

Continuity and coordination of care –improving the 'cancer journey'

Breast Services Enhancement Program

Learning from the past–informing the future

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–improving the ‘cancer journey’**

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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 1999–2003¹ (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.²

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, reading "Lyn Swinburne". The signature is fluid and cursive, with the first letter "L" being particularly large and stylized.

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

Western	Royal Melbourne Hospital, Royal Women’s Hospital, Western Health and associated private providers
North Eastern	Austin Health, Northern Hospital, Peter MacCallum Cancer Centre, St Vincent’s Health
Southern	Dandenong Hospital, Monash Medical Centre.
Inner and Eastern	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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Successful cancer care is not only about survival and morbidity... but also relates to the experience of the person with cancer... what the treatment process is like...

Optimising Cancer Care in Australia, 2003²

Continuity of care is the delivery of services by different providers in a coherent, logical and timely fashion, consistent with the patient’s needs and personal context.

Haggerty, Reid, Freeman et al, 2003³

In discussing their role in helping women along the breast cancer journey, the breast care nurses described themselves as the missing piece in the jigsaw—connecting women with the health care system... but their task was made more difficult when some of the pieces in the system were missing.

Hirst and Muir-Morris, 2001⁴

Summary of learnings

Evidence from the literature

- Continuity is an outcome of care. Care must be experienced as connected and coherent by patients across different sectors within the health care system.
- Enhancing continuity of care leads to improved patient outcomes, improved patient satisfaction and reduced health care costs.
- Improving continuity of care requires a systemwide approach focusing on informational, management and interpersonal aspects of continuity. Mechanisms to improve continuity include:
 - information systems
 - patient-held records
 - pathways and protocols
 - multidisciplinary care
 - GP communication
 - the availability of a key contact
 - care coordination.
- Different care coordinator models exist, depending on the illness and organisational context. Assessment and referral are key components of coordination roles.

Learnings from the Breast Services Enhancement Program

- A systemwide, multifaceted approach is needed to improve continuity of care. Further service mapping, including community-based services and the examination of the patient pathway from the patient’s perspective, may facilitate a better systemwide approach to enhancing continuity of care.
- There were significant achievements in improving continuity of care through the Breast Services Enhancement Program. Many achievements focused at the level of the individual client and at team levels, sometimes supported by improvements developed at the service level. These service improvements often required significant executive support. A few initiatives linked with wider system improvements.
- The capacity to improve continuity for the individual further sometimes depends on whole-of-system improvements. For example, the timely access to appropriate psychosocial support is constrained by the limited resources available within the acute and community sectors.
- Much of the work of the Program focused on improving the cancer journey for women with early breast cancer within the acute sector. Some achievements were gained in facilitating coordination across health sectors, but only one initiative addressed coordination across the acute and palliative care sectors.
- Further work is needed to achieve substantial gains in continuity across the acute care system, the primary health sector, and community and palliative care sectors. Mechanisms to integrate and value the role of the general practitioner better into the multidisciplinary team are crucial.

- As part of the team, the breast care nurse plays a significant role in care coordination for women with breast cancer, particularly early breast cancer. Care coordination for women with advanced breast cancer requires further exploration.
- The breast care nurse role has evolved and strengthened over the last five years. However, one role cannot fill all system gaps, and challenges for the future remain. The experiences of the breast care nurse role in care coordination (along with those of other care coordinators in cancer or chronic illness) may inform the development of future cancer care coordinator roles.
- Given that continuity is a patient outcome, mechanisms to measure continuity in cancer care need to be explored. The consumer feedback tool currently being trialled within Victorian breast services may provide insight into how women’s perspectives on continuity of care can be assessed.

Case study 1

The role of the breast care nurse in improving continuity

Susan was a 45 year old woman living in a small farming community some distance from the regional centre, who had been recently diagnosed with breast cancer. Susan had three children, worked as a full-time mother and assisted with farm duties. She was relatively isolated in her community and travelling for treatment affected the family’s financial resources.

Susan met the breast care nurse shortly after diagnosis. In addition to general clinical and support information and information about the team, the breast care nurse clarified the surgeon’s recommendations and encouraged Susan to consider her options for a few days. Susan was given the names and contact details of both the clinician and the breast care nurse.

The surgeon contacted Susan’s GP and they discussed her case together. Following breast conservation surgery, Susan’s case was reviewed in the multidisciplinary meeting, and a management plan recommended. Susan’s care included chemotherapy and radiotherapy.

The breast care nurse maintained regular contact during Susan’s treatment at the different regional services, prepared her for the different treatments and, with her permission, provided information about Susan to other service providers who were involved in her care. The breast care nurse formally assessed Susan’s psychosocial status and was alert to any ongoing psychosocial concerns. Based on her assessment, the breast care nurse ensured the following referrals:

- local district nursing for home care post surgery
- physiotherapy
- community breast care nurse to provide local support
- social work referral
- contact details provided about statewide and local community support groups.

Continuity is achieved through:

- ✓ contact with the breast care nurse at key points on the pathway
- ✓ key contact details are given to the woman
- ✓ multidisciplinary case discussion
- ✓ good ongoing communication with the local GP
- ✓ information transferred to other service providers on the treatment pathway
- ✓ referral to a range of other services based on formal assessment.

