure that the views of people who have experienced cancer are a key component of the cancer reforms. The project was supported by the Department of Human Services' Cancer and Palliative Care Unit.

## 2. Project aims

The aims of this project were to build on existing efforts of consumer and carer participation in cancer services and to provide appropriate levels of support for consumers and clinicians by developing a broader strategy for consumer and carer participation in the cancer service reforms (Department of Human Services 2005b).

Health Issues Centre was initially commissioned to develop a strategy for consumer and carer participation in cancer service reform. Consultations with the Project Advisory Group and findings from the study revealed that a guide that aimed to support cancer services enhance their consumer and carer participation was more appropriate. The word 'strategy' was then changed to 'a guide'. The final document, entitled *A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services*, is available from the Victorian Government's Cancer Initiatives website at [www.health.vic.gov.au/cancer](http://www.health.vic.gov.au/cancer).

This report provides an overview of the project methodology and of the review of the literature, an analysis of key findings, implications arising from the consultations and literature review, and an introduction to *A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services*.

## 3. Methodology

### 3.1 Establishment of the Project Advisory Group

The Project Advisory Group was established by the Department of Human Services with representatives from the Department's Cancer and Palliative Care Unit, Health Issues Centre, The Cancer Council Victoria, Carers Victoria, Breast Cancer Network Australia, St Vincent's Health, managers from Loddon Mallee, Grampians and Southern Melbourne ICS, and consumer and carer representatives. The role of the Project Advisory Group was to:

- provide input and feedback into the overall project
- provide input and feedback into the project methodology, documents produced, final consumer participation strategy, and dissemination of the strategy
- make recommendations to the Department regarding the ongoing implementation of the consumer participation strategy.

The advisory group met monthly from July 2005 to February 2006 at 595 Collins Street Melbourne. Two additional meetings were held. The first meeting aimed to workshop consumer participation tools and methods relevant to cancer services; the second brought advisory group members together with relevant stakeholders to obtain feedback on the draft guide and to develop recommendations to support its implementation.

Appendix 2 provides Project Advisory Group membership details.

### 3.2 Literature review

A literature review was undertaken to locate information on consumer and carer participation strategies (including policy initiatives, frameworks, tools and models) relevant to cancer service delivery in Australia. This literature review was intended to supplement a more comprehensive review of the literature on this topic undertaken by the Cancer Care Research Centre, University of Stirling.

The search was conducted in two parts. Part A involved a search of the Cochrane Library for effective practices in consumer participation, with specific regard to practices involving cancer patients. Part B included a broader search of the literature, focusing on consumer participation in cancer care in Australia.

**Part A:** The Cochrane Database of Systematic Reviews was searched for the terms 'consumer participation' or 'consumer involvement' in all text, and for records with 'cancer' in the title and 'consumer participation' or 'consumer involvement' in all text. All titles published by the Cochrane Consumers and Communication Review Group were also scanned for relevance.

**Part B:** The broader literature search involved three main strategies: a systematic search of published and indexed material, a systematic search of library online gateways and the World Wide Web, and a hand search of non-refereed consumer journals. The search was restricted to items published in English and involving populations in Australia. Material that addressed specific health areas other than cancer or addressed population screening was excluded.

### 3.3 Survey to identify current consumer and carer participation

Information about consumer and carer participation activities in cancer services was collected during the life of the project. In collaboration with the Project Advisory Group, it was decided not to conduct a formal survey to gather this information, but instead engage in a more targeted data collection strategy. Thus, a question regarding current consumer and carer participation activities in cancer services was included in the list of questions for key informants in the consultation process. Community Advisory Committee (CAC) resource officers and one GP/consumer liaison person were also sent an email requesting their contribution. Relevant information was also collected through the focus group discussions.

### 3.4 Stakeholder consultations

The following consultations were undertaken to ensure sound representation of consumers, carers and health service providers in the development of the guide.

#### a) Key informant interviews

Face-to-face and telephone interviews were conducted with 17 key stakeholders. These included representatives from the Ministerial Taskforce for Cancer, managers of ICS, clinicians, and representatives of key consumer advocacy groups. Key informants were asked for their opinions on the current cancer service system; the main issues to be addressed by a consumer participation strategy in cancer services; what a strategy for the cancer service reform should include; who they thought the strategy should be written for; and what support, barriers and enablers for consumer participation currently existed within cancer services.

#### b) Focus groups

Eighteen focus groups were held across Victoria in each of the ICS catchments (see Table 1 for distribution of focus groups and Appendix 3: Location of focus groups). Two senior project officers from Health Issues Centre facilitated the focus groups. All focus groups commenced with an outline of the rationale for the study, a brief introduction to the role of Health Issues Centre and an explanation of how focus group discussions would contribute to the development of the guide. All focus group discussions were recorded and fully transcribed.

#### Health service providers

Eight focus groups for health professionals were conducted in each of the ICS catchments with the exception of Hume Region. ICS managers worked with Health Issues Centre staff to recruit relevant service providers. Fifty-two staff participated in the focus groups, representing a range of professions involved in the delivery of cancer services and support. Focus groups aimed to capture health professionals' experiences of involving consumers and carers in cancer services; ideas on what the guide should include; barriers and enablers to the participation of consumers and carers in cancer services; and the capacity of cancer services to support consumer and carer participation.

#### Consumers and carers

A total of ten focus groups for consumers were conducted across each of the ICS catchments. Consumers and carers were recruited through The Cancer Council Victoria and Carers Victoria networks. Additional consumer focus groups were conducted in Horsham and metropolitan Melbourne to address a need identified by service providers regarding potential consumer interest in the project. One hundred and

thirteen registration forms were received from consumers wishing to participate and 76 people attended focus groups. Consumers and carers were all paid \$35 for participating.

Participating consumers and carers came with a diversity of cancer experiences. Most participants were members of cancer self-support groups, carer groups, representatives of The Cancer Council Victoria programs, Cancer Connect or CancerVoices Victoria. Carers were present in all focus groups. The focus groups aimed to capture consumers' and carers' ideas on how they wanted to be involved in cancer services; their capacity to participate effectively; what the guide should include; and experiences of consumer and carer participation.

**Table 1: Distribution of focus groups**

<b>Integrated Cancer Service</b>	<b>Consumers</b>	<b>Service providers</b>
Barwon South Western	✓	✓
Loddon Mallee	✓	✓
Grampians – Ballarat	✓	✓
Grampians – Horsham	✓	✓
Gippsland	✓	✓
Hume	✓	✗
North Eastern	✓	✓
Southern	✓	✓
Western Central	✓	✓
Extra Metro	✓	✗
<b>Total</b>	<b>10</b>	<b>8</b>

### **3.5 Cancer support group facilitator interviews**

In-depth follow-up phone interviews were conducted with five facilitators of cancer support groups. These facilitators were identified through the recruitment for consumer focus groups. Four of the five facilitators interviewed were based in regional Victoria. Two facilitators were paid staff of a health service, with the remaining three facilitators being volunteers. At the completion of the consumer focus groups, the cancer support group facilitators were contacted by telephone and invited to explore in more detail the opportunities and constraints of their participation in cancer services. Facilitators were encouraged to discuss their role within the support group, the role of members and the support they receive for their current work. They were also asked whether they saw other roles for their group members (for example, advocacy, lobbying government); whether they would be willing to participate in more advanced levels of participation; and, if so, what they would need for this to occur. Facilitators were also asked whether they saw a role for themselves in supporting and disseminating the proposed guide.

## 4. Literature review

The literature review sought to identify evidence-based strategies and tools that have been used for the effective involvement of consumers and carers in their health care. The review focused on cancer care and identified examples used in Australia.

The key findings of the literature review are summarised below. The complete literature review document is presented in Appendix 1.

### 4.1 Individual treatment level

The evidence from Cochrane systematic reviews suggests that consumer and carer involvement in their own treatment and care needs an environment that supports participation and the availability of tools to facilitate it.

There is some evidence that strategies directed at health professionals, such as training in communications skills to work with cancer patients or with a patient-centred approach, can help health professionals to engage their patients and their carers more effectively. However, a lack of robust definitions and poor research design may affect the ability to generalise these findings.

The main strategies that emerged which were directed at the individual patient level are shown below.

- The use of tools such as decision aids (for which there is good evidence of effectiveness). The evidence suggests that decision aids are effective tools for improving knowledge, increasing realistic expectations, reducing decision uncertainty, decreasing the number of people that are undecided about treatment, and encouraging an active role in decision making among people facing health treatment or screening decisions. In practice, a good quality decision aid needs to be available and health practitioners must be willing to use them.

