

# Building partnerships with consumers to improve service delivery

Breast Services Enhancement Program

Learning from the past—informing the future

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to improve service delivery**

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## Preface

Welcome to *Learning from the past—informing the future*, the learning series based on the experiences of the Victorian Breast Services Enhancement Program.

The Breast Services Enhancement Program commenced in 1999 as a key component of the Breast Disease Service Redevelopment Strategy 1999–2003<sup>1</sup> (BreastCare Victoria).

Since the implementation of BreastCare Victoria and the Breast Services Enhancement Program, there has been an increasing national and state focus on improving services for all people with cancer. As with breast cancer, in addition to improving discrete health outcomes such as survival and morbidity through evidence-based best practice, there is increasing emphasis on improving the experiences of people with cancer as they navigate our complex health system.<sup>2</sup>

These two aspects, improving clinical outcomes and the consumer experience, were the focus of the service redevelopment and quality improvement initiatives of the Breast Services Enhancement Program.

From 1999 to mid 2004, nine consortia of health services across Victoria joined to develop and implement the Breast Services Enhancement Program. Over sixty different initiatives of various sizes were implemented. The presence of the Breast Services Enhancement Program also enabled us to seize other unexpected opportunities to help achieve our goals.

This learning series provides examples of the many experiences of the Breast Services Enhancement Program—key learnings, critical success factors and challenges. We learned what worked well, what worked less well, what made the difference and what we could do differently next time.

The learning series addresses these topics:

- multidisciplinary care—improving consumer outcomes
- continuity and coordination of care—improving the ‘cancer journey’
- supporting sustainable change
- building partnerships with consumers for improved service delivery.

The learning series reflects the hard work of all program staff, clinicians, breast care nurses, consumers and other health and community workers, as well as members of the BreastCare Victoria Advisory Committee. We thank you all for your significant contributions, enthusiasm and commitment.

Each resource in this learning series draws on evidence from the statewide evaluation of the Breast Services Enhancement Program and on individual evaluation reports. Evidence has also been gleaned from further discussions with key stakeholders in the field.

While each resource stands alone, links are made with other documents in the series along with other useful references, resources and tools.

We hope that the experiences and learnings of the Breast Services Enhancement Program may be of assistance to you in your work, whether it is in achieving new initiatives within cancer reform or in other health care reform.

A handwritten signature in black ink, appearing to read 'Lyn Swinburne'. The signature is fluid and cursive, with a large initial 'L' and 'S'.

**Lyn Swinburne**  
**Chair, BreastCare Victoria Advisory Committee (1999–2004)**

### Acknowledgements

This learning series was written by Sheila Hirst on behalf of Cancer and Palliative Care, Victorian Department of Human Services. We thank those stakeholders who provided additional local knowledge and experiences to inform this series.

The learning series *Learning from the past—informing the future* is based on the experiences of the following nine Victorian consortia who participated in the Breast Services Enhancement Program 1999–2004.

#### Metropolitan consortia

<b>Western</b>	Royal Melbourne Hospital, Royal Women’s Hospital, Western Health and associated private providers
<b>North Eastern</b>	Austin Health, Northern Hospital, Peter MacCallum Cancer Centre, St Vincent’s Health
<b>Southern</b>	Dandenong Hospital, Monash Medical Centre.
<b>Inner and Eastern</b>	The Alfred, Eastern Health (Box Hill, Maroondah and Angliss Hospitals), Peter MacCallum Cancer Centre, and associated private providers

#### Regional consortia

**Barwon–South Western Region**

**Grampians Region**

**Loddon Mallee Region**

**Hume Region**

**Gippsland Region**



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*...the tentative and modest methods of consumer participation put in place are often inconsistent with the ambitious ideals claimed. The 'add one consumer and stir' recipe may achieve some measure of legitimation but has less guarantee in improving results or shifting directions.*

Bastion 1994<sup>3</sup>

*The input of the consumer was absolutely critical. That's the first time we have had the opportunity to have consumer input to what we are doing... They gave us very good advice that we didn't expect. They gave us more support to do things we also thought were important... not only did we think it was important, but they did as well. That gave the whole process a legitimacy that others might not have.*

Clinical Coordinator, Breast Services Enhancement Program<sup>4</sup>

*Sometimes the obvious things get lost when everyone is busy. As a consumer representative I was able to work with others on the committee to make sure we get the best services for women. There were a few times I said, 'Well what about...?' and the others would say, 'That's a great idea'.*

Consumer representative, Breast Cancer Network Australia<sup>5</sup>

## Summary of learnings

### Evidence from the literature

- Consumer participation in health care at an individual, service and system level makes a significant contribution to improving individual and community health outcomes.
- The greater the involvement of consumers in health care planning and delivery, the greater the perceived value, patient satisfaction and enhanced organisational culture.
- A systemwide approach is needed, which uses multiple approaches and with the consumer participation valued at all levels of the organisation.
- For effective consumer participation, there needs to be clarity of purpose matched with consumer needs and the approach used.
- Optimal consumer participation is facilitated through direct dialogue between providers and consumers, which improves understanding, develops mutual trust and creates the real partnerships needed to improve consumer outcomes.

### Learnings from the Breast Services Enhancement Program

- The program's strong commitment to consumer participation was reflected in the involvement of consumers at every level of the program. The projects that most successfully engaged consumers were also those that resulted in direct and tangible outcomes in improved care for individual women.
- Effective consumer partnerships help to ensure a patient-centred focus to service improvements and provide services with additional strength and legitimacy.
- Strong executive sponsorship and clinical leadership helps to create an organisational culture that values consumer participation.
- Other factors that optimise consumer participation include:
  - a clear purpose
  - early engagement with consumers
  - the allocation of a small level of resources to support consumers
  - staff's previous experience of working with consumers
  - ensuring that more than one trained consumer representative sits on steering or advisory committees
  - access to other consumer experiences.
- Developing and supporting an ongoing consumer reference group, with clear terms of reference and links to consortia steering committees, appeared to be most successful in facilitating joint decision making between service providers and consumers. In some instances, the decision making authority rested with the consumers in the development of particular consumer-focused initiatives.
- Multi-pronged approaches to consumer participation can facilitate diverse consumer input and advice into the development of specific projects.

- While some programs had a strong focus on engaging with consumers, at times, this was undertaken in isolation from providers. This inadvertently reinforced the divide between consumers and providers. Further opportunities to strengthen dialogue between consumers and providers need to be explored.
- Significant time and ongoing support is needed at both a service level and at a broader systems level to ensure that consumers have the skills and knowledge to participate in health service reform, and that their contribution as members of the team is actively valued. Formal training is part of this support.
- Further work may need to be undertaken with service providers at all levels to provide them with the skills to support the evolving role of consumers in health service delivery and redevelopment.



## Case study 1

### Engaging with consumers

#### Where we started

At the beginning of our Breast Services Enhancement Program, the key consortium stakeholders embraced the concept of consumer participation in the Program and ways to create optimal partnerships.

#### What we did

From the beginning we established a consumer reference group that informed the development and implementation of the Program. Once established, the group selected two members to sit on the steering committee. We developed clear guidelines on what the role was and the skills that women would bring to the reference group. We recruited women through local support groups and the Breast Cancer Action Group.

The women who volunteered shared a commitment to making a difference for women in the future.

The consumer reference group met frequently during the initial Program development, then before each steering committee. Minutes of the steering committee and consumer reference group were tabled at each meeting. Within the steering committee, consumer issues were always an agenda item.

#### What we achieved

The initial service plan was developed with and endorsed by the consumer group, and their priority project was an integral component of the plan.

Through the Program, the group's advice was sought on a range of issues, including the development of a GP telephone case conference initiative. The personal care record (patient-held record) was developed as a strong partnership between consumers and service providers. The consumers had specific input and strong decision making authority in this project.

The consumers decided the way in which they wanted to participate in the project. The consumer reference group met separately from the provider group working party, with the two groups coming together at critical times. The consumers decided on the title of the resource, specific content and the resource design.

In the evaluation of the Program overall, both clinical stakeholders and consumers were very positive about the ways in which consumers had been involved, with consumers feeling particularly empowered.

#### Achievement of principles of consumer participation

- ✓ Strong provider endorsement and commitment.
- ✓ Good support from Program staff to create real partnerships.
- ✓ Consumers engaged early in Program development and planning.
- ✓ Consumer reference group provided steering committee consumer representatives with support and broader consumer views.
- ✓ Consumers had decision making powers and views were respected.
- ✓ Provider and consumer dialogue enabled strong respect and trust to be developed between parties.