1 Introduction

Continuity and coordination of care—improving the ‘cancer journey’ is a resource in the learning series from the Victorian Breast Services Enhancement Program (the Program).

Given the complex nature of today’s cancer treatment, the person diagnosed with cancer often receives multiple treatments in a variety of different settings over extended periods of time.⁵ While cancer survival in Australia is relatively good—close to the best in the world—we could still do better.²

Discrete health outcomes such as survival and morbidity can be improved by ensuring that best practice evidence is routinely applied. In addition, we can improve the experience of the person with cancer as they navigate the complex health system.²

Strengthening the consumer’s cancer journey through enhanced continuity and coordination of care is the focus of this resource.

In the next section we first look at the context of the cancer journey and some of the issues faced when the Program commenced. Section 3 reviews the concepts and elements of continuity and coordination of care. Section 4 introduces the Program experiences and the three key themes for improving continuity of care and coordination for women with breast cancer. These are:

- the impact of individual approaches
- the breast care nurse role
- the impact of multiple interventions.

These themes and the specific learnings for each are explored in Sections 5, 6 and 7.

Section 8 summarises the key learnings from all the experiences in improving continuity of care for women with breast cancer.

Throughout the text the following symbols are used:

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

2 The cancer journey—the context

In 1996, Victorian treatment services for women with breast cancer and benign breast conditions were reported as being variable and fragmented.⁶ The challenge for the Breast Disease Service Redevelopment Strategy was to achieve the coordination of complex multidisciplinary care in a way that reflected the needs of women with breast disease at all points in the health system and at all stages of the care pathway.¹

Improving integration and continuity of care was therefore one of the Program’s four priority areas.⁷

Today, reviewing the Program’s achievements, improved continuity and coordination of care can be seen as an outcome of a range of strategies, including strengthening multidisciplinary care and improving women’s access to a breast care nurse.

Through the Program experiences, ways in which continuity and coordination of care can be effectively strengthened were learned—both within health services and across boundaries between systems. Work was also started to enhance the coordination of care for women with advanced disease.

However, many challenges were faced which raise questions for the future. These include:

- How can we maximise continuity of care for women with breast cancer (and all cancer patients) within and between health services and sectors?
- What organisational structures and roles need to be in place to enhance continuity?
- What are the different ways in which continuity can be enhanced? Is it the responsibility of the team, or of one key member within the team?
- Within the breast care nurse role, what is the relationship between providing direct specialist care and the care coordination role?
- What different models of care coordination can be trialled in the future?

Some of these questions have particular relevance for the future. Nationally, as well as within Victoria, there is increasing focus on the coordination of cancer care and the role of care coordinators.^{2, 8, 9} This raises significant issues for future service development.¹⁰ Within this resource, we explore the breast care nurse’s role in care coordination.

3 What the evidence tells us

Key messages

- Continuity is an outcome of care. Care must be experienced as connected and coherent by patients across different sectors within the health care system.
- Enhancing continuity of care leads to improved patient outcomes, improved patient satisfaction and reduced health care costs.
- Improving continuity of care requires a systemwide approach focusing on informational, management and interpersonal aspects of continuity.
- Mechanisms to improve continuity include:
 - information systems
 - patient-held records
 - pathways and protocols
 - multidisciplinary care
 - GP communication
 - the availability of a key contact
 - care coordination.
- Different care coordinator models exist, depending on the illness and organisational context. Assessment and referral are key components of coordination roles.
- Breast care nurses play an important role in coordinating care for women with breast cancer.

3.1 Why continuity and coordination of care?

As in all cancer treatment, breast cancer management is increasingly complex, requiring primary treatment from multiple providers, often over many months⁵ within the ambulatory care setting.¹¹ Without coordination, fragmented care and poor communication between care providers exacerbates the emotional distress experienced by cancer patients and their families.²

In a recent UK study, cancer patients with a diagnosis of less than one year on average had met 28 doctors since their diagnosis.¹² Patients also come in contact with many other health professionals, resulting in a challenging maze through which they have to travel.¹⁰

Given the geography and complex health system, this maze may be even more difficult in Australia. Individual care is provided in different settings across the public, private and community sectors, across metropolitan services and between rural and metropolitan services.² Significant health care reform may be required to ensure coordination of optimal clinical and supportive care for all people with cancer.^{2, 13}

Improving continuity and coordination of care is not unique to cancer services. It is currently a major driver of health care reform, particularly in the care of people with chronic illness or with complex needs.¹⁴

3.2 What is continuity and coordination of care?

While used widely and often interchangeably, continuity of care and coordination of care mean different things to different people, depending on the illness context and organisational setting.^{3, 14}

In primary health care, continuity of provider (for example, the general practitioner), may lead to improved coordination of care. In other settings (such as in mental health services), coordination of care aims to enhance patient continuity through the way that team members communicate and practice.³

The common elements of continuity of care are:³

- the care of the individual
- care is delivered over time
- care involves crossing disciplines and organisational boundaries.