- Audio-taping consultations or providing written summaries (where evidence of outcomes is limited). The evidence suggests that this practice may encourage more active participation in subsequent consultations and in decisions about care, although the impact on people with poor prognoses is not well understood. The Cochrane review recommends health practitioners offer people a tape recording or a written summary of a consultation, as they are useful as personal reminders and to share with families, friends and GPs.
- The use of question prompt sheets for initial consultations (which appear to be more effective when used in conjunction with other strategies). The evidence suggests that when people are given recordings or summaries they have better recall of information given to them and are more satisfied with it. However, technical, health literacy and cost issues need to be considered, including the need to ensure that advice is given about how long the information is likely to remain current.
- Interventions designed for communicating with children and adolescents about cancer (for which the evidence is weak).

### 4.2 Organisational level

The involvement of consumers at an organisational level requires a different approach, and the framework used by Nilsen's Cochrane protocol (2004) is useful. It proposes first that an assessment of the degree of consumer involvement—consultation, collaboration or consumer control—is needed. Secondly, an assessment is needed about where participation occurs, such as at a public meeting or in a committee. Third is an assessment of the type of involvement in decision making and whether it is implied or explicit. The last four parameters in Nilsen's protocol relate to how consumer involvement

is implemented. The first of these is the method of recruitment of those involved—consumers and health professionals. The second is concerned with the presence of training and support and consideration of whether financial and practical support is available.

The literature review offers some specific examples of consumer and carer participation activities in cancer services in Australia. These have been reported and/or published in scientific journals but have not been formally evaluated or included in Cochrane reviews. It is important to note that needs of specific groups with cancer, such as culturally and linguistically diverse or Indigenous communities, are poorly addressed in the literature.

## 5. Findings from the University of Stirling literature review

As part of a broader program of study on patient and carer experiences, the Cancer Care Research Centre at the University of Stirling, Scotland conducted a literature review to identify ways in which people affected by cancer have been involved in research, service planning and policy making, and in their own care. The results of the University of Stirling's review are largely in accordance with issues identified in this study—including findings from the literature review and those raised during the stakeholder consultations (as described in the next section).

### 5.1 Who is involved

The University of Stirling's review found that patients with various types of cancer, but particularly those with breast cancer, have become involved with cancer services (Cancer Care Research Centre 2005). However, younger and older people, people from deprived communities, people living in rural areas, people who are very ill and people from minority ethnic groups are often not involved (ibid).

In the UK there is some confusion around who is and who should be involved—for example, whether only patients should represent people affected by cancer, or whether their advocates can too; and whether those involved should be connected to a 'constituency' so that they are not just representing their own individual experience (ibid).

### 5.2 Levels of involvement

At the individual level, patients have been encouraged to self-care in order to better manage their symptoms. Some patients wish to be the ones who make the decisions about what treatments they are going to have, whereas others prefer to make the decision jointly with their doctor, or want the doctor to make the decision for them. The effects on those involved in self-care included improvements in symptom management and psychosocial well-being (ibid).

At an organisational level, people affected by cancer have joined management teams and boards of directors of policy-making, service planning and research organisations, and they have also have been involved in 'one-off' involvement exercises (commonly focus groups). Involvement in policy and planning has been associated with changes to virtually all aspects of health care services. The effects on those involved in research and/or policy and planning have included personal empowerment and more knowledge (ibid).

### 5.3 What is required for effective involvement

Essential requirements for the successful implementation of the patient and carer involvement agenda included training, information and resources—including finance, dedicated personnel and sufficient time. A change in attitudes and roles was also found to be required. In particular, there needed to be a shift away from professional paternalism towards partnership, where power and control is shared equally (ibid).

For successful involvement of patients and carers in decision making at an individual level, it was argued that they require individualised information and education in relation to their cancer, its treatment and how best to manage these effects (ibid).

## 6. Key findings from consultations

This chapter provides an overview of the key findings from the consultation. It has been divided into three sections to clearly reflect the themes emerging from the consultations and the initial project brief. Quotes used throughout this chapter are in italics.

### 6.1 Analysis of stakeholder consultations

This section provides an overview of the broad range of opinions elicited during the consultations. Consumer, carer and service provider views on the current cancer service system are provided together with the rationale for consumer and carer participation in cancer service reform; key facilitators required to implement participation; current levels of participation and future participation; and opportunities and constraints of participation.

#### Current cancer service system

Most ICS managers agreed that cancer services are of good quality and are widely available, but coordination between providers is lacking. Most consumers, carers and The Cancer Council Victoria agreed that lack of coordination and access to services needs to be addressed. Lack of a patient-centred focus and difficulties with transition from children's to adult care were mentioned as issues by consumers and carers. Some regional health service managers argued that local services are of a good quality and are well coordinated with metropolitan services; however, they suggested that specialisation and high numbers of cases in metropolitan regions means that services and treatment are often better in metropolitan areas than regional areas. The lack of radiation services in regional centres due to the centralisation of these services was mentioned as an example. Consultation also revealed that consumers and carers often use a mix of private and public cancer services.

Several consumers and carers indicated that as a result of using both private and public services they often experienced confusion, a lack of coordination of their care, difficulties with referrals, increased costs and lack of choice:

*One of the problems for people with cancer is how are things going to be billed, how much is it going to cost, should I go private, should I be a public patient, what's the best way to do it? The doctors don't know how to talk to them about anything to do with finances, and if you ask them how much it's going to cost upfront, they'll say I can't really tell you because we don't really know what has to be done. (Consumer)*

#### Rationale for consumer and carer participation in cancer service reform

Most service providers and consumers and carers agreed that consumers and carers offer a unique perspective to the quality improvement of cancer services. This perspective comes from their lived experience as users of cancer services. Their first-hand experience can offer a perspective to cancer services that differs from that of clinicians and managers. Most service providers, consumers and carers agreed that consumer and carer participation is essential at the individual level of care and treatment, but also at organisational and program level, where consumers and carers are able to make a contribution to the planning and evaluation of cancer services:

*One of the things which is interesting when it came to doing the [patient management] frameworks discussion with the consumers was just how consumers do look at things differently. (Service provider)*

Consumers and carers suggested they are able to provide examples of both positive and negative experiences from their treatment and care, which could be useful for cancer service quality improvement. As people who live and work within the community, consumers and carers indicated they often had good connections with local groups and community institutions. Service providers saw this local connection as an important contribution to the development of cancer services and the effectiveness of screening and health promotion campaigns. In several ICS catchments, service providers saw the potential for engaging consumers in the implementation of the patient management frameworks.

### Key facilitators

Service providers indicated that the target audience for the guide should include the full range of staff who have a role in cancer services. CEOs, boards of management and unit managers were highlighted as people who need to be involved if consumer and carer participation is to be implemented and enhanced. These people were seen to have very significant influence on the systems, structures and services provided within health services and were perceived as having responsibility for quality improvement, safety, risk management and community relations where consumer participation may already be happening. Health professionals, including clinicians and allied health staff, were also identified as having a role in enhancing consumer participation. In some regions, ICS directors and managers identified themselves as key facilitators of coordinating consumer input at a planning level, specifically in regard to the implementation of the patient management frameworks. Cancer service volunteers and cancer support groups were also identified by consumers, carers and service providers as key facilitators in the development of consumer participation.

The Department of Human Services and the Ministerial Taskforce for Cancer were acknowledged by service providers and consumers and carers as having a key role in the implementation, monitoring and sustainability of consumer participation across the system.

### Current levels of consumer and carer participation

The targeted consultation with key informants about current participation in cancer services showed that participation was taking place at a national level and throughout Victoria in health services and in the community sector. Participation activities were taking place at all levels, from individual care to the organisational and program levels. A summary of the findings is given below.

At a statewide level, consumers and carers are involved with The Cancer Council Victoria through the Cancer Connect Program and affiliated cancer support groups, with the peak body Carers Victoria, and with the newly established CancerVoices Victoria. Consumers and carers are also engaged in a variety of national activities through tumour specific groups such as the Breast Cancer Network Australia and the Prostate Cancer Foundation of Australia. Several consumers and carers were involved in consultations for the development of the Department of Human Services' patient management frameworks and some are members of the Ministerial Taskforce for Cancer or participated in the National Inquiry into Services and Treatment for Persons with Cancer (Commonwealth of Australia 2005).

At a health service level, consumers and carers are engaged in a variety of ways within a hospital or across a health service. At a ward/program level, consumer and carer participation is being implemented through patient satisfaction surveys, feedback processes, production and delivery of medical information,

consumer working groups, employment of consumer advocates or consultants, and research trials. At the organisational level, consumers and carers are involved in service delivery planning, service evaluation, reference groups for specific program or projects, CACs and information and document development committees.

At a local community level, consumers and carers are active in cancer support groups, as volunteers in hospitals and community services, and as individual members of Cancer Connect, a peer-support telephone service for people with cancer. These consumers and carers identify their role as providing social support and friendship to community members with whom they share the cancer journey. Some members of these groups are also involved in promoting screening, in community education programs, in providing advice to the health service and in fundraising activities.

### Future consumer participation

Service providers, consumers and carers suggested that a range of strategies should be available to support consumer and carer participation at all levels of the participation continuum.