The role of consumers as active participants in health care has resulted in more responsive health services.

# 1 Introduction

*Building partnerships with consumers for improved service delivery* is another resource in the learning series based on the experiences of the Victorian Breast Services Enhancement Program.

Over the last two decades the role of consumers as active participants in health care, at both an individual level and at the broader community level, has been increasingly emphasised. This has resulted in the development and delivery of more responsive health care services.<sup>6,7</sup>

Breast cancer consumer advocates played an important role in the development of the Breast Disease Service Redevelopment Strategy.<sup>1</sup> Not surprisingly, continuing consumer involvement was a cornerstone of the strategy's overall implementation, as well as in the development and implementation of the Breast Services Enhancement Program (the Program).

This document first briefly reviews the context of consumer participation in health care and in breast service redevelopment at the commencement of the Program. The next section then reviews some of the key learnings from the literature.

Section 4 introduces the learnings from the Program, and Section 5 provides an overview of the development of consumer partnerships within the Program and a summary of key achievements. Section 6 considers in some detail the different ways in which consumers were involved in the Program, and some of the critical success factors and challenges. Section 7 summarises our key learnings from the experiences. Section 8 provides information on finding consumer representatives and other resources to assist in the future development of consumer participation in health services.

Throughout the text these following symbols are used:

- ★ denotes **benefits** or outcomes of service improvement
- ✓ denotes **critical success factors** of service improvement
- ◇ denotes **challenges** to service improvement



## 2 Building consumer participation –the context

When the Program was established in 1999, consumer participation in the acute health sector tended to focus on mechanisms to gain consumer feedback.<sup>8</sup> At this time, community advisory committees to hospital boards had yet to be instigated in any substantial way.<sup>9, 10</sup> There were therefore limited models on which the Program could build. However, we did have some advantages.

At the start-up of the Program, the Victorian Breast Cancer Action Group (the first Australian breast cancer consumer lobby group) had been established for five years. In 1998 Breast Cancer Network Australia (the national peak body for breast cancer consumers) commenced, with its head office in Victoria. Victorian advocates were already involved in a range of national, state and local breast cancer initiatives.

Many key Victorian stakeholders at a policy and service level had strong commitment to strengthening consumer participation in breast service redevelopment. This is reflected in consumers' strong involvement in the development and implementation of the Breast Disease Service Redevelopment Strategy, with a consumer as the chair of the Advisory Committee.

The Program provided another opportunity to integrate consumer participation further into local breast service improvement initiatives. Consumers were successfully involved at many levels in the implementation of the Program's nine consortia.

Even with strong commitment to developing partnerships with consumers, many challenges were faced as we grappled with these questions:

- How can diverse consumer perspectives be involved in meaningful ways?
- What are the different mechanisms and approaches to optimising consumers' participation in service improvement and redevelopment?
- How can we find the right consumers for the right job at the right time, in a way that meets their needs?
- How can we facilitate consumers' involvement in decision making in an active, rather than a tokenistic, way?
- How can consumer views be integrated into different program levels?
- How can we work together to blend consumer and service provider perspectives (which sometimes conflict) to improve outcomes for women?
- What level of support is needed to assist consumer representatives?

Not surprisingly, we did not always get things right first time. We learned as we went along, and consumer participation evolved with this learning. This resource reflects our achievements, the critical success factors, our learnings and the challenges.

The next section looks at the evidence, much of which has been drawn from major review documents and resources developed to support health organisations to engage effectively with consumers.



### 3 What the evidence tells us

#### Key messages

- Consumer participation and partnerships in health care at an individual, service and system level makes a significant contribution to individual and community health outcomes.
- The greater the involvement of consumers in health care, the greater the perceived value, patient satisfaction and enhanced organisational culture.
- One approach to consumer participation alone will have limited impact.
- A systemwide approach is needed, using multiple approaches, with the value of consumer participation endorsed at all provider levels, including executive sponsorship.
- Clarity of purpose for specific initiatives needs to be matched with consumer needs and the approach employed.
- Optimal consumer participation is facilitated through early engagement and direct dialogue between providers and consumers to facilitate improved understanding and the development of mutual trust.
- Time is needed to reap the benefits of consumer participation and to turn participation into true partnerships between providers and consumers.
- Consumers need support and skills with additional training as required to maximise their capacity to contribute at service and system levels.
- Health service staff need improved understanding and skills to work more effectively with consumers in health service improvement.

See Section 8 for a listing of useful 'how to' resources to support consumer participation in health service organisations.

Over the last two decades, the need for consumer participation in health care policy and service delivery has been increasingly emphasised, with the view that services should be focused on the interests of the consumer and community, rather than on those of providers or funders.<sup>6,9</sup>

Recent Australian reports have documented growing evidence of different consumer participation mechanisms, the benefits to consumers and services, as well as factors that influence effective consumer participation.<sup>11, 12</sup> This experience has resulted in a range of published resources to assist organisations move from the 'rhetoric' of community participation to effective action in order to achieve improved services and health outcomes.<sup>12, 13, 14</sup>

## 3.1 Definitions

### 3.1.1 Consumers

Although at times perceived to be problematic,<sup>14</sup> the use of the term ‘consumer’ has been adopted worldwide by consumer movements to describe those who directly or indirectly use or are affected by health care services.<sup>3</sup>

‘Consumer’ is also used as an overarching term for users of health care services, carers or communities; however, each subgroup may have different and sometimes conflicting interests.<sup>13</sup>

### 3.1.2 Consumer representatives and participation in health care

The 1978 World Health Organisation’s Alma Ata<sup>15</sup> indicated that:

*...people have the right and duty to participate individually and collectively in the planning and implementation of their health care.*

In taking part in health care planning for the community, a consumer representative voices consumer perspectives and takes part in the decision making on behalf of consumers. This view is different from the bureaucratic, service provider or professional view.<sup>16</sup>

Whether at an individual, service or systems setting, real consumer participation and partnerships with service providers means joint problem solving, joint decision making and joint responsibility.<sup>17</sup>

Within the context of this resource, the major emphasis is on developing consumer partnerships at the service and systems level. This may include policy development, strategic planning, service planning, delivery, evaluation and monitoring.<sup>7</sup>

## 3.2 Benefits of consumer participation and partnerships

The benefits of consumer participation in health care include:

Consumer participation in health care improves individual and community health outcomes.

- making a significant contribution to individual and community health outcomes<sup>18</sup>
- enabling consumers to be more informed about health care choices, both individually and collectively<sup>7</sup>
- designing more accessible, responsive and effective health services<sup>18, 19</sup>
- higher levels of consumer satisfaction, which result in health services with greater levels of consumer participation<sup>7</sup>
- adding the human element to policy making, which connects abstract policy with human reality<sup>20</sup>
- developing an open system with clear information, public accountability and transparent decision making<sup>6, 19</sup> (this value is also evidenced in the requirement of health services to demonstrate their commitment to consumer participation as part of health service accreditation programs).<sup>12</sup>

The barriers to consumer participation must be clearly addressed if consumer participation in health care is to be effective.

### 3.3 Barriers to consumer participation

Differences in social power, culture and attitudes all affect consumer participation. Depending on the context, specific barriers include:<sup>12</sup>

- unsympathetic attitudes among some staff to consumer participation<sup>12</sup>
- different values and perspectives about what is important in health care<sup>12</sup>
- lack of clarity of purpose of consumer participation<sup>11</sup>
- communication problems associated with the use of jargon<sup>12</sup>
- consumer barriers, such as language, culture, illness, lack of interest or understanding of the value of participation<sup>12</sup>
- consumer passivity or unquestioning acceptance of medical advice<sup>7</sup>
- consumer cynicism and loss of interest when consumer input does not lead to change<sup>7</sup>
- a lack of adequate resources to support consumer participation<sup>12</sup>
- an organisational assumption that consumer participation can be done at almost no cost.<sup>12</sup>

The benefits of stronger consumer participation may not be realised unless these barriers are adequately addressed. There needs to be a clear match between the purpose of the participation, the nature of the consumer voice, and the levels and ways in which that voice is actively sought and heard.<sup>3, 11</sup>

### 3.4 Whose voices—who are the consumers?

Draper<sup>11</sup> defines a range of consumer voices from the individual to the community (see Table 1).