Other terms used to describe continuity of care include:

- continuum of care
- case management
- service coordination
- integration
- seamless care.³

Continuity of care—definitions

Continuity of care requires the delivery of services by different providers in a coherent, logical and timely fashion, consistent with the patient’s medical needs and personal context.³

A service system that facilitates continuity of care is one where all services required (**comprehensiveness**) are delivered over time (**longitudinally**) by service providers who establish secure and dependable relationships (**relationships**), and when appropriate care is available (**accessibility**) and flexible enough (**responsiveness**) to meet patient needs.¹⁴

Three overlapping approaches to improve continuity of care have been described³ as:

- informational continuity
- management continuity
- interpersonal or relational continuity.

Table 1 outlines the elements of each approach and possible strategies to achieve them.

Table 1: Approaches and strategies to improving continuity of care

Approach	Descriptors	Strategy examples
Informational continuity	<ul style="list-style-type: none"> Information links care between one provider and another, and between health care events and can be disease- or person-focused. 	<ul style="list-style-type: none"> Electronic information transfer. Enhanced documentation through medical records, letters between providers. Patient-held records One-on-one and multidisciplinary communication.
Management continuity	<ul style="list-style-type: none"> Services are designed and delivered in a complementary and timely manner, optimising both consistency and flexibility of services. 	<ul style="list-style-type: none"> Shared management protocols. Individualised care plans. Multidisciplinary review meetings. Ensuring regular contact with the patient. Referral mechanisms to ensure patients gain access to appropriate services.
Interpersonal or relational continuity	<ul style="list-style-type: none"> Provides links between past, current and future care Provided through ongoing relationship with one key provider such as the general practitioner <p>or</p> <ul style="list-style-type: none"> Provided through a core group of staff giving a sense of predictability and coherence. 	<ul style="list-style-type: none"> Agreed key contact for patient. Keeping the numbers of carers involved to the minimum are encouraged. Good communication skills to optimise understanding, trust and mutual respect.

Regardless of the approach, continuity of care is increasingly seen as an outcome of care.^{3, 15} Care must be experienced by the patient as connected and coherent.

From the patient’s perspective, this is achieved when:¹⁴

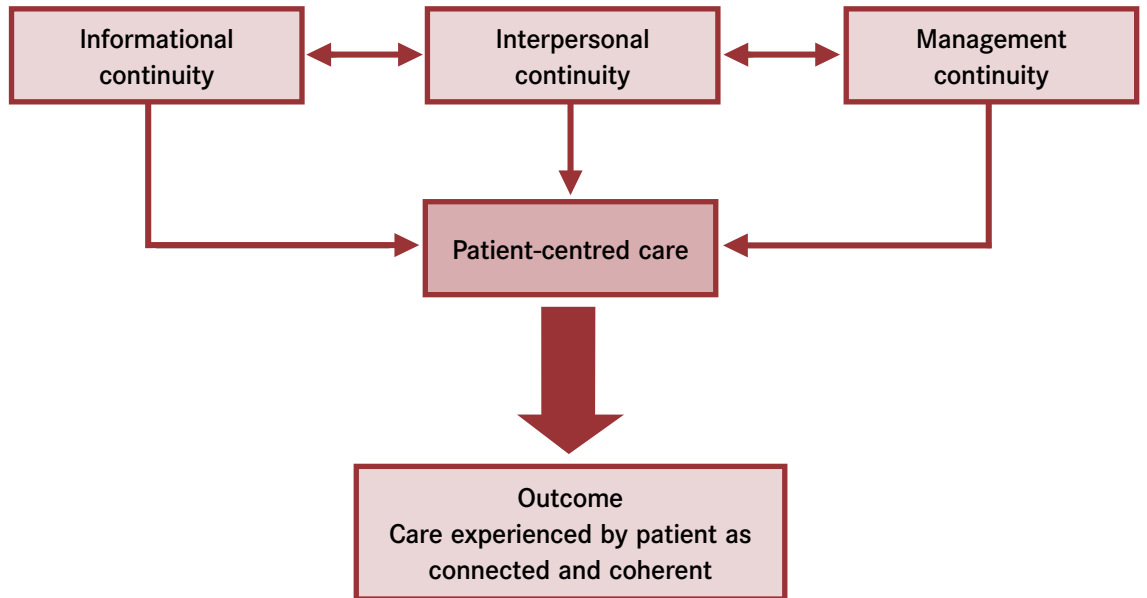
- a provider knows what has happened in the past
- different providers agree on the management plan
- a provider who knows them will care for them in the future.

As such, continuity provides a benchmark for measuring quality of care.¹⁶

Continuity is a patient outcome and is achieved when patients experience care as connected and coherent.

Figure 1 models the approaches to achieving continuity of care.

Figure 1: Approaches to achieving continuity of care



Demonstrated **benefits** of improved continuity of care include:

- ★ lower inpatient morbidity, mortality and improved patient satisfaction¹¹
- ★ improved communication between health care providers and patients, and between health care providers^{17, 18}
- ★ streamlining of services, avoiding both gaps and duplication of assessment or service provision¹³
- ★ lower health care costs¹⁶
- ★ in ambulatory care, clients perceived improved levels of health status¹¹
- ★ improved use of adjuvant therapies for women with early breast cancer in services with greater coordinating mechanisms.¹⁹

3.3 Enhancing continuity of care

In recognition of the importance of continuity of care the Program Guidelines⁷ emphasised:

...the development of strategies to enhance continuity of care and care management within and across primary, community, acute and palliative care settings.