Many participants agreed that strategies for consumer and carer participation need to be supported by relevant systems, structures and policy. Further, the lived experience of consumers and carers needs to be valued by providers in order for meaningful consumer participation to occur. Consumer and carer participation strategies identified by consumers, carers and service providers were generally consistent with the Department of Human Services' policy for consumer, carer and community participation in health services (Department of Human Services 2005d, 2006) and other relevant consumer participation

resource material (Department of Public Health, Flinders University and South Australian Community Health Research Unit 2000).

Consumers, carers and service providers saw consumer and carer participation as important at the individual level as well as at the service development level:

*I guess 'consumers' is a tough word in the cancer area but it's the word we continue to use. It means clinicians and people with cancer work together in partnership to try and get through their disease, it's quite a close relationship. But to try and develop a program where consumers can contribute in a very meaningful way are issues which we're not quite clear about. So I guess that's where I stand at the moment, as a person who's obviously dealt with thousands of consumers in a clinical sense but not so much in this sort of interactive policy development.*  
(Service provider)

At the individual level, consumers spoke about wanting more information, more control over their care and treatment and greater involvement of their carers. They discussed potential consumer and carer participation approaches which included the provision of more information to consumers about services and treatment and the use of question prompt lists. At a service development level, consumers and carers said they would like to be involved in providing feedback to planners of cancer services regarding their own cancer journey. Consumers and carers are also able to identify gaps and weaknesses in their cancer service and referral processes, and provide practical solutions and suggestions which could improve the cancer journey for other consumers:

*Patients actually want to know what the internal processes involved in their actual management and care is, and how some of those decisions are reached.*  
(Service provider)

Service providers suggested that regularly informing consumers and carers about new developments, treatment options and support services at the cancer service was essential for enhancing participation. Several service providers identified the patient follow-up or review meeting after treatment as a good point at which to approach consumers and carers for their feedback and to inquire whether they were interested in participating. Where service providers were supportive of consumers and carers being involved in committees with staff, they advocated for more than one consumer or carer to be part of a committee.

Health promotion and community development techniques were identified by staff as possible mechanisms to enhance the engagement of the broader community in cancer service issues. The further development of techniques and tools to capture feedback from consumers and carers was also proposed.

## Opportunities and constraints of participation

### Policy context

Health professionals said the current Department of Human Services policy context was supporting their consumer and carer participation work by providing legitimacy and resources. Other clear examples of consumer and carer participation in health care included CACs in metropolitan health services, breast cancer participation processes, and consumer involvement in mental health services.

### Statewide initiatives

Consumers and carers identified The Cancer Council Victoria as a potential platform to facilitate and strengthen consumer and carer participation in cancer service reform. The Cancer Council Victoria currently provides training and support to cancer support groups,

manages the Cancer Connect volunteer program, and has recently supported the establishment of Cancer Voices Victoria. Cancer Voices Victoria is a consumer advocacy group that consumers and carers believe has the potential to have a meaningful impact on the cancer service system by highlighting issues important to them.

### Constraints of participation

Service providers, consumers and carers identified the following factors as contributing towards the limited involvement of consumers and carers in cancer services:

- lack of commitment and understanding by senior managers, middle management and health service boards
- lack of internal systems and structures to recruit, support and sustain participation
- lack of dedicated resources, which makes it difficult for managers to allocate staff to consumer and carer participation, provide training to staff and consumers and carers, and develop materials and systems to enhance participation
- perceived fear of service providers of working with consumers and carers outside the normal service provider role
- frailty, sickness and time commitments of consumers and carers
- transport costs in regional areas
- difficulties in ensuring a diversity of consumer and carer perspectives:

*We need to look at different ways of gaining feedback at different levels. For example, people who are really tired but have got really good ideas. We should be able to look at different ways of capturing their feedback at different times throughout their journey. (Service provider)*

## 6.2 Capacity of consumers and carers to participate in cancer reforms

This section includes an overview of the key findings on the capacity of consumers and carers to participate in cancer reforms. It describes the current participation of consumers and carers in cancer services, and identifies barriers and enablers to enhancing the capacity of consumers and carers to participate in cancer reforms.

During the consultations, consumers and carers reported that when they had been involved in participation it was mainly at the individual level; that is, in response to their care and treatment, or through involvement as a member of a cancer support group. Several consumers and carers were able to provide examples of their involvement in committees, advisory groups or health service planning days, although these experiences were minimal and generally ad hoc.

The consultations revealed four main areas where consumers and carers were engaged: cancer support groups, feedback and advice, committees and advocacy.

### Cancer support groups

Cancer support groups were viewed positively as providing consumers and carers with an opportunity for information sharing, informal support and friendship. Cancer support groups were seen to also have a role in community education and screening promotion. Volunteers usually facilitated cancer support groups and were often people who had experienced cancer and were now well. In some regions, staff members of community health services often organised such groups. Members of cancer support groups expressed a range of views regarding their interest and capacity to participate directly with health services or in lobbying activities. Some members of cancer

support groups were positive and interested in the idea of active involvement in health service planning and policy. However, others expressed hesitation at taking a more active role while they were still recovering or because they saw the role of their groups as providing friendship and support.

### Feedback and advice

Consumers and carers shared a range of experiences of being asked to provide feedback to health services on the treatment and care received. When asked to provide feedback this usually occurred through surveys, direct discussions with clinicians or formal research. Consumers indicated they were rarely asked to provide input into structural or system issues within health services or in the development of material (such as guidelines or resources) but indicated they had valuable suggestions which they would be willing to contribute.

### Committees

Several consumers and carers had experience as members of health service committees or working parties. Several consumers and carers were members of metropolitan health service CACs. Others were active members of specific tumour committees such as with BreastScreen or Brain Tumour Australia.

### Advocacy

Several consumers and carers shared their experiences of being involved in advocacy groups and campaigns. Examples of their involvement ranged from structured processes, such as being a member of Cancer Voices Victoria and the Breast Cancer Action Group, to local community campaigns where they had been involved in advocating for more cancer nurses, lobbying to improve access to services and transport, and direct action resulting from referral issues and lack of care coordination. Directly advocating on behalf of others about

treatment options and access to treatment services was also identified as a role many consumers and carers took on.

## Enablers

Consumers and carers strongly felt that they have a unique perspective which could be valuable in the planning and development of cancer services. Through their lived experience as users of the system they are able to articulate issues relating to information provision, access to services, role of carers, post-acute care, treatment options and social support. Consumers and carers believed their experiences, both positive and negative, could provide additional perspectives to assist health planners and health professionals.

Consumers and carers expressed a willingness to have a greater say in cancer services, not just in relation to their direct treatment but also about issues related to the whole cancer journey. These aspects included the role of specialists, referral pathways, location of services and transport arrangements. Consumers and carers shared stories of their cancer treatment and were grateful for the services and care they had received. Many were interested in offering their time and skills to the cancer service and to advocating for and supporting other consumers and carers. Some gave examples of how they had been involved in lobbying in the breast cancer field. In some cases, strong lobbying work had resulted in a positive response from health services and had allowed structures and systems to be established for meaningful participation:

*I think we should be involved in committees to let the medicos and hospital committees etc know how a consumer feels and what a consumer's needs are. Sometimes I feel they haven't got a clue. It's like when we had our babies and we took them to the maternal health nurse and she'd never had a baby ever and she told us how to bring up ours. We really truly need to give them information from us as consumers. (Consumer)*

Consumers and carers indicated an interest in engaging with cancer services if the latter developed a range of participation strategies to cater for their busy lives, diverse interests and encompassing all stages of the cancer journey. Several consumers and carers indicated they would not be able to attend monthly meetings at the cancer service but would be able to complete a survey about their treatment or to participate in a community information forum.

## Barriers

Consumers and carers were often sceptical about the cancer service system and of the perceived commitment by cancer services to allow them to make a contribution. Some consumers and carers provided examples of previous involvement which they felt had been tokenistic, where they believed they were not being listened to, and where their efforts were perceived as not contributing to change:

*When I was trying to set up the group in (name of town) I was actually kicked out of a meeting because they felt threatened by something that was non-medical. Why would you run a group that's not medical they said. I knew that the doctors and nurses are supposed to do the medical part but I just felt there was a need for people to come and talk to people who had actually been through cancer so that they could advise them on what's going on. (Consumer)*

Consumers and carers were often unaware that they could have a greater say in their treatment or provide a contribution to the planning and delivery of cancer services. Illness and fatigue were identified as barriers limiting their ongoing participation, as were lack of transport and the costs associated with transport. Several consumers and carers suggested that, although they had a story to tell, they lacked the skills in advocacy and communication to enable them to participate on a committee with health professionals or in a discussion on health policy or in decision making:

*I think there should be structures within the hospital system, especially with cancer, where consumers know they are safe to give their responses and they won't be victimised later on. (Consumer)*

### 6.3 Capacity of Integrated Cancer Services to support consumer and carer participation

This section includes an overview of the key findings that relate to the capacity of ICS to support consumer and carer participation. It includes a summary of views expressed by clinicians, service providers and managers about consumer participation, an analysis of the current capacity of cancer services to support participation, and identification of the barriers and enablers for strengthening consumer and carer participation in cancer service reform.