**Table 1: The range of consumer voices**

<b>Individual</b>	<ul style="list-style-type: none"> <li>• Individuals who are receiving or have received health care services.</li> </ul>
	<ul style="list-style-type: none"> <li>• Carers and/or family members who support individuals who receive health care.</li> </ul>
	<ul style="list-style-type: none"> <li>• Groups of consumers (who may share a common experience or chronic illness).</li> </ul>
	<ul style="list-style-type: none"> <li>• Potential consumers, such as those with unmet needs or from population groups with particular needs of access issues.</li> </ul>
	<ul style="list-style-type: none"> <li>• Community members, including future users and the wider community, which benefits from health care services.</li> </ul>
<b>Community</b>	<ul style="list-style-type: none"> <li>• Taxpayers and citizens who ultimately pay for services.</li> </ul>

For more information on sourcing consumers for participating in health service improvement, see Section 8.

As consumers are as diverse as the population,<sup>12</sup> the continuing challenge for organisations and consumer representatives alike is to ensure that these diverse voices are heard within the system. Strategies to address this include:

- ensuring consumer representatives are representing a view broader than their own, either through formal links to a constituency body or through supporting their access to differing perspectives<sup>11, 12</sup>
- using multiple approaches to elicit diverse consumer feedback and involvement<sup>11, 12</sup>
- proactively identifying those consumers, often marginalised, who are not represented and developing strategies in order to link to them to develop appropriate models of participation.<sup>7</sup>

### 3.5 Levels of consumer participation

Consumer participation occurs at three levels:

- the level of the individual
- the health service
- the health system,<sup>21</sup> as described in Table 2.

**Table 2: Levels of consumer participation<sup>21</sup>**


Level of consumer participation	Key elements
Individual care	<ul style="list-style-type: none"> <li>• Active consumer participation in decision making in individual care leads to improvements in health outcomes.</li> <li>• Access to quality information facilitates decision making and supports an active role for consumers in managing their own health.</li> </ul>
Health services	<ul style="list-style-type: none"> <li>• Active consumer participation leads to more accessible and effective services.</li> <li>• Effective consumer participation in quality improvement and service development activities in health services is most effective when a range of methods are adopted.</li> <li>• Effective consumer participation uses methods that facilitate participation by those traditionally marginalised by mainstream health services.</li> </ul>
Health system	<ul style="list-style-type: none"> <li>• Active involvement of consumers at all levels of development, implementation of health strategies and programs, is integral to their success.</li> </ul>

At all three levels, the effectiveness of consumer participation is affected by the degree in which consumers are actively involved in decision making, along a continuum of participation, from:

- minimal participation, where consumers offer feedback or receive information but have little say in subsequent actions
- to
- joint planning
- to
- consumer or community control.

Titled 'The ladder of participation', Table 3 illustrates this continuum.

**Table 3: The ladder of participation\***

Degree	Level of participant action	Example
High 	Management delegated to consumers	Shifting some or all of the decision making authority (including control over resources) from staff and management to consumers.
	Partnership	Decisions are made jointly by consumers and staff. Partnerships rely on common goals, mutual value and respect.
	Consultation	Consumer views and opinions are sought and incorporated into decision making about services.
	Information seeking	Staff seek information (as opposed to opinions or views) from consumers.
	Low	Information giving

\* This model is taken from the resource, *Hospital and Community Partnerships, A Guide to Consumer Participation*,<sup>14</sup> adapted from the UK Health for All Network, 1991, and Armstein's 'Ladder of Citizen Participation', 1969, as cited by Women's and Children's Hospital, 1999.

The ladder demonstrates the shifting focus of decision making between services and consumers. Where an initiative is placed on the ladder depends on the level of consumer activity or passivity and the degree of decision making influence.<sup>3</sup> The initial level of and approach to consumer participation depends on the organisation's own commitment to consumer participation, its culture and competing interests.<sup>7</sup>

## 3.6 Implementing approaches to consumer participation

Different processes or approaches are needed for the different levels of community participation<sup>7, 12</sup> for example:

- at the lowest level, ‘information giving’ strategies may include the use of information brochures and other public information strategies
- consultation may involve surveys, focus groups and public meetings
- partnerships may include involving consumers on steering or advisory committees.

### 3.6.1 Consumer feedback and consultation

Consumer feedback mechanisms as a means of information seeking are one way of facilitating consumer participation in health care. However, feedback mechanisms have not necessarily resulted in practice changes, rather they have sometimes been seen as an end in themselves.<sup>7</sup>

Consumer feedback is not an end in itself—it must lead to action.

Where change has occurred it has often been within the context of a specific project or within part of the system, but the learnings have not transferred into the broader system.<sup>7</sup> While there has been strong reliance on consumer feedback as one mechanism for consumer participation, Draper<sup>11</sup> indicates that this is only the first step.

In gleaning consumer feedback or undertaking a consumer consultation, Draper<sup>11</sup> argues that the use of a third party (such as a worker, a hospital unit or a government body) acting as a ‘messenger’ between consumers and service providers may also have its difficulties. Sometimes such messengers are challenged or disbelieved, often on methodological grounds. Draper<sup>11</sup> also asserts that while ‘third party’ studies have a role, they do not in themselves create change.

For change to happen, service providers must go beyond seeking feedback to engaging with consumers, through:

- inquiring with consumers
- planning with consumers
- acting with consumers
- evaluating with consumers.

### 3.6.2 Differing perspectives—consumer participation in steering and advisory committees

The inclusion of consumer representatives on a range of committees is increasingly seen as an important requirement, even a ‘given’.<sup>18</sup> However, this inclusion may be tokenistic unless barriers of power, culture and attitude are addressed.<sup>3, 12</sup> This tokenism is reinforced if consumer views are represented by a lone consumer.<sup>3</sup>

The power differential between service providers and consumer representatives may have a significant impact, making it difficult for consumer representatives to voice their concerns and have their contributions valued. To strengthen communication, providers may need to improve their listening skills—and consumers their assertiveness skills.<sup>12</sup>

Evidence indicates that the greater number of consumers involved in committees results in:

- increased consumer participation across the service
- stronger valuing of this involvement
- changes in organisational culture.<sup>7</sup>

While successes occur, consumers and providers may have different expectations and perspectives on consumer involvement and achievements. In one study of consumer participation in a national research committee,<sup>3</sup> the following differences were identified:

- consumers felt themselves powerless and marginalised; whereas providers perceived consumers as powerful and astute committee members
- providers saw the consumer voice as one view among the many views of multiple stakeholders; consumers saw their view as one view contrasting with the 'one interest bloc' of the other stakeholders.

In addition, consumer and provider views of achievements may conflict. In the challenging world of changing health service systems and cultures, providers' perceived that significant change had been achieved, whereas consumers felt that 'more work was needed'.<sup>7</sup>

To optimise participation and reduce marginalisation, partnerships and dialogue between providers and consumers need to be strengthened.<sup>11</sup>

### 3.6.3 Creating stronger partnerships and dialogue

Creating a listening dialogue between service providers and consumers is essential for strong partnerships.

As consumer participation evolves, the benefits of earlier partnerships are increasingly recognised. This facilitates consumer involvement in setting the agendas for policy and service development, as well as selecting the questions and processes for further consumer involvement. By jointly shaping the way issues are defined, consumers and service providers begin to develop partnerships and achieve a balance of power, develop greater trust, and achieve mutual benefits.<sup>22</sup>

Critical to this development of stronger partnerships is the creation of a listening dialogue between consumers and health care providers.<sup>11</sup> This requires commitment and goodwill, as well as skills in working with groups of people to accept, understand and value different perspectives, and to work through conflicting perspectives. It also takes time and effort on all sides.<sup>22</sup>

### 3.7 Strengthening approaches to consumer participation

Improving consumer participation, partnerships and dialogue requires strengthening of the capacity and skills of both the service and consumers.<sup>7, 12</sup>

For the successful evolution from minimal involvement to the optimal systemwide integration of consumer participation and partnerships, the following **critical success factors** identified from the literature are highlighted:

- ✓ Strong executive commitment that is clearly demonstrated in organisational support and commitment to change and action.<sup>7, 11</sup>
- ✓ Promoting the value of consumer participation to providers at all levels.<sup>11</sup>
- ✓ Seeking consumer input into their preferred ways of participating.<sup>11, 12</sup>
- ✓ Engaging consumers in direct dialogue, early in process.<sup>11</sup>
- ✓ Using multiple approaches.<sup>11</sup>
- ✓ Ensuring clarity of purpose for different consumer participation initiatives.<sup>11</sup>
- ✓ Ensuring match between purpose, consumers and method of participation.<sup>11, 12</sup>
- ✓ Creating a supportive environment for consumer participation<sup>8</sup>
- ✓ Building trust and mutual understanding between consumers and providers.<sup>22</sup>
- ✓ Providing support for consumers through:<sup>3</sup>
  - providing resources as needed
  - reimbursement of expenses
  - facilitating their participation in skill workshops and relevant conferences.
- ✓ Looking to long-term engagement. Allowing time for mutual trust to develop and time for the processes to bear fruit before outcomes are measured.<sup>23</sup>

## 4 Learning from the Breast Services Enhancement Program experience

Across the life of the Program, there were substantial achievements that have both strengthened the service system and women's experiences as they have journeyed through it.