It is at these interfaces between systems or subsystems that care often fails.²⁰

Within chronic illness, Mayor²¹ argues that systems to improve coordination between the primary and secondary health sectors are essential, and may require new models of care and mechanisms to facilitate information sharing. These models of care emphasise:

- changes in health care organisation
- delivery system redesign
- the availability of specialist liaison practitioners
- self-management strategies
- decision information support systems.^{21, 22, 23}

Not surprisingly, this requires a whole-of-system approach, with multiple interventions,^{11, 15} rather than a reliance on one approach.

For example, as indicated above (Section 3.2), a continuing relationship with one provider does not necessarily result in continuity as experienced by the patient.³ Similarly, processes such as pathways and protocols in chronic disease management aimed at facilitating standards of care and communication do not necessarily lead to improved patient continuity. Once developed, greater emphasis is needed on pathway implementation, facilitating the required information sharing, strengthening multidisciplinary teams and their commitment to coordination, and enhancing communication between service providers and with the patient.²⁴

Multiple interventions required to enhance continuity of care therefore require a blend of informational, management and relational approaches to continuity.

Within services caring for women with early breast cancer, Bickell and Young¹¹ identified the following coordination mechanisms:

- tracking of referrals
- multidisciplinary meetings with a patient management focus
- patient support programs, including patient educators and ‘systems navigators’
- use of protocols
- computerised systems
- feedback on performance data
- services available at one location.

Multiple approaches are needed across the system, with a blend of informational, management and interpersonal approaches to enhance continuity of care.

Multidisciplinary meetings and patient support systems were perceived by service providers as the most valuable. Services with the greatest number of coordination mechanisms demonstrated evidence of improved use of adjuvant therapies.¹¹

The following discussion briefly reviews the evidence for some specific initiatives introduced through the Breast Services Enhancement Program, which included the development of databases, patient-held records, and the establishment of multidisciplinary meetings. This is followed by a more detailed review of the role of care coordinators.

3.3.1 Information systems

The need for efficient electronic information transfer to avoid confusion, service duplication or delays because of poor communication between providers and services is seen as critical in enhancing continuity of care.^{3, 13} Improving access to electronic patient records is a priority of the Department of Human Service’s HealthSmart strategy.²⁵

3.3.2 Patient-held records

Some evidence suggests that patient-held records have benefits for both consumers and health professionals.²⁶ They potentially give patients more control of their information, a greater ability to be involved in treatment and care,^{26, 27, 28} and reduce patient uncertainty.²⁹ However, their use and benefit for patients is influenced by health providers’ commitment to assist in completing the record.²⁷

Patient-held records facilitate consumer access to information, increase their involvement in care and reduce uncertainty.

Evidence indicates that patient-held records can improve communication between providers to ensure timely and appropriate care.²⁶ In one study, patient-held records were particularly beneficial to primary health care providers, but this (and another study) indicated their limited benefit to acute health care providers.^{27, 28}

3.3.3 Multidisciplinary care

Evidence indicates that multidisciplinary meetings (as a component of multidisciplinary care) facilitate not only clinical management in accordance with best practice, but also communication and referral between health professionals and between providers and patients.^{13, 17, 18}

The establishment of multidisciplinary clinics, where all clinical specialists are available on one site, may also do much to facilitate continuity of care. In addition, such clinics may facilitate a more concerted effort to provide optimal information and psychosocial care.³⁰

For more evidence about multidisciplinary care see the learning series resource *Multidisciplinary care—improving consumer outcomes*.

As indicated, the effectiveness of multidisciplinary pathways and protocols in facilitating inter-professional communication depends on the implementation strategy and their integration with other coordinating mechanisms.^{3, 24}

3.3.4 General practitioner communication

The general practitioner plays a role in the care coordination of cancer patients² by providing patient information and referral into the acute system, in follow-up care,^{31, 32} and in palliative care.³³ However, as with all health professionals, for general practitioners to contribute to coordinated multidisciplinary care, they need to have the necessary knowledge and information—and the confidence that their input is valued.³

To improve coordination between primary health and acute care, general practitioners have been encouraged to participate in multidisciplinary case conferencing through the Commonwealth Government’s Enhanced Primary Care (EPC) package. Due to organisational barriers, GPs’ uptake of this case-conferencing item has been limited. Suggestions to improve uptake have included specialist services organising the case conference, booking a formal GP consultation timeslot and the GP teleconferencing into the meeting.^{34, 35, 36} Others have suggested that one-on-one telephone consultation with individual members of the multidisciplinary team may be more efficient.³⁶

3.4 Coordination of care

The need for a key contact for the patient is emphasised within cancer and chronic illness literature.^{13, 14, 18, 22} It is with this key contact that a relationship of understanding, trust and mutual respect develops and enhances continuity beyond just a series of processes.³⁷

This key contact function is often seen within a care coordinator role undertaken by general practitioners, specialist nurses or allied health workers. Other terms for the role include case managers, care facilitators and service coordinators—the role emphasis subtly changes in different contexts. Two common elements are assessment and referral.³⁸⁻⁴¹

Within emergency departments, care coordinators focus on assessment and referral to services for identified patient groups. Such roles have reduced hospital admissions, repeat presentations to emergency departments and improved patient’s access to community support services.³⁸

In a Victorian hospital that participated in the hospital admission risk program, care facilitators were appointed to support older people with complex needs. Liaison with other service providers and the provision of direct care were assessed to be the most important functions of these roles. Assessment, referrals and client education were the second most important cluster of activities. Early evaluation indicates a significant increase in the number of services accessed by clients, facilitating home care and self-management.³⁹

Assessment and referral are critical components of the care coordinator role.