The level of understanding and commitment to consumer and carer participation demonstrated by service providers, clinicians and managers was varied and was influenced by their different positions and experiences. Service providers, clinicians and managers offered a range of perspectives on consumer participation as detailed below.

#### Clinicians and service providers

Some service providers and clinicians expressed their total commitment, understanding and support for consumer and carer participation and were able to provide examples of how they were doing it and the benefits gained. However, others showed a lack of understanding and/or commitment, were sceptical, and were unaware of the requirements of health services to engage consumers and carers as part of accreditation and quality improvement processes. For some clinicians the shift from thinking of consumers as sick patients to seeing them as people who could make a positive contribution to the delivery of cancer services was a difficult one. Other clinicians felt that involving consumers and carers in having a say about their treatment and care was best patient practice and already part of their current work. Some service providers and clinicians questioned why consumers and carers would want to participate when they are ill and when their carers are generally very busy:

*You've got to have that strong medical leadership in these kinds of management decisions. The consumers cannot have the expertise that the medical people can bring to that situation, and they, I suspect, acknowledge that as well. Empowering or encouraging consumers to actually be involved in the process, is fine but I think there still has to be the emphasis on the science in the whole process, and make it accessible to consumers. (Service provider)*

Where clinicians and service providers expressed support for consumer and carer participation they saw the role of implementing consumer and carer participation as the responsibility of management and senior staff. They identified support structures, such as systems, tools, methods, financial resources and a commitment from the board of management, as necessary to enhancing consumer participation.

When consumer and carer participation was happening within a cancer service, it was often the result of action by particular staff through either the nature of the position or their skills and interests. Breast care nurses and social workers were mentioned as two examples of service providers who had a role in consumer and carer participation. These staff typically engaged consumers and carers at an individual and information provision level. Further, where service providers were undertaking consumer and carer participation at an individual level, it was often in isolation, using ad hoc systems and structures.

### Management

The health service managers interviewed were generally supportive of consumer participation and were able to articulate a potential role for consumers and carers. Many identified the great benefit and potential for involving consumers and carers in the planning and management of cancer services but believed they personally lacked the knowledge and skills to facilitate this. Several managers saw a role for consumers and carers in quality improvement, risk management, promotion of services and education of service providers and clinicians. A number of managers referred to CACs but others were unable to see the relationship between CACs and cancer services. Some managers saw consumer participation as implemented by CACs as being

sufficient, while others could see the need for consumer and carer participation in cancer services specifically.

Managers identified the following conditions as essential to support consumer and carer participation within their cancer service: systems, structures, clinical education, skilled staff, resource allocation, and real commitment by the board of management and the Department of Human Services.

### Enablers

Managers identified the Department of Human Services policy context as a key driver for consumer and carer participation. Other service providers spoke more broadly about a 'momentum' for consumer participation, which was requiring health services to look into the engagement of their consumers and carers and the broader community.

Service providers, clinicians and managers were able to identify systems and structures within their health services which they saw as supporting consumer and carer participation. These systems and structures included knowledge and education around consumer participation, CACs, accreditation processes, quality and safety frameworks, active volunteer programs, and key staff (for example, social workers and breast care nurses) well placed to facilitate the interface between consumers and carers:

*So I think really the community advisory boards should be the coordinators, would bring in the consumers and clinicians together. (Service provider)*

## Barriers

Service providers and clinicians generally did not recognise the capacity for consumers and carers to advocate for themselves. Several indicated that they tended to advocate on behalf of consumers. Failed experiences of consumer participation in the past also caused service providers and clinicians to be hesitant towards embracing it again. Service providers and managers identified their own lack of knowledge and understanding of consumer and carer participation as contributing to some fear about it.

Other barriers identified by service providers, clinicians and managers included: attitudes of clinicians and administrators, lack of commitment and understanding of consumer and carer participation, lack of framework and systems in place to support consumer participation, lack of human and financial resources, lack of flexibility of models of participation, broad geographical areas, competing constraints of the medical versus social model of health, and assumptions that consumers and carers were too fatigued or busy to want to participate.

A general lack of knowledge and understanding of the role of CACs and the opportunities and potential support these committees could offer a cancer service were also identified as potential barriers:

*All hospitals have consumer advisory boards so I know I've got one, but like I said, I have no interaction with it. So for all I know they could be having some great consumer engagement but if they keep it between the managers of the organisation and the consumers and it never gets down to the clinical area then I don't know how useful it would be. (Service provider)*

## Implications for the guide

The key lessons from this consultation have been incorporated into *A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services*—specifically, the principles for planning strategically for participation and the methods and organisational infrastructure required to support participation.

## 7. Developing a guide to enhance consumer and carer participation

The development of *A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services* ('the guide') was based on findings from the literature review, the consultation process and input from members of the Project Advisory Group. The guide is informed by evidence-based consumer participation methods and the current Department of Human Services consumer participation policy context. The full version of the guide is available from the Department of Human Services Cancer Initiatives website at [www.health.vic.gov.au/cancer](http://www.health.vic.gov.au/cancer)

### 7.1 Aim of the guide

The guide aims to assist ICS to strategically plan for consumer and carer participation as part of their overall quality improvement approach. It responds to the needs and capacities of service providers, consumers and carers to meaningfully participate in cancer services reform. The guide includes practical consumer and carer participation methods, case studies and references to support planning.

### 7.2 Context for the guide

Cancer services are delivered through a continuum of services at all levels:

- primary and community-based health services—such as GPs, community health services and community-based palliative care services
- secondary level health services—such as specialist oncology, radiotherapy and screening services
- tertiary levels of health care services—such as surgery, intensive care and palliative care units located in hospitals.

The methods outlined in the guide assume that consumer and carer participation could potentially take place in any of these settings. The methods could also be used at all levels of an organisation. These levels, as defined in the Department's consumer participation policy (Department of Human Services 2006), include the individual, unit or program, and health service or organisational levels. Further, the methods cover a variety of types of participation, including consumers and carers receiving and providing information, participating in consultations, and acting as partners in service planning, delivery, research and evaluation of health services.

The guide is divided into two parts. **Part I** outlines the policy context for consumer participation in cancer services. It describes the principles, definitions and evidence for consumer and carer participation; systems and processes that need to be in place for effective consumer and carer participation; and levels and types of participation.

**Part II** presents practical principles for planning strategically; a draft set of goals and objectives to guide the strategic planning process; a summary table of types of participation; and an example of a model for strategic planning. A description of a range of methods for cancer services to use in developing their own consumer and carer participation plan, including relevant case studies and references, are included in the guide's appendices.

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## Appendix 1: Literature review on consumer participation in Australian cancer services

### Introduction

This literature review was commissioned as part of a project funded by the Department of Human Services to develop strategies for consumer and carer participation in cancer services reform. Its aim was to locate literature on consumer<sup>1</sup> participation strategies (including policy initiatives, frameworks, tools and models) relevant to cancer service delivery in Australia.

The larger project included a consultation with health service providers, consumers and carers, and aimed to develop models for consumer participation in cancer service reform that could be implemented in the Integrated Cancer Services (ICS) within each of eight regional areas within Victoria.

This literature search was intended to supplement a more comprehensive review of the literature on this topic currently undertaken by the Cancer Care Research Centre, University of Stirling. The aim of the Stirling review was ‘to find out what is known about involving people affected by cancer to influence research, policy, planning and practice. Three main questions were to be addressed: Why does involvement happen? How does involvement happen? Does involvement have an influence?’

The Stirling review was also undertaken to gather evidence from the perspectives of policy makers, service planners, health and social care practitioners, and people affected by cancer. For example, questions from the perspectives of people affected by cancer would include: why do people affected by cancer think they are involved in research, policy, planning and practice? In what ways do people affected by cancer describe how they were involved? In what ways do people affected by cancer perceive/demonstrate that they have influenced research, policy, planning and practice? The complete Stirling review is available at: [www.cancercare.stir.ac.uk/documents/Phase1LitReview.pdf](http://www.cancercare.stir.ac.uk/documents/Phase1LitReview.pdf).

### Literature search

The search was conducted in two parts. Part A involved a search of the Cochrane Library for effective practices in consumer participation, with specific regard for practices involving cancer patients. Part B included a broader search of the literature focusing on consumer participation relating to cancer care in Australia.

**Part A:** The Cochrane Database of Systematic Reviews was searched for the terms ‘consumer participation’ or ‘consumer involvement’ in all text, and for records with ‘cancer’ in the title and ‘consumer participation’ or ‘consumer involvement’ in all text. All titles published by the Cochrane Consumers and Communication Review Group were also scanned for relevance.