Consumer input into many of these achievements was critical. This input came from a variety of sources, including consumer representatives on program steering committees and working parties, and through focus groups, surveys and consultation with individual women and support groups. Working with women on specific initiatives helped to identify other needs, which were subsequently addressed. However, we were not successful all the time. This resource captures some of our experiences and challenges.

### 4.1 Where we started

As indicated, there was a strong commitment to active consumer involvement in the Program's development and implementation. There was also a strong statewide and growing national consumer advocacy movement.

Program staff and service providers in each of the nine consortia came with different experiences of consumer participation. Some had significant experience of consumer participation on committees and working parties, whereas others had relatively little experience and were unsure how to engage with consumers.

Similarly, consumers came to the table with varying experiences. Some were very experienced; whereas for others, it was the first time they had been involved in such a way. Providing support for these consumers was therefore an important priority.

### 4.2 The key themes

The next section provides an overview of consumer involvement in the Program and the key achievements that resulted from the partnerships with consumers.

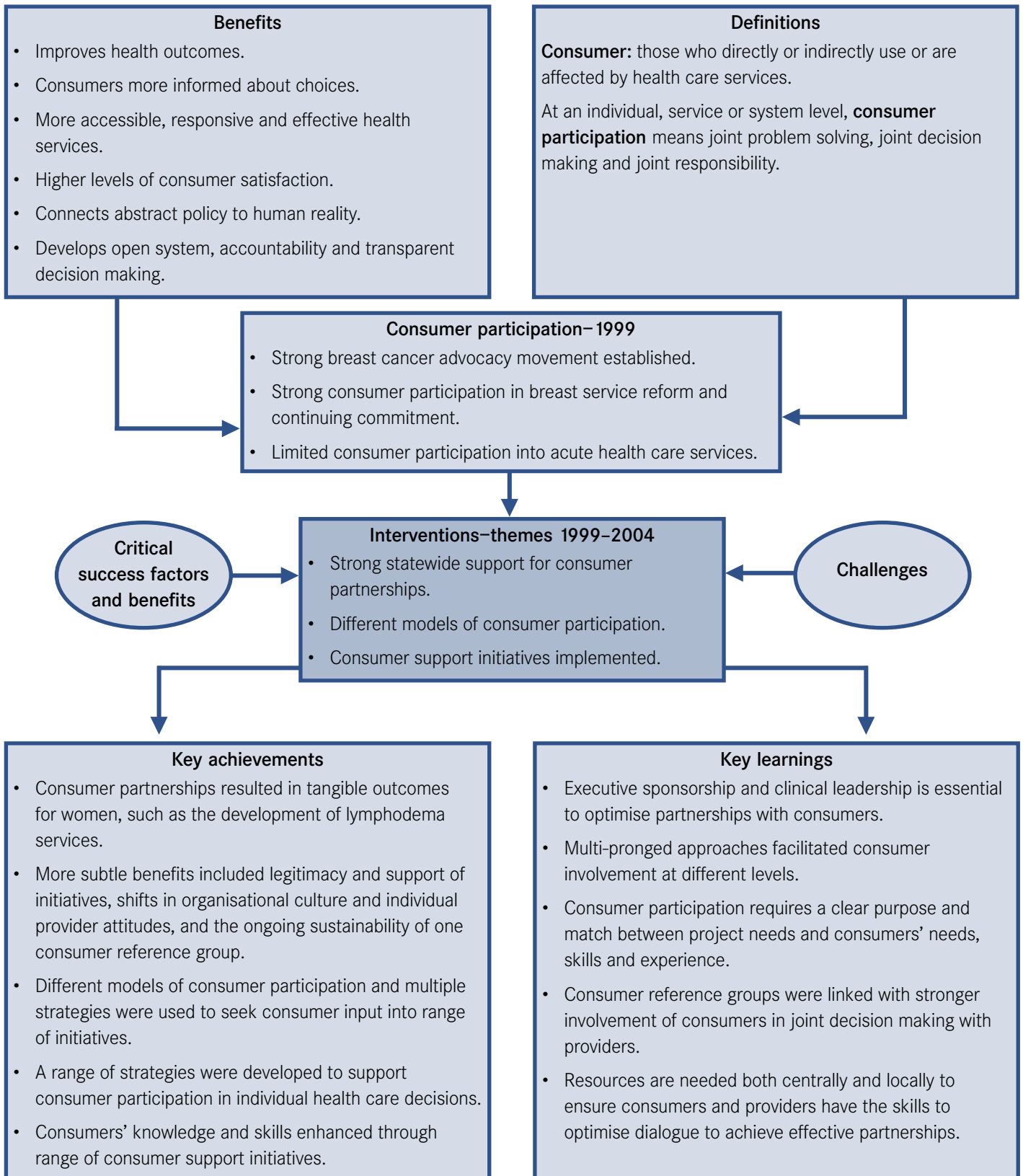
Section 6 looks in more detail at how effective dialogue with consumers developed, and some of the critical success factors and challenges. The section includes:

- engaging and supporting consumer representatives on steering committees
- other approaches that evolved to strengthen partnerships with consumers
- how consumer participation at a service level impacted at an individual level
- evaluating consumer participation.

Section 7 summarises our key learnings.

Figure 1 provides an overview of the Program initiatives in strengthening consumer participation.

**Figure 1: Building partnerships with consumers for improved service delivery**



## 5 Consumer partnerships across the system

### Key messages

- Encouraging active consumer participation was a core value underpinning the Program's development.
- Consumers were involved at every level of the Breast Disease Service Redevelopment Strategy—at a system, service and individual level.
- The development of dialogue and partnerships between consumers and service providers was strongest in initiatives that had direct benefits for women currently accessing the service system.
- Dialogue and partnerships with consumers resulted in both tangible benefits for women and a range of more subtle benefits for women, service providers and organisations.

Encouraging active consumer participation was a core value underpinning every level of the Breast Disease Service Redevelopment Strategy. This translated into a strong commitment to consumer involvement in the Program.

This commitment to building partnerships with consumers at every level of the program is demonstrated in Table 4.

**Table 4: Building consumer partnerships in BreastCare Victoria**

Level	Mechanisms for consumer partnerships	Role
<b>System</b>	Department of Human Services BreastCare Victoria Advisory Committee Consumer-Committee chair	<ul style="list-style-type: none"> <li>• Statewide policy development.</li> <li>• Strategic planning and implementation.</li> <li>• Consumer education fund established to support consumer training and professional development.</li> </ul>
<b>Service</b>	Breast Services Enhancement Program steering committees.	<ul style="list-style-type: none"> <li>• Development and implementation of service plans.</li> <li>• Local policy development.</li> </ul>
	Breast Services Enhancement Program project working parties.	<ul style="list-style-type: none"> <li>• Development of specific Program initiatives.</li> </ul>
<b>Individual</b>	Surveys, telephone interviews, focus groups with individual consumers.	<ul style="list-style-type: none"> <li>• Input and feedback into individual projects.</li> </ul>

At the BreastCare Advisory Committee level, consumers strongly supported the Strategy's directions to strengthen women's access to multidisciplinary care, breast care nurses and improved information and psychosocial care. These were key directions for the Program at a service level.

## 5.1 Building consumer partnerships at the service level

Early in the Program, it was clear that having representatives on steering committees alone was insufficient and there was a need to gain greater consumer input in a variety of ways. Mechanisms to strengthen this consumer participation included the development of:

- consumer reference groups
- working parties
- individual consultation approaches to women.