Within the Victorian Coordinated HealthCare Trial⁴⁰ for people with chronic conditions, service coordinators were appointed to work collaboratively with general practitioners. GPs played the care coordinator role and were responsible for the medical component of assessment and care planning. The service coordinator was responsible for:

- the development of a comprehensive generalist assessment and overall care plan
- coordinating, costing and implementing the service care plan
- ongoing patient monitoring and review.

Lydall-Smith et al⁴⁰ identified similarities and differences between the service coordinator role and that of a case manager. Both service coordinators and case managers have:

- detailed knowledge of services available and organise services for clients
- undertake assessments, but at varying levels
- liaise with service providers
- develop, monitor and review plans.

Compared with case managers, service coordinators:

- always undertake a comprehensive generalist assessment
- have a greater caseload
- may be more short term
- provide no direct patient care
- have less in-depth knowledge of a patient's social relationships and support

3.5 Care coordinators in cancer care

A recent UK systematic review, as reported by Yates,¹⁰ elicited evidence from 13 studies on interventions to improve service coordination for supportive and palliative care for cancer patients. In addition to those interventions discussed earlier, the appointment of nurse coordinators was an important approach to enhancing coordination. However, 11 out of the 13 identified studies focused on interventions to enhance continuity in palliative care. Interestingly, a recent Australian study identified significant gaps in links and relationships between acute care and palliative care services.¹⁸

In one UK model of cancer support,⁴¹ the coordinating role of the cancer support nurse is clearly emphasised. Within a strong regional network of treatment, community support and hospice care services, along with links with the primary health team, the cancer support nurse ensures patients gain access to services to meet their needs. A comprehensive home assessment is undertaken. While continuing contact with the patient may be maintained, the emphasis is on referral to the relevant treatment or support service. The workload of each cancer support nurse was estimated to be 130 new referrals per year.

In Australia, the Clinical Practice Guidelines for Psychosocial Care for Adults with Cancer⁵ identifies Level 2 evidence that:

- Specialist breast nurses improve understanding and provide continuity of care throughout the treatment process for women with breast cancer.

While care coordination is not the sole focus of the specialist breast care nurses’ practice, the increasing establishment of such roles in Australia has been an important development to improve coordination and support for women with breast cancer.¹⁰ The National Breast Cancer Centre (NBCC) undertook a major Australian project to trial an evidenced-based specialist breast care nurse model.⁴² The trial results identified that the role led to the following **benefits**:

- ★ improved team functioning and appropriate use of each team member’s skills and resources
- ★ care delivered more smoothly, including referrals
- ★ improved information transfer between health professionals
- ★ women being prepared for each treatment stage.

Another Australian study reinforced the role that specialist oncology nurses play in care coordination and facilitating effective communication within the team and with patients.⁴³

Other recent evidence also affirms the benefit of a nurse case manager:

- in facilitating access to adjuvant radiotherapy and improved postoperative arm function¹⁹
- within a community-based model, in helping older women with breast cancer manage coexisting medical conditions, providing support and education, giving assistance with activities of daily living and helping to navigate the health system⁴⁴
- in lung cancer patients, in improving advance care planning, referral to hospice programs and improved symptom management.⁴⁵

As part of the Victorian Breast Disease Service Redevelopment Strategy implementation, a comprehensive descriptive study of 153 breast care nurses’ practice was undertaken.⁴⁶ This study identified significant variation in practice, with limited opportunity for joint consultation with other health professionals and limited referral rates to some professional groups. A similar finding was found in the NBCC breast care nurse study, where few women with breast cancer were referred to psychological support services.⁴⁷

Yates¹⁰ identifies a number of factors that may influence the practice and outcomes of care coordinator roles, including:

- ◇ inadequate preparation of care coordinators and other team members
- ◇ poorly designed interventions
- ◇ lack of access to services and systems of support
- ◇ lack of a clear role definition and identification of core competencies required.

Similarly, the NBCC study identified the need for breast care nurses to develop enhanced skills in communication and screening for psychological distress. The study also identified the need for improved access to psychological services to enhance referral.⁴⁷

The coordinating role of breast care nurses also needs to be considered within the context of their other, more direct care functions, such as the provision of clinical care, patient information and education and the provision of practical and emotional support. In addition to the organisational context in which specialist breast care nurses work and their role preparation, the breast care nurse role may be influenced by the availability (or lack) of ongoing organisational and professional support.^{13, 48}

Finally, in considering the cancer care coordinator role, Yates¹⁰ raises a number of important questions, including:

- To what extent should future roles be focused on care coordination activities, or more directly meeting the individual’s supportive care needs, or a combination of both?
- Do all patients require access to care coordinator services?
- What is an appropriate caseload and casemix for care coordinators?
- Should care coordinators work within one institution, in primary care, or across sectors?
- How does the care coordinator role interact with other generalist or specialist roles? How should blurred and changing practice boundaries be managed?
- What are the requirements for the further development of appropriate systems of support and interdisciplinary approaches to care?