**Part B:** The broader literature search involved three main strategies: a systematic search of published and indexed material, a systematic search of library online gateways and the World Wide Web, as well as a hand search of non-refereed consumer journals. The search was restricted to items published in English and involving populations in Australia. Material that addressed specific health sectors other than cancer or addressed population screening was excluded.

*1 In this review ‘consumer’ is used as a generic term to refer to consumers/users of the health services, carers or family members or friends who look after someone who is sick, and community members interested in the health services system.*

### 1. Systematic search of published and indexed material

Published and indexed material was located by searching electronic databases from 2000 to 2005. The search was conducted in August 2005 using a simple search strategy comprising the medical subject headings (MeSH) ‘consumer participation’ and the text word ‘cancer’.

The following databases were searched for research material:

- Cochrane Central Register of Controlled Trials (CENTRAL)
- Cochrane Library
- MEDLINE
- OVID
- PubMed.

### 2. Systematic search of Australian library online gateways and the World Wide Web

The search included looking for relevant publications on Australian library online gateways and Australian websites on the World Wide Web using a simple search strategy comprising the keywords ‘cancer’, ‘Australia’ with ‘consumer participation’ or ‘patient participation’ or ‘carer participation’ or ‘caregiver participation’ or ‘consumer involvement’ or ‘patient involvement’.

#### (a) Library online gateways

The websites searched were:

- National Resource Centre for Consumer Participation in Health
- Health Issues Centre
- Consumers’ Health Forum of Australia
- National Health and Medical Research Council
- Victorian Department of Human Services
- NSW Department of Health
- Australian Council of Social Service (ACOSS)

#### (b) World Wide Web

The Australian websites searched were:

- Google Scholar
- Google.

### 3. Hand search of Australian non-refereed consumer journal

An Australian non-refereed consumer journal was hand-searched. The journal of the Health Issues Centre was known to include reports of consumer participation in health services in Victoria and consumer experiences of cancer.

All retrieved abstracts and websites were scanned for relevance. The full article was retrieved if it related to consumer participation and cancer services.

#### Literature review limitations

There are several limitations to the literature review, as detailed below.

- The extensive literature on consumer participation—much of which does not appear on indexed databases—is dispersed across a wide range of publication types.
- It is difficult to access some reports, particularly since the loss of funding to the National Resource Centre for Consumer Participation in Health.

## Findings from the literature review

### Part A: Search of Cochrane Library

The search of the Cochrane Library identified eight relevant reviews and one protocol that provide some guidance on how to involve consumers in their care.

The Cochrane systematic reviews included:

- interventions to promote a patient-centred approach in clinical consultations (Lewin 2001)
- decision aids for people facing health treatment or screening decisions (O'Connor 2003)
- recordings or summaries of consultations for people with cancer (Scott 2003a)
- written and verbal information for patients being discharged from acute hospital setting (Johnson 2003)
- two reviews specifically addressing the issue of improving communication with children and adolescents, either about their own cancer (Scott 2003b) or a family member's cancer (Scott 2003c)
- personalised risk communication for informed decision making about entering screening programs (Edwards 2003)
- communication skills training for health care professionals working with cancer patients, their families and/or carers (Fellowes 2004).

The protocol identified in the search is:

- Interventions for promoting consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Nilsen 2004).

### Patient-centred care

The Cochrane review of interventions to promote a patient-centred approach in clinical consultations was limited by considerable differences, or heterogeneity, in the types of interventions used and methodological issues in the original studies. Despite the lack of a widely accepted definition of patient-centred care, it appears that strategies to promote it within clinical consultations may be effective in achieving care that is perceived to be patient-centred. If such care is considered a worthwhile goal in its own right, the review authors conclude that investment in the development of relevant training is probably justified. However, evidence is limited about how strategies to promote patient-centred care affect behaviours or health status, or whether these interventions might be applicable to health providers other than doctors.

### Decision aids

Decision aids for people facing health treatment or screening decisions are effective in improving people's knowledge of treatment and screening options and outcomes. They also increase realistic expectations, reduce uncertainty about decisions (also known as decisional conflict), decrease the proportion of people remaining undecided, and encourage a more active role in decision making among those seeking care. Compared to simpler versions, the review found that more detailed decision aids improved knowledge only marginally, but increased realistic expectations and the agreement between their values and actual choices significantly.

*The Cochrane review on decision aids raises a number of important issues. The first consideration is whether informed decision making is achieved among people not given decision aids, even though some are available. Second, most studies in the review found decision aids reduced preferences for major elective surgery in favour of more conservative options. This suggests that the widespread use of decision aids could have significant implications about how resources are used. Third, not all decision aids have been evaluated. Further, there is considerable variability in the contexts in which decision aids have been used and in their design. At the time of the review's publication there was no consensus as to what should be included in a decision aid.*

*Decision aids for cancer treatment and screening are among the 34 trials in the Cochrane review. Those for treatment decisions include an aid for prostate cancer patients considering treatment (Davison 1997), and for women considering breast cancer surgery (Street 1995; Goel 2001). Eight decision aids for cancer screening options are included. Four of these are for PSA testing (Wolf 1996; Davison 1999; Volk 1999; Shapira 2000), three for colon cancer screening (Pignone 2000; Wolf 2000; Dolan 2002) and one for breast cancer risk (Green 2001).*

The authors of the review conclude that to implement decision aids in practice the following conditions are needed: there needs to be a good quality decision aid available to use; health practitioners must be willing to use decision aids; the health system needs to be effective in supporting the decisions that people make; and both health practitioners and consumers need skills in shared decision making.

A list of relevant decision aids can be found at:  
<http://decisionaid.ohri.ca/AZsearch.php?criteria=cancer>

### **Recordings or summaries of consultations**

The review of recordings or summaries of consultations for people with cancer found no randomised controlled trials that assessed effects on survival or physical health status of people with cancer. Most studies evaluated psychological outcomes. There are limits to the ability to generalise the results because of methodological limits in the included studies. However, the review authors conclude that recordings and summaries of consultations do not increase anxiety, although this may not be true for people with poor prognoses. The authors recommend that health practitioners offer people tape recordings or written summaries of their consultations as most found them a useful personal reminder to share with their families or friends and their GPs. People who are given recordings or summaries of consultations tended to remember more of the information given to them, and some were more satisfied with the information they received. There is some evidence to suggest that the provision of consultation recordings or summaries may encourage more active participation in subsequent consultations and in decisions about care.

The Cochrane review identifies four important aspects of providing information to patients through recordings or written summaries, for which data are sparse or absent, but need consideration. First, the technical aspects of recording consultations, including the prospect of recording failure and the potential need for technical support to replay tapes, needs to be taken into account. Second, written summaries must take account of variable levels of literacy, including poor health literacy, so that the information is correctly conveyed. Third, people given recordings or summaries of consultations

need to be advised about how long the information contained in them is likely to remain current. Fourth, the costs of the interventions also need to be considered. None of the studies included in the review contained economic evaluations.

### **Written and verbal information at discharge**

The Cochrane review comparing written and verbal information versus verbal information only for patients on discharge from hospital is important because giving information at this time is part of everyday practice to help people manage various aspects of their own care. However, evidence for this common practice is limited and only a small number of trials have been conducted and these have methodological limitations. Both trials included in the review involve parents of children discharged from hospital. Despite their problems, both trials are consistent as they show that, when given together, verbal and written health information significantly increased knowledge and satisfaction.

Other outcomes were common to both trials. Issacman (1992) assessed whether people returned for additional care to the Emergency Department following discharge, whether there was a need to call a doctor for advice after discharge, and whether parents reported the filling of prescriptions within 24 hours of discharge. This latter outcome was used to assess adherence to prescribed care. The study found that people given verbal information were more likely to return to hospital compared with those given standardised verbal information or those given written information in addition to verbal information. However, there was no significant statistical difference between groups about who called a doctor following discharge or in the proportion that reported filling prescriptions within 24 hours of discharge.

### **Communication with children and adolescents about cancer**

Two Cochrane reviews specifically address the issue of improving communication with children and adolescents, either about a family member's cancer (Scott 2003c) or their own cancer (Scott 2003b). Both reviews found the results of located studies difficult to interpret because of inherent problems with the studies' design, and because of the difference (heterogeneity) in the studies' aims, designs (both reviews used study designs other than randomised controlled trials), types of interventions, the outcomes that were measured, how the outcomes were assessed, who took part in the studies, and how the analyses were performed.

Although the review shows that the evidence is not strong, the authors conclude that some interventions may be helpful in communicating with children and adolescents about cancer.

The review that looks at communicating about a family member's cancer includes only 'before' and 'after' studies. While this increases the likelihood of bias (or systematic error) in the findings, the results of the review are cautious. It found that structured group interventions (including facilitated group discussion, art therapy, role-play and informal social interaction, and a camping program with recreational, educational and psychosocial support components) may lead to improvements in knowledge and understanding, in coping, anxiety, adjustment and wellbeing. The review authors recommend that health practitioners continue to use their judgement about how to better communicate with children and adolescents about cancer and that account be taken of the family member's medical condition (especially their prognosis); the child or adolescent's level of cognitive, emotional and physical development; the child or adolescent's readiness and ability to communicate; and the person they might prefer to speak to about their concerns.