In this way, the Program clearly sat on the ‘consultation and partnership’ rungs of the ‘Ladder of participation’ (see Table 3, page 9). In a small number of initiatives, consumers were given the decision making authority.

Regardless of approach, the common purpose of these approaches was to create dialogue and partnerships between women and service providers through:

- gaining women’s input and advice on project directions, development and evaluation, in order to assess needs or to gain input or feedback on the development or evaluation of specific resources
- providing information about the Program overall and its specific activities.

See Section 6 for more details on how the different models of consumer participation evolved.

## 5.2 Building partnerships with consumers—achievements

The Program’s approach to consumer participation resulted in many achievements. These included some tangible benefits for women and service providers, as well as subtle shifts in service provider attitudes and in the organisational culture.

The development of dialogue and partnerships between consumers and service providers was strongest in initiatives that resulted in direct benefit for individual women currently accessing the service system. These projects mainly addressed women’s information and psychosocial needs.

The following points summarise the tangible **benefits** for women.

- ★ The development of a range of community consultation reports that clearly reflected local consumer views and provided directions to local consortia for future initiatives.
- ★ The development of new information resources that addressed issues identified by consumers. These resources included patient-held records and a suite of information resources for women with benign breast conditions.
- ★ The development of local information packs providing women with consistent clinical information and information about community-based services.
- ★ Paper- and web-based services and resources directories.
- ★ Short-term and ongoing support activities, including ‘end of treatment’ educational group programs and the establishment of new support groups.
- ★ Information and educational consumer forums, including regional seminars on breast health or breast cancer care, and special forums for women with advanced breast cancer and young women with breast cancer.

Other more subtle **benefits** for consumers and service providers included:

- ★ Consumer advice influenced the development of other more clinically oriented initiatives such as the development of lymphodema services and GP teleconferencing.
- ★ At times, consumer views challenged service providers' prevailing views, leading to subtle changes in attitudes and practice, including the amount and timing of information provided to women along the treatment pathway. Consumers often indicated that they wanted more information, earlier.
- ★ Consumer partnerships provided support and legitimacy to consortia initiatives.
- ★ The presence of consumers on consortia steering committees and working parties served as a reminder to service providers of the Program's focus on implementing organisational change to improve consumer outcomes.
- ★ Consumers gained a better understanding of the challenges facing health services.
- ★ Consumers acted as advocates for the Program. For example, in one consortium, consumers strongly advocated for increased funding for breast care nurse services.
- ★ Increasing acceptance by service providers of the benefit of consumer participation in local service improvements.
- ★ The development of networks of consumers across regional consortia provided Program staff with a ready resource to access diverse consumer perspectives on a range of issues as they arose. These networks also facilitated promotion of local consortia initiatives.
- ★ One model of consumer representation with a consumer reference group within a large service provider gained strong clinical and executive support. This model has been sustained within the service, and is being used to support and inform the development of consumer partnerships as part of the broader cancer reform agenda.

The following section discusses the ways in which consumers were involved in the local Program development, and some of the critical success factors and challenges that influenced partnerships between consumers and service providers.



## 6 Building partnerships with consumers—approaches and challenges

### Key messages

- Different models of consumer participation evolved within individual consortia. This included consumer reference groups, specific project working parties and individual input.
- Each model had different benefits and challenges, and facilitated varying levels of diversity in consumer voices and varying levels of input and involvement in decision making.
- Consumer reference groups that supported consumer representatives on steering committees appeared to result in greater decision making roles and stronger partnerships between consumers and service providers. Decision making was mostly in conjunction with service providers. At times, the consumers had the authority to make the final decisions on relevant program initiatives. Consumers involved in this consumer reference group model were the most satisfied with their role.
- Some consumer representatives felt that they had a seat at the table, but not a voice.
- Structures and process that validated the consumer role in program committees included:
  - formalisation of their role through the terms of reference
  - consumer issues as a regular specific item on steering committee agendas
  - more than one consumer representative on committees.
- Support for consumers included funding for:
  - their participation in science and advocacy training
  - other skills development
  - attending professional conferences.

### 6.1 Engaging consumers in consortia steering committees

During the initial start-up phase, all program steering committees included between one to three consumer representatives.

It quickly became evident that one consumer representative was insufficient, and additional consumer representatives were needed on the steering committee or as part of a broader consumer reference group (see Section 6.3)

#### 6.1.1 Finding consumer representatives

Consumer representatives involved in consortia steering committees needed:

- knowledge of breast cancer services and health service delivery
- access to diverse women's views and experiences—not just their own
- skills and experience of working with committees
- good communication and advocacy skills.

Wherever possible, consumers had undertaken a consumer science and advocacy training program before commencement as a consumer representative (see Section 6.1.2). In addition, consumer representatives ideally needed to have knowledge and experience of treatment and care within a service covered by the local consortium. This added credibility and relevance to the consumer representatives' views in the eyes of other stakeholders, and reduced the likelihood that the consumer view would be dismissed with the attitude, 'This doesn't happen in this service'.

The Victorian Breast Cancer Action Group played an important role in the identification of suitable consumer representatives. However, the requirement to find two or three trained consumer representatives for each consortium (a total of 18–27 representatives) was challenging. To find trained consumer representatives within some geographic areas with personal experience of being treated by local services added to this challenge.

As a result, potential consumer representatives were also identified through:

- local support groups
- women's health services
- individual women identified by service providers.

Note: Breast Cancer Network Australia's 'A Seat at the Table' project to identify and support breast cancer consumer representatives, was launched in 2000. For more information about this model, and the resources for consumers and organisations, see Section 8.

For more information about the Consumer Advocacy and Science Training Program see Section 8.

## 6.1.2 Supporting consumer representatives

To support consumer representatives, a number of strategies were put in place at both a local and statewide level.

When they had not done so, consumer representatives on steering committees (as well as on other committees and working groups) were encouraged to participate in the three-day consumer science and advocacy program held by Breast Cancer Network Australia.

In addition, local support for consumers included:

- ✓ general orientation to the service and local training opportunities
- ✓ payment of an honorarium or reimbursement of expenses
- ✓ support to attend local forums
- ✓ end-of-year celebrations.

At a state level, BreastCare Victoria's commitment to consumer participation was reflected in a range of activities. These activities provided additional and ongoing support, as well as skill development to consumer representatives, including:

- ✓ two statewide consumer workshops that provided consumer representatives with initial information about the establishment of the Program and a later update
- ✓ funding to support a small grant program for Victorian consumers, coordinated through Breast Cancer Network Australia (BCNA), through which:
  - forty-six consumer representatives attended 19 conferences, with ten attending more than one
  - sixteen consumers participated in a Consumer Advocacy and Science Training Program
  - eight consumers attended a public speaking training workshop conducted by BCNA.

To optimise consumer partnerships in health service reform, consumer representatives need specific training and support, which should be offered through centrally based state or national consumer organisations. This could then be supplemented by local service support and training.

## 6.1.3 Consumer representatives on steering committees—supporting their voice

*Just because the consumers are there on the steering committee reminds the clinicians what they're there for—that the Program's purpose is to improve services for consumers.*

Program manager

Although some service providers had participated in national and state committees with consumer representatives, the Program provided many stakeholders with their first experience of consumer representatives at a health service delivery level. Some service providers were uncertain, and others cynical about the value that consumer representatives would bring to the table.

Where consumer representatives and clinicians had a professional 'patient-doctor' relationship, facing each other in a steering committee was initially quite confronting.

Not surprisingly, in the early stages of the Program, the initial dialogue between consumer representatives and other stakeholders was tentative, but improved over time. However, in some consortia, consumer representatives found it difficult to express their views, or felt that their contributions were not valued.

*I don't feel as though I have a voice. You're asked to go on these things... we've got a seat, but have we got a voice?*

Consumer representative

Some of the **challenges** to effective consumer representation include:

- ◇ unsupportive or dominant clinical stakeholders
- ◇ a mismatch between the skills, experiences and needs of the consumer representatives and the needs of the Program
- ◇ a single consumer voice at steering committee meetings
- ◇ consumer representatives not having adequate access to other consumer perspectives or experiences
- ◇ some project initiatives, such as clinical databases, which had limited apparent direct benefits for consumers, and so it was more difficult for consumers to engage.