The experiences and learnings of the Breast Services Enhancement Program in enhancing continuity and coordination of care can inform future discussions.

4 Learning from the Breast Services Enhancement Program experience

Through the Program, many of the achievements in improving continuity of care resulted as by-products or outcomes of strategies within other priority areas. The successes and challenges link both with the evidence and with current directions in developing coordinated health care systems for all patients.

4.1 Where we started

When the Program started, there was clear recognition that improved coordination of care was needed to ensure that women had access to optimal clinical and supportive care systems. Specific issues included:

- communication between different disciplines was perceived to be suboptimal within and between systems
- within the sequential model of care there were varied opportunities to optimise coordination through multidisciplinary discussion
- there was limited and delayed communication between hospitals and general practitioners and other community services.

In addition, although the number of breast care nurses had increased significantly from the mid 1990s, there remained:

- significant gaps in access to breast care nurses
- the scope of practice was varied, depending on the local context
- limited referral between breast care nurses across the system
- limited organisational and professional support for the breast care nurse role.

4.2 The key themes

Across the nine consortia, a range of individual strategies that enhanced informational, management or relational aspects of continuity can be identified (see Table 3, page 18).

However, within programs, a number of approaches (both planned and unplanned) came together to strengthen continuity across the system further.

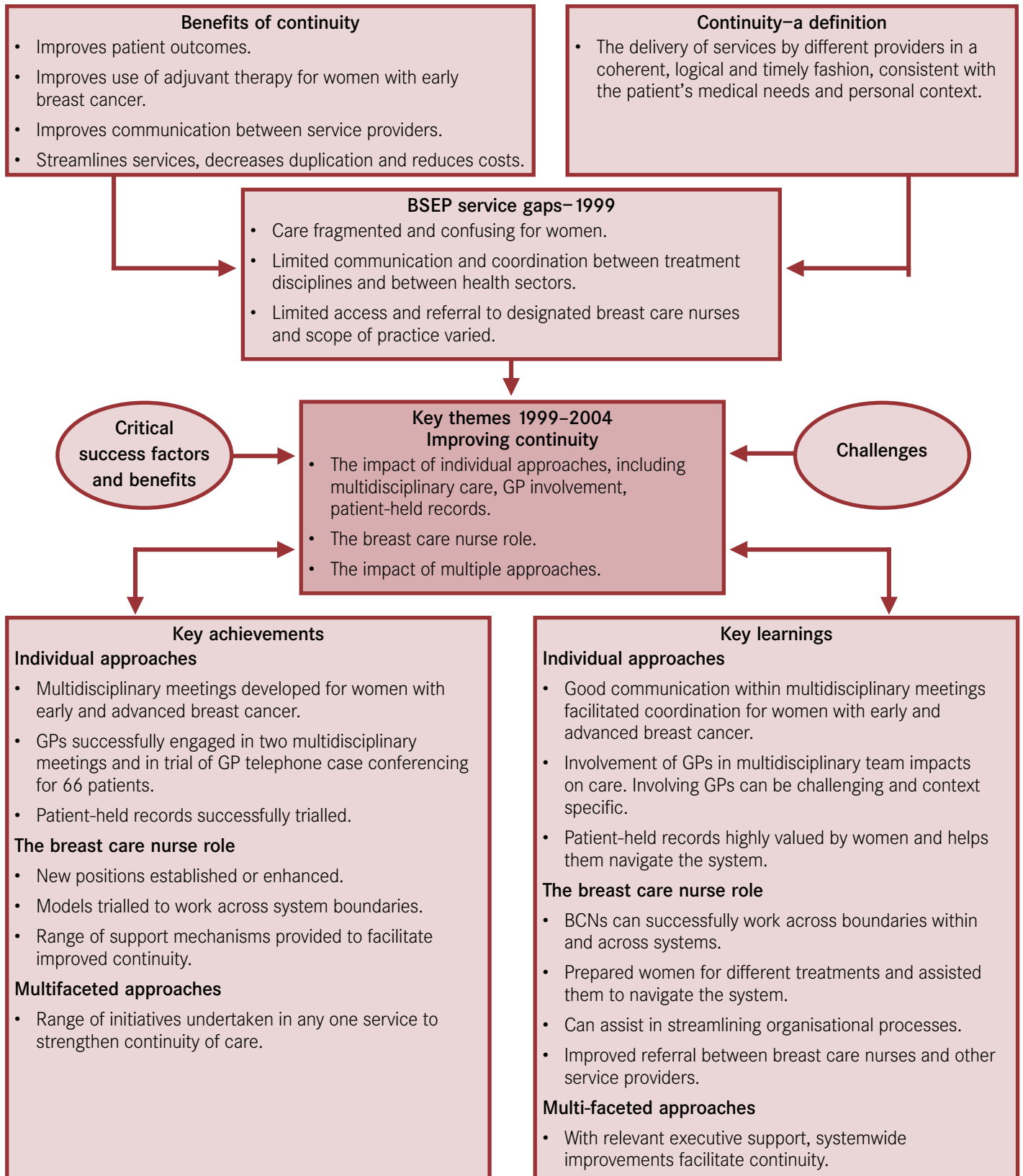
The experiences and learnings of the Program in improving continuity and coordination of care are therefore drawn together in the following sections under these three areas:

- impact of individual approaches
- breast care nurse role
- impact of multiple interventions.