*The review about communicating with children or adolescents about their own cancer includes more studies covering a range of study designs. It found weak evidence to suggest that some interventions, such as computer-assisted learning, art therapy, and school and social re-integration programs, may lead to improvements in knowledge and understanding and in psychological, social and behavioural outcomes.*

### **Personalised risk for informed decision making about screening programs**

The Cochrane review found that the uptake of screening tests is increased by communication of personalised risk (whether written, spoken or visually presented) but there is no evidence that this is related to more informed decision making. For example, the review also found that when the personalised risk information was more detailed, the uptake of tests was lower.

Although the review includes 13 studies, the data they provide are limited in a number of ways. First, the studies measure only a narrow range of outcomes, with most concerned with the assessment screening uptake. Few other outcomes are measured in the studies and the review could not report on a range of key outcomes because of insufficient data. Outcomes such as knowledge, perception of risk, anxiety, and satisfaction with the decision, would give a fuller and more useful picture of the effects of interventions communicating personalised risk. The second limitation is that most of the included studies (ten of 13) relate to mammography programs, which means that there needs to be some caution when generalising the findings to other clinical areas. The third issue is that 'high risk status' appears to be an important effect modifier so that interventions appear more effective among people of high risk status.

Four of the 13 studies in the review involved people believed or known to be at higher risk than average for the population. Finally, there is a lack of relevant data about screening, which makes the provision of personalised risk information to consumers in a systematic way difficult.

### **Communication skills training for health care professionals**

The Cochrane review found that training in communications skills can help change the behaviour of professionals working with cancer patients, but the authors conclude that it is not clear if this was affected by the enthusiasm of participants, including the facilitators.

The review focus is the training of health professionals to communicate with patients about cancer as this is believed to be inherently different to communicating with people about illnesses that are not life-threatening. The review included three trials involving 347 health professionals, but they involved quite different approaches, although they had similar content.

One provided an intensive three-day course for oncology doctors while the others were modular courses, one for doctors and the other for nurses. The trials assessed different outcomes. One found that training resulted in oncology doctors using more focused questions, expressions of empathy and appropriate cue responses at follow-up compared with those in the control group. The second trial found that trained doctors controlled the follow-up interview more than untrained doctors but neither study found differences in the summarising, interrupting and checking among trained and untrained doctors. The third trial found trained nurses used more emotional speech than their untrained counterparts, particularly regarding anxiety and distress. Patients interviewed by trained nurses used more emotional terms, but no differences emerged in questionnaires.

**Protocol: Interventions to promote consumer involvement**

The results of the review looking at the effectiveness of promoting consumer participation in the development of health care policy and research, clinical practice guidelines and patient information material is yet to be published, but the protocol provides a useful framework for describing consumer involvement. Originally used in a systematic review of consumer involvement in setting research agendas, it incorporates a number of useful parameters for consideration.

The first of these is an assessment of the degree of consumer involvement: by consultation, by collaboration or by consumer control. The second aspect to consider is the forum in which the participation occurs, such as a public meeting or in a committee. Third is an assessment of involvement in decision making, and whether this is implied or explicit. The last four parameters of the framework relate to the assessment of how the involvement is implemented. The first of these is the method of recruitment of those involved—consumers and health professionals. The second is concerned with whether any training and support is given, and how this is done. The final two are concerned with how financial support is provided, either through the payment of fees or honoraria, and whether practical support, such as administrative support, is available.

## **Part B: Search of broader literature**

### **Policy initiatives addressing consumer participation**

Several documents relating to policies around consumer participation in health services relevant to cancer care in Australia were located, with a range of evidence from personal opinions through to a randomised controlled trial.

### **Policy for consumer participation in public health services**

Policies on consumer participation developed by the Department of Human Services (2005a; 2005b) identify four levels of consumer participation. Priority actions for Victorian public health services are assigned to each level (see Table 2). The individual level is about the active involvement of consumers and, if appropriate, their carer(s), in their own care and treatment.

The program or department level is about consumer participation in the settings where services are delivered, such as through formal and systematic feedback mechanisms or planning at the ward or program level.

Consumer participation in the health service organisational level is focused around organisational policies or issues, such as involvement in quality improvement or service planning.

The final level incorporates participation at a statewide level, such as through the committees or projects of the Department of Human Services or other statewide organisations. This approach offers a useful categorisation of the levels of participation and will be referred to throughout this review.

**Table 2: Priority actions in consumer participation**

<b>1. Individual care level</b>
<p>1.1 Promote the rights and responsibilities of patients to the community, consumers and carers.</p> <p>1.2 Communicate clearly and respectfully with consumers and carers.</p> <p>1.3 Provide accessible information to consumers, carers and community members about health care and treatment.</p> <p>1.4 Communicate and provide information about treatments and care to consumers and carers that is developed with consumers and, where appropriate, carers.</p> <p>1.5 Listen and act on the decisions the consumer and, where appropriate, their carer(s) make about their care and treatment.</p>
<b>2. Program/department level</b>
<p>2.1 Involve consumers, carers and community members from the planning stage through to evaluation and monitoring.</p> <p>2.2 Create welcoming and accessible services for the diverse members of your community.</p> <p>2.3 Provide training to staff in communication skills and how to involve consumers and carers in decision making.</p> <p>2.4 Promote the importance of consumers and carers providing feedback to improve services.</p> <p>2.5 Establish links with community organisations to provide emotional support and ongoing information to consumers and carers.</p> <p>2.6 Involve consumers, carers and community members in the development of clinical guidelines and research.</p>
<b>3. Health service organisational level</b>
<p>3.1 Integrate participation of consumers, carers and community members, representatives or nominees into the quality and safety program.</p> <p>3.2 Involve community representatives or nominees in the review of system level issues regarding consumer and carer feedback and complaints.</p> <p>3.3 Involve consumers, carers and community members, representatives or nominees in all aspects of the organisation's planning and development.</p> <p>3.4 Provide staff training and education on how to use the different types of participation.</p> <p>3.5 Ensure position descriptions include participation components.</p> <p>3.6 Evaluate, monitor and report on participation to the community and the Department of Human Services.</p>

#### 4. Department of Human Services level

- 4.1 Use the same processes of working with and accessing consumers, carers and community members, representatives or nominees across the Department.
- 4.2 Provide support, guidance and resources to health services and consumers, carers and community members on participation.
- 4.3 Provide training and education to Department staff on how to use the different types of participation, and evidence-based participation and communication.
- 4.4 Encourage health services to evaluate and monitor participation within a quality improvement framework.
- 4.5 Encourage the inclusion of participation skills and knowledge in the tertiary education of health professionals.
- 4.6 Advocate for a whole of Department policy on participation.

Source: Department of Human Services, 2006, *Doing it with us not for us, Participation in your health service system 2006-09: Victorian consumers, carers and the community working together with their health services and the Department of Human Services*, pp. 25-36, Department of Human Services, Melbourne.

#### Policy review of guideline development

There is one Australian example of consumer involvement in the development of guidelines in the literature. Redman (2003) reviewed the experience of policy development for the introduction of systematic psychosocial support for women with breast cancer in Australia. She concluded that the involvement of consumers in the policy development process led to the acceptability of the guidelines to consumers. This in turn encouraged breast cancer advocacy

groups to be active in lobbying for the adoption of the policy. Redman described this as 'vital' to bringing about the change to practice. The primary research study that informed the development of the policy included consumers by surveying women diagnosed with breast cancer, asking them to rate the importance of draft guidelines for psychosocial support, and identifying priority areas for clinicians to address in consultations (Rankin 2000).

## Strategies to support consumer participation

Only three strategies to support consumer participation in cancer care at the service, program or organisational levels in Australia were identified in the literature. These included a plan to establish a liaison position, advocacy training, and formulating advice for involving consumers on committees. However, there was an absence of any formal evaluation of these proposed strategies.

### Liaison position

The 2001 Community Health Plan developed by the Central Grampians Primary Care Partnership recognised the need for adequate resources to support systemic participation by consumers in the priority areas of cardiovascular disease and cancer. The plan proposes the formation of a liaison advocacy position to conduct focus groups, develop consumer information, and support consumer advisory group meetings and consumer nominees on other committees (CGPCP 2001). However, no evaluation of this model was found in the literature search and it does not appear to have been implemented.

### Advocacy training

At the service or program level, one study showed that consumer participation increased among women with breast cancer following three-day advocacy training in the following areas: participation on boards and committees; working on clinical trial recruitment issues; working on patient resource materials; and involvement in breast cancer advocacy. However, the training had no effect on other key advocacy areas, such as lobbying for services or reviewing research protocols. The study provided no information about the effectiveness

of involving consumers in bringing about change or having voices heard in decision making processes (Davis 2001).