**Critical success factors** in those consortia that were more successful in achieving productive partnerships with consumers through the steering committee included:

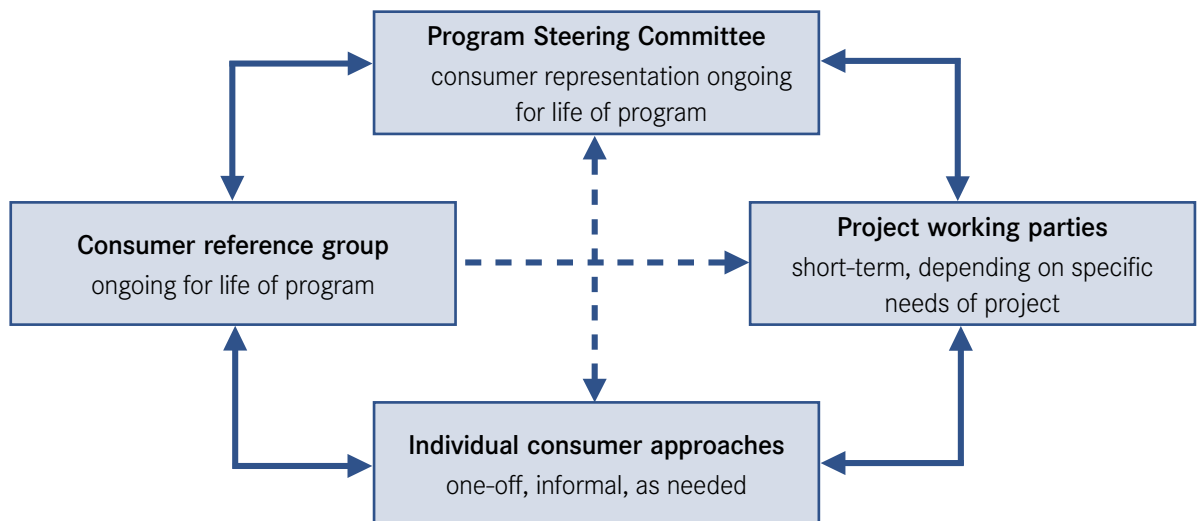
- ✓ strong clinical and Program leadership that championed and supported consumer engagement
- ✓ early active engagement of consumers in the development of the initial service plan
- ✓ integration of consumer representatives' priority issues into the service plan
- ✓ two or more consumer representatives on steering committees, with good access to other consumer views
- ✓ clear terms of reference
- ✓ allocation of consumer issues as a clear item on each committee agenda
- ✓ project initiatives that addressed psychosocial aspects of best practice.

## 6.2 Strengthening partnerships with consumers

After the Program's establishment, different approaches of consumer participation were introduced into local consortia to support consumer representatives on steering committees, and to further strengthen dialogue and partnerships with consumers.

Gradually, three different models of developing partnerships with consumers evolved. These models were not mutually exclusive, but were used in a complementary manner.

**Figure 2: Complementary approaches to building consumer partnerships**



### 6.3 Model 1: Consumer reference group

In this model, three individual consortia developed a consumer reference group to provide ongoing advice and support to the whole Program. Representatives from this consumer reference group were also members of the Program's steering committee.

In one consortium, this larger consumer reference group was established at the start-up phase of the program (see Case study 1, page xii). At least two other programs established similar consumer reference groups.

These groups were established for the life of the Program, and met formally on a quarterly basis, or more frequently, as needed. One consumer reference group has been maintained since the Program's completion, and has served as a model of consumer participation within the health service and within the current broader cancer reform agenda (see Case study 2, below).

#### Case study 2

##### Engaging with consumers—a consumer reference group

###### Where we started

We are a large provider of breast services, including a major screening service. We initially had only one consumer representative on our BSEP steering committee. We had a consumer group for the breast screening program, but decided that we needed to develop a stronger group across all breast services. In particular, we wanted to establish:

- a productive role for consumers in practice review, service planning and policy development
- an environment where breast health professionals would accept and value consumer input.

###### What we did

We appointed a consumer adviser who worked closely with staff to identify and select appropriate consumer members. These members reflected a level of diversity in terms of residential area, ethnicity, age and disease status. We established clear terms of reference and reporting structures for the group.

Considerable time was spent on providing initial orientation and training, with members also participating in an external consumer advocacy and science program.

###### What we achieved

- ✓ The consumer reference group has been established for over three years, with eight to ten members meeting quarterly. In addition to giving us advice and support on specific initiatives, the group alerts us to other relevant issues.
- ✓ The group provided important advice and comments, which assisted in the development and evaluation of a range of our BSEP initiatives. Nearer the end of the program, they lobbied the hospital executive for ongoing funding support for two major initiatives.
- ✓ Members of the group now contribute to broader health service and screening program committees.
- ✓ The group is regarded highly by service providers and health service executives. It is seen to be well placed to support the organisation engage better with consumers with other cancers.
- ✓ Ongoing worker support is currently provided through the associated screening program.

Consumer reference groups were most successful in providing support and advice to the whole Program, and in supporting consumer representatives on consortia steering committees.

The consumer reference groups made a significant ongoing contribution to the development and evaluation of a range of initiatives in the three consortia. While all three consumer reference groups started with eight to ten participants, there was some attrition over time, leaving smaller core groups.

One consortium experienced some difficulties. In developing a project for women with advanced breast cancer, Program staff used other mechanisms for drawing in specific consumer input that was not represented within the consumer reference group. As the consumer reference group meetings had fallen away at this time, the project was not discussed with group members, who then felt excluded. This impacted negatively on relationships between consumers and Program staff.

**Critical success factors** in developing and maintaining consumer reference groups included:

- ✓ drawing on a diverse group of consumers
- ✓ clear terms of reference and fit with organisational structures
- ✓ providing local support and training to strengthen the group's specific understanding of the health services and particular issues
- ✓ involving the reference group in specific work
- ✓ ensuring that their input was valued and acted upon
- ✓ consumers considering that they influenced decision making (where relevant), and who were given the decision making authority for some initiatives
- ✓ ensuring consumers were able to see range of achievements over time
- ✓ consumers were offered financial support to reimburse costs.

Some of the **challenges** included:

- ◇ the level of support needed to maintain the group, balanced against other Program demands
- ◇ gaining diversity of consumer experiences and skills
- ◇ maintaining the group's interest over time, particularly as the Program timeline was significantly extended
- ◇ developing a range of communication approaches to keep the group informed
- ◇ managing consumer attrition over time
- ◇ recruiting and integrating new members during the Program
- ◇ ensuring that consumers are not overloaded or taken for granted.

## 6.4 Model 2: Project working parties

Within this model, consumers participated in a number of project working parties.

The consumer membership was dependent on the project purpose. Within some working parties, consumers were part of a broader stakeholder membership; in others they were the major contributors.

While steering committee or consumer reference group members participated in some working parties, working parties also provided an opportunity to draw in other consumer perspectives. These 'new' consumers did not necessarily require the level of skill and experience needed by the broader Program consumer representatives.

Overall, project working parties tended to meet more frequently during periods of project development, and were discontinued once the project was completed.

**Critical success factors** in the development and maintenance of project working parties included:

- ✓ clarity of purpose
- ✓ consumers participating had a specific interest in project topic
- ✓ provision of opportunities for other consumers to contribute
- ✓ lessening of the burden on a small number of consumer representatives
- ✓ diversity of input
- ✓ ongoing dialogue was facilitated between consumers and service providers on specific issues of mutual interest.

The **challenges** included:

- ◇ working parties placed significant additional load on consumer representatives involved in steering or other project committees
- ◇ more organisational time needed to find and support new consumers.

Project working parties facilitated increased and diverse consumer input.

## 6.5 Model 3: Individual and more informal consumer approaches

Program staff linked to individual consumers in a variety of ways. Depending on the project and purpose, this ranged from formal processes to contact individual women (at times this required institutional ethics committee approval), or more informally, using established communication networks.

The range of strategies used included:

- focus groups
- individual telephone or face-to-face interviews with consumers
- surveys
- meetings with support groups.

The more individual approaches facilitated initial consumer consultation and led to specific directions for consortia initiatives and pre-testing and evaluation of resources and activities.

These approaches tended to be one-off, or were used irregularly or sometimes occurred serendipitously. For example, one consortium offered ‘an end of treatment’ education and support group over several weeks. Group participants identified problems of women’s variable access to information resources. This group became the reference group for the development of consistent regional information packs.