Section 8 summarises the key learnings across all three areas.

Figure 2 summarises the rationale, key initiatives, achievements and learnings.

Figure 2: Continuity and coordination of care—improving the ‘cancer journey’



5 Improving continuity and coordination —the impact of individual approaches

Key messages

- A number of strategies were trialled to improve continuity of care for women.
- Multidisciplinary meetings can enhance coordination of care across providers. Poor communication within meetings reduces benefit.
- Multidisciplinary meetings may be useful for women with advanced breast cancer, facilitating coordination of care across treatment and palliative care sectors.
- GPs have an important role in the multidisciplinary team to improve outcomes for women.
- Different strategies for achieving GP engagement are required, depending on the geographic and organisational context.
- Use of patient-held records demonstrated their effectiveness in providing information to women, empowering them and assisting them navigate the health system.
- The development of an information management system that has the potential to facilitate information access across service providers is a complex, resource intensive strategy building on an existing IT infrastructure. It requires continuing executive, clinical and IT stakeholder sponsorship to achieve its goal.

Overall, Program initiatives tended to focus on improving continuity of care within or across the treatment sector. A smaller number of initiatives crossed the interface between the acute and primary or community health care sectors.

Some initiatives resulted in subtle shifts in practice, but reflected an underlying emphasis on providing patient-centred care. Much broader organisational support was needed for other changes, such as bringing all breast services onto one site in a multi-site health service.

Table 3 lists a range of initiatives undertaken across the nine consortia under the three approaches to continuity.

While categorised under one specific approach, some strategies addressed more than one approach; for example, establishing multidisciplinary meetings facilitating information transfer between providers (**informational continuity**) may require organisational changes (**management continuity**).

Table 3: Program initiatives to improve continuity of care

Continuity approach	Breast Services Enhancement Program initiatives
Informational continuity	<ul style="list-style-type: none"> • Establishment of multidisciplinary meetings for women with early breast cancer and advanced breast cancer. • GP attendance at multidisciplinary meetings. • GP case conferencing. • Development of patient-held records. • Development of resources targeted at different points in the diagnostic/treatment pathway for women with benign breast conditions and young women with breast cancer. • Development of information packages, including information about community support services. • Development of a joint data and information management system to facilitate information access across regional health services.
Management continuity	<ul style="list-style-type: none"> • In multi-site health service, all related breast services brought onto one site (see Section 7). • New multidisciplinary clinics established in two sites. This ensured that the patient stayed in same room with the service providers moving between rooms. • Development of clinical pathways and protocols. • In sequential model of care, development of a protocol to minimise duplication of appointments for surgical and oncology follow-up. • End-of-treatment support groups to facilitate women’s transition back into the community sector.
Interpersonal or relational continuity	<ul style="list-style-type: none"> • Development and strengthening of breast care nurse role (see Section 6). • Names of key contact/team members and contact details provided to women.

The following four individual initiatives and their key learnings are discussed in more detail:

- multidisciplinary meetings
- improving communication with general practitioners
- patient-held records
- development of an information management system.

5.1 Multidisciplinary review meetings

The establishment of a multidisciplinary meeting—one approach to strengthening multidisciplinary care—is an important mechanism to enhance communication and coordination of care across service providers. Within the Breast Services Enhancement Program, 12 multidisciplinary meetings were developed, and an additional nine were strengthened.

Such multidisciplinary meetings also enabled non-clinical team members such as allied health workers to provide more responsive care.

I can go in and not be totally blank when I am talking to someone... I have a bit of understanding of why people have this, or why people have that, and that helps me in my care.

Allied health worker

Continuity approach: multidisciplinary meetings strengthen informational and management continuity.

For more information see *Multidisciplinary care—improving consumer outcomes*—another resource within this learning series.

However, other Program evidence indicated that within a multidisciplinary meeting, poor communication, leading to no agreed management plan between providers, resulted in suboptimal, fragmented care, which confused women.

5.1.1 Improving coordination of care for women with advanced breast cancer

The establishment of a multidisciplinary meeting for women with advanced breast cancer made an important start in trialling an initiative that crosses boundaries between treatment and palliative care services. It also aimed to strengthen links with the woman’s general practitioner.

Case study 2

Improving continuity of care for women with advanced breast cancer.

Where we started

We (medical and radiation oncologists) see many women with advanced breast cancer, and they just don't gain access to the same supports as women with early breast cancer.

There was no multidisciplinary team, and women just got lost in the woodwork. It was also really hard to encourage women to accept supportive palliative care services.