### Involving consumers in committees

The literature, particularly the grey literature, offers some guidance on how to support consumer participation at the program and organisational level through involvement on steering committees or reference and advisory groups.

One study reported feedback from consumers with colorectal cancer who took part in a project to support the best use of evidence in cancer care practice. Consumers participated in the project in three ways. All took part in the initial study interviews, then some joined consumer reference groups, and a small number became members of the project implementation group (Naksook 2003a).

The study is interesting because it also asked consumers why they thought others did not participate in the project. Consumers active in the project believed this was because it was confronting and difficult to adjust to cancer diagnosis and manage pain. Consumers who took part in the study said their understanding of their cancer and the treatment options increased, and they found learning about the experiences of others beneficial to them (Naksook 2003a).

The other paper that looked at this issue was advice based on the experience of the author. Ford identified five key issues that health services should take into account when involving consumers: recruitment of appropriate consumers; the terms of reference for the committee; the committee's effectiveness; its budget; and evaluation (Ford 2001). These issues emerge in other literature and are further developed below.

## Recruitment

Consumer participation at the service or program level necessarily involves a process of recruitment. Recruitment of both health consumers and health professionals is an aspect of the conceptual framework of consumer involvement discussed in Nilsen's Cochrane review (2004). The most commonly cited concern about consumer participation is how this will be done to ensure representation. This issue is addressed in Oliver's framework by asking whether recruitment is through a public process such as the mass media or through more personal approaches such as direct mail or email (Nilsen 2004).

When the population from which people are to be recruited includes cancer patients, sensitive strategies that take account of emotional and physical issues are needed (Naksook 2003a). Ford (2001), who was addressing a broader audience, suggested a number of strategies to find consumers, such as using advertisements, local council contacts, targeting appropriate support groups or using local noticeboards and word-of-mouth networks. Although these strategies were adopted for the Peter MacCallum Cancer Centre Community Advisory Committee (CAC), concerns about a lack of diversity among participating consumers remained a challenge. In particular, the CAC found that some potential consumer participants felt their English skills were inadequate (Moss 2003).

Critical to the participation of consumers with colorectal cancer were both the invitation from the health provider to take part in the project and encouragement from their doctors. From their experience of the initial interviews, some consumers were encouraged to be involved in the reference and implementation groups (Naksook 2003a).

## Terms of reference

The terms of reference of committees are important; they clarify the role and authority of the committee so that consumers know what is expected of them (Ford 2001; Naksook 2003a). The conceptual framework for consumer involvement in research focuses on whether consumer involvement in decision making is implicit or explicit (Nilsen 2004).

One example was found in the literature where both the facilitators and consumer participants in a consumer reference group, established to develop a proposal for a coordinated plan trial in Victoria, attributed part of the success of the group to the existence of a clear focus. Although this group was not successful with their application, the exercise did result in positive experiences in collaboration for those involved (Bourke 2002a).

## Effective committee processes

Good committee processes and useful tasks are important to the involvement of consumers. These include position descriptions for committee members, formal letters of confirmation and timely meeting papers (Ford 2001; Bourke 2002a; Naksook 2003a; Moss 2003). Consumer confidence is developed through training, support, being informed of outcomes—especially about any changes that come about from their input—and participation in any strategy to disseminate findings (Naksook 2003a). Effective committee processes can be seen in two parameters of the conceptual framework used in Nilsen's Cochrane protocol (2004): firstly, through the provision of training and support for consumers and health professionals; and secondly, through the availability of administrative support (Nilsen 2004).

## Budget

Financial support is included in the consumer participation conceptual framework used by Nilsen (2004)—it is clearly an important factor for participation. Committees with consumer members need to budget for items such as sitting fees, venue hire and the reimbursement of costs such as travel, parking, taxi fares and child care (Ford 2001). There does not appear to be an association between payment and commitment to attendance, although it is important for the participation of those on low incomes (Bourke 2002a).

## Evaluation

Consumer participation on committees should be subject to ongoing process and impact evaluation (Ford 2001). Ongoing evaluation was also supported by Naksook (2003a) who found some participants were unavailable at the end of the project. This is an important consideration among a group that includes cancer patients. Failure to continue participation may not relate directly to their health status. For example, when the Peter MacCallum CAC conducted an evaluation at the end of their first year, two of the eight members chose not to continue, one because of a change in personal responsibilities and the other to engage more actively in promoting change in the health system (Moss 2003). Weir and Tito (2003) suggest three main areas need to be addressed when monitoring the effectiveness of consumer participation strategies—process, performance and outcome. That is, how is consumer participation being facilitated? Is consumer participation occurring effectively? Has consumer participation changed anything?

Consumer input into an evaluation can have a strong influence in the results of the evaluation but can also increase the length of time before its completion. In one study to assess the needs of women with breast cancer, consumers had a strong influence on many aspects of the project

including the sampling method used, the choice and framing of questions, and the inclusion of service information within the survey. The reported results include high rates of response and completion of the questionnaire. Local knowledge added to the interpretation of the findings, making the study more relevant and acceptable to the local community (Bourke 2002b).

The conceptual framework for assessing consumer involvement used in the Cochrane review (Nilsen 2004) appears to provide the most comprehensive approach to an evaluation and offers an opportunity for consistency in approach of future evaluations of consumer involvement.

## Tools to support consumer participation

Three different tools that could be used to encourage consumer participation at the individual level were identified in the recent Australian literature: question prompt lists, audiotapes and survey instruments to assess needs. The literature search did not identify any evaluations of decision aids used in Australia relating to cancer care.

### Question prompt lists

The value of cancer patients using question prompt lists to facilitate consumer participation in consultations with their doctors is supported by a high level of evidence, although the three Australian randomised controlled trials published in the last five years focused on the initial consultation with the oncologist (Brown 2001; Brown 2002; Brown 2004; Butow 2004).

Question prompt sheets were found to change patient behaviour in consultations but also appeared to be more effective when used in conjunction with other strategies. People given a question prompt sheet alone asked more questions about prognosis, although the total number of questions asked was unchanged (Brown 2001). When incorporated with a

video of an experienced oncologist discussing treatment options with a patient demonstrating different patient styles, people given question prompts were more likely to declare their information and treatment preferences to their oncologists (Brown 2004). If prompt sheets were packaged with information on clinical decision making and patients' rights, cancer patients asked significantly more questions, tended to interrupt more, and were more likely to challenge the information given to them (Butow 2004). However, there were potential adverse effects as well. Anxiety increased among people given prompt questions and consultations were longer unless the oncologists specifically addressed the prompt sheet questions. When they did so, not only did anxiety and consultation times reduce, patient recall also improved (Brown 2001). Doctor behaviour also changed when referring to question prompt sheets as they were more likely to raise new themes (Brown 2004). Lack of endorsement of the question prompt list by the doctor was associated with less likelihood that patients would achieve the preferred level of participation in their care decision making. Consumers want to participate in decisions about their care but this cannot happen without sufficient information and encouragement to ask questions (Jefford and Tattersall 2002).

A qualitative study that used interviews, focus groups and questionnaires with cancer patients, carers and health professionals found that a question prompt list about palliative care was strongly supported (Clayton 2003).

In interviews with a clinical psychologist to help frame policy around 'do not resuscitate' (DNR) orders, cancer patients supported the use of medical protocols around which to discuss this difficult issue. The findings raised some important insights for health professionals working in this sensitive area. Autonomy was important to the consumers interviewed, but they saw their autonomous rights as including

the right not to make decisions. They felt they needed to rely on their doctors to judge the right time for these discussions (Oliver 2002).

### Audio-taping consultations

A review of the evidence on the use of audiotapes in consultations with oncologists, by Tattersall and Butow (2002), was published in the year prior to the Cochrane systematic review of recordings or summaries of consultations for people with cancer (Scott 2003a). The findings were similar and supported the use of audiotapes for enhancing consumers' participation in their care. The authors concluded that audiotapes improved patient recall and satisfaction with their consultation and were useful to family members.

### Survey instruments

Although not strictly tools to promote consumer participation, survey instruments can provide useful information to facilitate participation and to assess the impact of strategies on consumers. For example, the Supportive Care Needs Survey reliably assesses the generic needs of patients with cancer in five key areas: psychological (emotions and coping); health system and information (about treatment centre and the disease, diagnosis, treatment and follow-up); physical and daily living (coping with physical symptoms, side effects of treatment and performing usual physical tasks and activities); patient care and support (health care providers showing sensitivity to physical and emotional needs, privacy and choice); and sexuality (sexual relationships [Bonevski 2000]). Two different statewide surveys have been used regularly in Victoria—a survey of recent mothers, and an annual survey of public hospital inpatients, the Victorian Patient Satisfaction Monitor (Draper 2001).