Consultation approaches also had unexpected personal benefits for individual women. For some young women with breast cancer, participation in a project focus group provided them with their first opportunity to talk with other young women in the same circumstances (see Case study 4, page 30).

The **critical success factors** in these individual approaches included:

- ✓ the ability to access a greater diversity of consumers
- ✓ flexibility of approach
- ✓ matching purpose, consumers and the right methodology
- ✓ an ethics committee approval (where gained), which provided additional legitimacy
- ✓ minimal long-term commitment for women
- ✓ a small payment that was available for some women to acknowledge their contribution.

The **challenges** were:

- ◇ A mismatch between consultation method and women’s interest. For example, in a project looking at the particular needs of women with benign breast conditions, women were invited to attend focus groups. However, only four out of 18 women contacted were interested in attending such focus groups. Telephone interviews were undertaken instead, and were used successfully again later in the project.
- ◇ Evaluation overload. In one program that had developed a strong network of individual consumers, consumers were asked to complete a range of surveys in a relatively short time period, placing a significant burden on them.
- ◇ Timely access to service users. Gaining input and feedback from women currently using a specific service can be particularly important, but often requires ethics committee approval. While this may add rigor and legitimacy to the approach and protects women’s privacy, it is time consuming and labour intensive and can reduce flexibility and service responsiveness.
- ◇ Limited dialogue. The nature of the consultations reduced the opportunity of facilitating direct dialogue between consumers and service providers.

Consumers' contribution in all levels of project development can result in tangible benefits for other women and service users.

## 6.6 Multiple approaches to consumer participation

As indicated in the literature, multiple approaches to consumer participation are critical. Across all nine consortia, it was clear that consumers participated at varying levels and in diverse ways.

Consumers made their strongest contribution in the development of many tangible and visible initiatives that improved services for women with breast cancer or other breast conditions. These included the development of patient-held records and information sheets on benign conditions. They felt that they contributed less to the more clinical aspects of the Program.

Two case studies are presented to demonstrate how multiple approaches were used to achieve Program objectives.

### Case study 3

#### Improving women's access to timely and relevant information

##### Where we started

As we were developing our service plan, it was clear that there was no consistency of the information provided to women at different points on the treatment pathway. Women also told us that the end of treatment was a particularly difficult time for them, and they experienced less support. Service providers indicated that they had few resources to offer women at this time.

##### What we did

We established a working group made up of health professionals and a consumer representative from our steering committee. A large number of resources were reviewed by this expert panel in accordance with preset criteria. The resources were shortlisted and two consumer groups were then asked to rate the usefulness of each resource according to specific criteria. The results were then aggregated and two information packages developed; the first pack was to be given at time of diagnosis and the second on completion of treatment.

We piloted the information packs at a number of services. We undertook a telephone survey with 28 women who had received one or both packs to gain their further feedback.

##### What we achieved

- Consumer input played an important role in developing the packages.
- Women's responses to receiving the packages was very positive, clearly indicating that they were able to select the resources that were most relevant and of interest to them. They provided us with additional input on when they would like to receive some resources.
- Women made a significant contribution to this project, and their ready selection of resources to meet their needs challenged service providers concerns that the packs were 'information overload'.

For more information on sustainability, see *Supporting sustainable change*, another resource in this learning series.

The **critical success factors** in this project included:

- ✓ the issue was clearly identified as being significant for women
- ✓ consumers were involved at all stages in different ways
- ✓ different approaches were used, depending on the purpose.

The **challenge** for this project was:

- ◇ long-term sustainability of the resource packages, once trialled.

## Case study 4

### Addressing the needs of young women with breast cancer

#### Where we started

At the time that the initial service plan was developed, there was an interest in addressing the needs of young women with breast cancer. While there were consumer representatives on the steering committee, there was not strong endorsement of the role of consumers in this consortium.

#### What we did

We established a small working party comprised of young women with breast cancer, a social worker and a breast care nurse to guide the project.

##### *Phase 1: needs analysis*

Four focus groups were held attended by a total of 37 young women. Women highlighted a range of issues, including their wish for an information checklist. This checklist would assist women to ask service providers questions about hormone-related issues at different points in the treatment pathway.

The steering committee enthusiastically endorsed the project approach, the findings and recommendations of the consultation.

##### *Phase 2: development of improvement strategies*

We worked with the working party to develop the draft information checklist and gained service provider input into it. It was pilot tested with a small number of other young women using telephone interviews and then through three further focus groups. This evaluation assisted in fine tuning the checklist and women confirmed that they wanted to receive it early in the treatment pathway.

As part of the overall young women's project, we also developed a partnership with a number of young women consumer support groups and with other service providers to develop a Young Women's Forum. Based on consumer input, the forum provided both clinical information and consumer perspectives on the identified issues.

Finally, a consumer participated in the development of a clinician resource to support the information checklist. This was a much more challenging part of the project, and we met with significant provider resistance.

#### What we achieved

- Strong consumer involvement in a project within a consortium that was initially not very responsive.
- Strong support for the consumer consultation process and findings.
- Young women's information checklist developed and endorsed for women by women.
- Consumer forum successfully held for over 80 young women statewide.
- Clinician resource developed and registrar training piloted, but the ongoing use is uncertain and depends on local clinical champions within each service.

This project was clearly conceptualised as a consumer driven project and consumers participated in a variety of ways. The **critical success factors** were similar to the previous case study.

Some of the **challenges** included:

- ◇ a perception that some service providers considered the consultation was an end in itself
- ◇ in spite of the strong provider support for the consumer consultation and endorsement of the findings, there was limited recognition that the findings identified clinical practice issues that may have required practice change
- ◇ the project focused strongly on consumer participation and because of unavoidable delays had challenging deadlines
- ◇ the project may have been enhanced if stronger, earlier and ongoing dialogue had been facilitated between consumers and a broader group of service providers
- ◇ more time and stronger involvement of service providers may have facilitated better clinician ownership of project's clinical aspects.

## 6.7 Strengthening consumer participation in individual care

As indicated in Table 2 (Section 3.5), two elements of consumer participation in individual care are highlighted:

- Active consumer participation in decision making in individual care leads to improvements in health outcomes.
- Access to quality information facilitates decision making and supports an active role for consumers in managing their own care.

A number of initiatives had strong consumer participation at a system and service delivery level, which resulted in improved consumer participation at an individual level (see Figure 3).

**Figure 3: Strengthening individual consumer participation**



For more information on patient-held records, see *Continuity and coordination of care—improving the cancer journey*—another resource in this learning series.

For example, patient-held records developed with strong consumer input assisted individual women currently being treated to:

- ★ understand treatment options
- ★ make informed decisions
- ★ navigate the treatment pathways
- ★ gain knowledge of support services.

In another project, a suite of information sheets was developed for women presenting to a breast clinic with a breast problem that was ultimately diagnosed as a benign breast condition. In response to women's input, the resources:

- ★ provided information at different points in the diagnostic pathway
- ★ responded to women's need for the facts and acknowledgement of their emotional response (this contrasted with service providers' focus on the facts)
- ★ encouraged women to seek further advice and support from their general practitioner
- ★ were translated into nine languages with input from bilingual women.

*Even though I have had fibroadenomas in the past, it (an information sheet on fibroadenoma) was really helpful—gave me lots of facts and new information. For example, lots of women get them—knowing that was really helpful. I liked the fact that it dealt with the facts and the emotions. Doctors can tend to forget this and not acknowledge the anguish you go through.*

Consumer

Other initiatives used to strengthen individual women's capacity to be active participants in their care included:

- ★ development of local information packs providing clinical information and information about community based services
- ★ paper- and web-based services and resources directories
- ★ short-term and ongoing support activities, including 'end of treatment' educational group programs and the establishment of new support groups
- ★ information and educational forums, including regional seminars on breast health or breast cancer care, and special forums for women with advanced breast cancer, and young women.

For more information about specific projects, refer to Section 8 and [www.health.vic.gov.au/cancer](http://www.health.vic.gov.au/cancer)

*It (the information pack) gave me all the information that I needed, and helped me to make a decision regarding lumpectomy or mastectomy.*

Consumer

## 6.8 Evaluating consumer participation

Evaluating consumer participation can be considered from three perspectives:

- how it affects the development of strategies to enhance services for women
- the experiences and perceptions of the consumer representatives
- the experiences and perceptions of other program stakeholders.