## Factors affecting consumer participation

### Role of information

Information plays an important role for consumers and their families in their capacity to participate in their care. The provision of sufficient information and encouragement to ask questions helped consumers and their families feel in control, included in decision making, and better able to cope with their situation (Jefford and Tattersall 2002; Henman 2002; Wilkes 2000). Information helped people feel they could coordinate treatment (Wilkes 2000), helped people establish priorities and concerns when they felt they had no choices (Henman 2002), and increased participation in decision making (Jefford and Tattersall 2002). When this happens and more options are made available, both physical and psychological outcomes improve (Jefford and Tattersall 2002).

### Roles in decision making and care

Consumers' satisfaction with their oncology consultations and the amount of information and emotional support their doctors give them is higher for those who perceive the experience as shared decision making, regardless of their preferred role. Least satisfied were those who felt decisions were made either by themselves or their doctor exclusively (Gattellari 2001).

The range of strategies oncologists use to manage an initial consultation can be influenced by the type of behaviour exhibited by the patient. In a study where interactions were recorded of a 'consultation' between an oncologist and an actor 'patient', the strategies employed to engage the patient varied according to whether the patient was active or passive. Oncologists responded by using strategies that included explicit agenda-setting, active listening, checking understanding, endorsing question-asking,

offering to delay decisions, and non-verbal behaviours that conveyed empathy and warmth. Patients perceived to be passive were given fewer details and less complex information but more strategies were employed to help understanding, such as the use of diagrams. Emotional issues were raised more frequently by the doctor compared to consultations involving active patients, who were less likely to have their fears addressed, and more likely to be encouraged to make their own decision about treatment and to seek a second opinion (Brown 2002).

Observational studies and personal accounts found in the literature explored the experience of being a patient and revealed barriers to participation at the individual care level. The capacity for consumers to participate in their care can also be affected by the expectations others have of their behaviour. Participant observation of home nursing found that patients' experiences of being nursed were based on themes of gratitude, vulnerability and compromise (Hall 2001). These staff expectations of patient behaviour restricted consumer participation in care. Although not specifically related to cancer patients, Hall found that people receiving home nursing made many compromises to be 'good' patients and most had no 'choice' about their care as there were few options. Patients were expected to be agreeable, compliant, submissive and grateful (Hall 2001). Oliver-Weymouth (2000) felt her mother was afraid to 'rock the boat' and raise concerns about her role as her stepfather's carer because of the limited choices available to them, and concerns about retribution, even though her mother's capacity to provide care diminished over time.

Although health professionals may appear to take on the rhetoric surrounding consumer participation, an Australian observational study revealed that active participation by consumers is often excluded from nursing practices

because of the way in which nursing labour is divided in the health care setting, limiting communication between nurses and their patients (Wellard 2003).

### **Roles in service planning, delivery, evaluation and organisational level involvement**

The literature search did not identify any specific factors related to participation in cancer services at these program and organisational levels. However, the recent Department of Human Services participation indicators paper (part of the process to develop a health consumer participation policy in Victoria) did identify a range of areas where the literature suggested activity was necessary to support effective participation across a health service (Department of Human Services 2005a; 2005b).

### **Consumers with specific needs**

The literature around the different types of specific need groups was sparse, with only three papers located. Three groups were identified in the literature review—consumers and carers from rural areas, groups with different cultural understandings of cancer, and people from non-English speaking backgrounds.

These groups were included in a systematic search of literature undertaken by Silburn (2000) for the Consumer Focus Collaboration. The review included only one study that specifically addressed the needs of cancer patients. Most material located in the review focused on groups of consumers identified as having poor access to services. The review identified a number of structural issues that needed to be addressed in order to remove barriers to consumer participation, including a lack of developed systematic strategies addressing specific needs; a focus in the

literature on the reasons for marginalisation rather than on reform of organisational structure and culture; the presence of discriminatory attitudes towards some groups; solutions that focused on one-off strategies rather than an integrated approach; and lack of response to research findings.

The review identified some solutions discussed in the literature, including the development of a long-term commitment to involving consumers; the employment of community members; consulting with consumers about appropriate strategies for their involvement; developing transitional processes; ensuring confidentiality and anonymity; involving both consumers and health providers in determining questions and solving problems; and building consumer feedback and participation into quality assurance and other activities.

### **Rural consumers**

Two studies were identified that raised the issue of psychological need among rural cancer patients and their carers, but specific solutions were not identified. Unmet psychological need has the potential to inhibit consumers' participation in their care (Clavarino 2002; Bourke 2002b).

### **Cultural understanding**

Two papers were found that provide insight into the impact of cultural beliefs about cancer and its impact on patient behaviour and needs.

Eisenbruch (2004) interviewed 16 Chinese people through familial cancer clinics. Despite an apparent acceptance of the causes of cancer in terms of the information given in genetic counselling, there was also a strong influence of traditional Chinese family beliefs that included specific cultural ideas about inheritance of disease largely through the paternal line, the role of 'bad luck' and the 'risk' of cancer.

There was a belief that cancer is extremely contagious and that attending the clinic was dangerous. At least four people declined to participate in the study because they felt talking about cancer may aggravate or cause it. Faulty genes were believed to be related to retribution for ancestral misdeeds and offending ancestors. The author suggested that to overcome some misunderstanding it would be helpful to point out, at the beginning of genetic counselling sessions, that everyone has some faulty genes.

A report of a forum in the Northern Territory to discuss reasons for cancer death rates being twice as high for Indigenous Australians includes some detail about the cultural beliefs of Indigenous people. A spiritual link is believed to exist between the body parts of Aboriginal people and members of their extended family. When cancer occurs in a particular organ it is seen to result from an offence to the associated relative. If such a cancer is viewed as 'payback', or retribution for a wrong deed, the person afflicted may not pursue treatment. Participants at the forum, which included oncologists, epidemiologists, academics, Aboriginal health workers and Indigenous cancer survivors, were told that a lack of respect of beliefs can lead to a corresponding lack of trust in health professionals and health services. One practical barrier identified that would apply to regions outside the Northern Territory was the absence of an informed community. Future directions suggested for improving the health outcomes for Indigenous Australians with cancer included greater involvement of Indigenous representatives; use of liaison officers; increased capacity among the Indigenous health workforce; and improved cancer control in Indigenous communities (Lowenthal 2005).

### Consumers from non-English speaking backgrounds

Cancer patients with poor English skills are less likely to be given comprehensive information about their treatment options or their self-care needs (Naksook 2003b). Information is rarely available in the first language of those patients with a non-English speaking background (NESB), making it difficult to ask questions or to engage in the first level of consumer participation—individual care. Other levels of consumer participation may be impeded by concerns about language skills (Moss 2003).

There have been efforts to engage NESB consumers in focus groups and interviews (Naksook 2003b) but a systematic approach is needed. Ferris (2000) recommends that health providers' resource materials should include a book about communicating with people from different cultures and non-English speaking backgrounds; that medical receptionists should find out about language needs when appointments are made so telephone interpreter services can be arranged in advance; that there is a need for a register of health practitioners who can speak other languages; that warning labels on prescriptions should include other languages; and that all health providers be required to attend seminars run by interpreters and people of non-English speaking backgrounds.

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## Appendix 2: Project Advisory Group membership

Pauline Church	Consumer representative
Lauren Cordwell	Health Issues Centre
Tere Dawson	Health Issues Centre
Phillippa Hartney	Loddon Mallee Regional Integrated Cancer Service
Julie Hassard	The Cancer Council Victoria
Claire Higgins	Department of Human Services
Jackie Kearney	Department of Human Services
Sue Lockwood	Consumer representative
Tony McBride	Health Issues Centre
Jane Miller	Southern Melbourne Integrated Cancer Service
Colleen O'Hara	Grampians Regional Integrated Cancer Service
Margot Rosenbloom	Carer representative
Terri Smith	Breast Cancer Network Australia
Michael Summers	Carers Victoria
Mary-Jane White	St Vincent's Health
Peter Williams	The Cancer Council Victoria

## Appendix 3: Location of focus groups

Integrated Cancer Service	Consumers	Service providers
Barwon South Western	Barwon Health Geelong Hospital	Barwon Health Geelong Hospital
Loddon Mallee	Bendigo Health Care Group Bendigo	Bendigo Health Care Group Bendigo
Grampians	Jerrold's (at the Menzies) Restaurant Ballarat	Jerrold's (at the Menzies) Restaurant Ballarat
Grampians	Wimmera Health Care Group Horsham Hospital	Wimmera Health Care Group Horsham Hospital
Gippsland	Latrobe Regional Hospital BreastScreen, Traralgon	Latrobe Regional Hospital BreastScreen, Traralgon
Hume	Ave Maria Village Community Centre, Shepparton	
North Eastern	Northcote Library Northcote	Epworth Eastern Hospital Box Hill
Southern	Frankston Library Frankston	Monash Medical Centre Moorabbin
Western Central	North Yarra Community Health Carlton	St Vincent's Hospital Fitzroy
Extra Metro	La Trobe University City Campus, Melbourne	