The experiences and perceptions of consumer participants and other program stakeholders were elicited through individual interviews midway through the Program, and a stakeholder survey was undertaken near its completion.

As demonstrated, many projects that had very active consumer involvement in their development and implementation had clear benefits for women entering the health service for the first time. Many consumers involved in the development of these initiatives spoke highly of their experiences. However, evaluation findings reflected a diversity of views from both service providers and consumers about consumer involvement.

Consumers from two of the Programs with consumer reference groups considered these processes to be highly consultative, and indicated that they had actively contributed to planning and decision making. Feedback from clinical stakeholders in these two Programs also revealed positive views about the consumer involvement.

*The input of the consumer was absolutely critical. That's the first time we have had the opportunity to have consumer input to what we are doing... they gave us very good advice that we didn't expect. They gave us more support to do things we also thought were important... not only did we think it was important, but they did as well. That gave the whole process a legitimacy that others might not have.*

Clinician

These experiences reflected good processes and support within the consortia, enabling strong partnerships to evolve.

Other evaluation findings demonstrated the Program's more mixed success in engaging with consumers. From the stakeholder survey across all Programs, respondents indicated that consumer input was valued, with a score of 3.8 on a five-point scale (5 being high).

Some consumer representatives however did not feel that their views were valued by local steering groups. Program staff also clearly indicated that even with the best of intentions, it had been sometimes difficult to facilitate good levels of dialogue between consumers, staff and service providers—particularly within the broader steering committee role. This was exacerbated when there were competing views of service providers, consumers and staff, and tight timelines.

The role of the consumer in a clinically dominated setting was seen to be particularly challenging, and required significant preparation and support to manage the role. Some consumers considered that the emphasis of meetings on clinical aspects of care was a barrier to their contribution. This barrier was reinforced with inconsistent attention being paid to psychosocial aspects of best practice care within steering committee meetings, in which consumers may have had a stronger interest and contribution.

Other factors that created **challenges** to consumer participation included:

- ◇ consumer skill levels and experiences to ensure the right match between consumers and the task and the consortium
- ◇ consumers' work or home commitments, or continuing health problems
- ◇ overload when consumers participated in both steering group committees and other working parties
- ◇ consumers' changing life priorities. For instance, in one consortium two consumers who were very active initially in the Program, resigned when they felt it was time to 'move on' from the breast cancer experience. This left a significant gap.

The negative experiences of some consumers in the Program, particularly those involved formally within its management structure, are clearly acknowledged. More supportive service provider skills and executive sponsorship to enhance consumer participation at this level are clearly needed at times.

However, these difficulties need to be balanced by the Program's continuing commitment to consumer participation in the many approaches used to engage with consumers. In spite of the challenges, the underlying Program value and commitment to consumer participation clearly led to:

- ✓ valuable outcomes in enhanced services and resources for women
- ✓ stronger legitimacy and support for the Program initiatives, providing benefit to service provider as well as consumers
- ✓ more subtle changes in service provider attitudes and organisational culture
- ✓ the increasing acceptance of the need for and strengthening of more ongoing dialogue between consumers and service providers to build effective partnerships
- ✓ the establishment of models of consumer participation that will inform future service development.

## 7 Learnings arising from consumer participation

- ✓ As an underlying core value, the Program's strong commitment to consumer participation was reflected in the involvement of consumers at every level of the Program. The projects that most successfully engaged consumers were also those that resulted in the most direct and tangible outcomes in improved care for individual women.
- ✓ Effective partnerships with consumers ensure a patient-centred focus to service improvements and provide services with additional strength and legitimacy.
- ✓ It is not always easy to translate a commitment to consumer participation into appropriate levels of input at a system, service and individual levels. It is particularly challenging for consumer representatives to actively contribute in clinically dominated settings.
- ✓ Strong executive sponsorship and clinical leadership will help to create an organisational culture that values consumer participation.
- ✓ Consumer representatives may be found through national and state consumer organisations, other peak bodies, local community health and support services or support groups. Ideally, consumers should undertake specific training to strengthen their skills and confidence as consumer representatives, particularly before working on steering and advisory committees.
- ✓ Early engagement of consumers is beneficial to ensure their active involvement in the planning and implementation of service improvements.
- ✓ Other factors that optimise consumer participation include:
  - having a clear purpose
  - the allocation of a small level of staffing resources and a small budget to support consumer participation and reimburse expenses
  - staff's previous experience in working with consumers
  - ensuring that more than one consumer representative sits on steering and advisory committees.
- ✓ Developing and supporting an ongoing consumer reference group with clear terms of reference and links to the consortia steering committee appeared to be most successful in facilitating joint decision making and partnerships between service providers and consumers. In some instances, the decision making authority rested with the consumers in the development of particular consumer specific initiatives.
- ✓ Regardless of the approach used, the purpose and scope of the consumer participation must be clear. The approach used must match consumer needs.
- ✓ Multi-pronged approaches are important and effective, particularly in gaining diverse consumer input and advice into specific strategies.
- ✓ While some Programs had a strong focus on engaging with consumers, this was sometimes undertaken in isolation from service providers. This reinforced the divide between consumers and providers. Further opportunities to strengthen dialogue between consumers and providers need to be explored.

- ✓ Significant time and ongoing support is needed at both a service level and at a broader systems level, in order to ensure that consumers have the skills and knowledge to participate in health service reform, and that their contribution as members of the team is actively valued. Formal training is part of this support.
- ✓ Further work needs to be undertaken with service providers to provide them with the skills to support the evolving role of consumers in health service delivery and redevelopment.

## 8 Resources and tools

### Finding consumer representatives

A number of organisations can assist in identifying and supporting consumer representatives to sit on a range of national, state and local health service and policy committees.

These organisations also provide a range of resources, checklists and training programs to assist consumers and to support health services to strengthen their consumer participation.

**Breast Cancer Network Australia (BCNA)** program '**A seat at the table**' recruits, trains and supports breast cancer consumer representatives. It also offers a kit to assist organisations to get the most out of their consumer representatives. Breast Cancer Network Australia also links to each state breast cancer advocacy groups. Contact: (03) 9805 2500 or 1800 500 258 or [www.bcna.org.au](http://www.bcna.org.au)

**Consumers' Health Forum of Australia (CHF)** provides consumer representatives to a wide range of national health committees. For state or local consumer representatives, CHF can assist by referring enquiries to the relevant CHF member organisations. CHF also has a publication: *Guidelines for Consumer Representatives*. Contact (02) 6273 5444 or [www.chf.org.au](http://www.chf.org.au)

**Health Issues Centre of Victoria's** consumer nominee program aims to ensure that a wide range of views are heard in health policy debates and that consumer perspectives inform the development of the health care system. Contact (03) 9479 5827 or [www.healthissuescentre.org.au](http://www.healthissuescentre.org.au)

**The Victorian Quality Council** is part of Metropolitan Health and Aged Care Services Division in the Department of Human Services. A number of resources are available to support organisations to integrate consumer participation into their services on <http://qualitycouncil.health.vic.gov.au> and include:

- *Finding consumers and carers. A guide to sourcing consumers, carers and community members for collaborative health service improvement*
- *Enabling the consumer role in clinical governance—a guide for health services.*

Other mechanisms to source consumers can be through specific peak bodies in each state, local community health and support services, support groups and through individual service providers. However, consumers identified through these sources may need additional training and support.

## **Breast Services Enhancement Program resources**

To access a range of reports and other resources in this learning series see [www.health.vic.gov.au/cancer](http://www.health.vic.gov.au/cancer)

### **The learning series**

The following resources are also part of this learning series:

- *Multidisciplinary care—improving consumer outcomes*
- *Continuity and coordination of care—improving the cancer journey*
- *Supporting sustainable change.*

### **Other useful resources**

A number of resources developed through the former National Resource Centre for Consumer Participation in Health are available on [www.participateinhealth.org.au/clearinghouse/Docs](http://www.participateinhealth.org.au/clearinghouse/Docs). These include the following Consumer Focus Collaboration resources:

- *Improving health services through consumer participation—A resource guide for organisations*
- *The evidence supporting consumer participation in health.*

The National Health Service Modernisation Agency (UK) has developed a series of 'Improvement Leader Guides', including *Involving patients and carers: creating continuous and effective involvement*. To access this and other service improvement guides see [www.modern.nhs.uk/improvementguides](http://www.modern.nhs.uk/improvementguides)

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