What we did

After a lot of discussion about the best way forward, we established a fortnightly multidisciplinary meeting. It is attended by medical and radiation oncologists, palliative care specialist nurses and physicians, breast care and radiation oncology nurses and social workers from the hospital and community palliative care service. Any team member can bring cases to the meeting.

We agree on key actions for care and who is responsible for them. At subsequent meetings, we check on whether the actions have been undertaken and whether additional care is needed.

What we have achieved

- Over 15 months a total of 70 women have been presented, some on several occasions.
- Improved communication between service providers in different areas.
- Improved symptom management and women's access to support services.
- Improved staff understanding of and referral to community services.

Although we have encouraged women's local GP to attend the meeting, we have not been successful in achieving this. However, a letter and a care plan are sent to the GP after a case discussion.

Critical success factors in this advanced breast cancer project included:

- ✓ strong commitment and leadership by two key stakeholders facilitating the engagement of others
- ✓ support from Program staff in original establishment phase
- ✓ strong team commitment to trialling a new developmental model
- ✓ a collaboration was developed between local Program staff and regional palliative care services, resulting in additional funding to support this initiative.

Future **challenges** include:

- ◇ improved links with general practitioners
- ◇ sustainability of the coordination role.

5.1.2 Learnings about multidisciplinary review meetings

- ✓ Multidisciplinary meetings do much to enhance continuity of care through optimal communication and coordination between service providers. Poor communication processes within multidisciplinary meetings can result in fragmented care and conflicting information being provided to women.
- ✓ Multidisciplinary meetings for women with advanced breast cancer bring together a range of treatment, supportive and palliative care providers. Such meetings improve women’s access to a range of support services in a more coherent fashion, enhance women’s earlier access of palliative care services and provide support for service providers.

5.2 Strengthening the general practitioner’s role in the multidisciplinary team

One metropolitan program identified the following barriers to facilitating communication between acute care and general practitioners:

- cultural differences and ingrained prejudices between sectors
- communication tends to be limited with a one-way focus of information transfer from the acute sector to the GP
- communication delays in providing information (up to five weeks) from acute providers to GPs
- GPs not seen as part of multidisciplinary team and the value of their input not acknowledged
- potential conflict between the role of the breast care nurse and the GP
- GPs’ limited knowledge of breast disease/breast cancer management.

To facilitate improved communication with GPs, several Programs offered educational forums for GPs on their own or as part of broader professional education programs. GPs perceived the **benefits** of these meetings were their improved understanding of:

- ★ breast disease assessment and management
- ★ the value of multidisciplinary care for women with breast cancer
- ★ the role of the breast care nurse
- ★ services offered within any particular health service or region.

GP educational programs may be very useful for general information and communication between GPs and acute care providers. More specific approaches may be needed for improving continuity of care for individual women.

In one metropolitan program, over 90 GPs attended one of three forums developed with local divisions of general practice. Very positive feedback was received. However, the participants reflected only a small percentage of all GPs across the region. It is likely that more specific communication is needed with individual GPs to impact on the coordination of care for women with breast cancer.

Continuity approach: communication with individual woman’s GP may improve informational and relational continuity.

5.2.1 Improving communication with individual women’s general practitioners

Two approaches were successful in improving communication to women’s GPs. These were:

- GP participation in multidisciplinary meetings
- GP telephone case conferencing.

Participating in multidisciplinary meetings

Two regional Programs successfully attracted GPs to participate in multidisciplinary meetings when their patients were being discussed. GPs participated in person or via telephone or video-conferencing (see Case study 3, below).

Case study 3

Improving continuity of care through increasing GP participation in regional multidisciplinary meetings

Where we started

Before BSEP, there was no multidisciplinary meeting, and communication with GPs occurred in an ad hoc fashion.

What we did

Initial meetings were held with the local GP division and with individual GP practices about the development of the multidisciplinary review meetings.

GPs are notified when their patients were being discussed and invited to participate in the multidisciplinary meeting. The GP liaison officer attends all meetings and provides feedback to GPs unable to attend.

What we achieved

The woman’s GP was present for 30 to 50 per cent of all case presentations. The demonstrated **benefits** were:

- ★ Treatment recommendations were guided by the GPs’ input on the woman’s other health problems, social setting and family support.
- ★ GPs felt more informed and confident about treatment options, which enabled them to support women when making their treatment decisions.
- ★ In the case of a woman with a complex psychiatric history, the GP negotiated the most acceptable treatment in her situation with the woman.
- ★ Improved support for women. If GPs were involved early in the decision making processes, they were more able to support women through their care.
- ★ GPs indicated that participation in the multidisciplinary meeting had influenced their referral practices.

Critical success factors in these projects included:

- ✓ within rural regions, stronger relationships exist between general practitioners and local acute care providers
- ✓ the GP liaison officer role enabled GPs to be involved in care, even if unable to attend the meeting
- ✓ the nature of rural GP practice may result in stronger relationships with their patients, and GPs are seen to play a greater role in supporting acute care
- ✓ the demonstrated benefit of having GPs involvement in decision making reinforced the importance of GPs’ input and role in the multidisciplinary team to acute care providers.

In contrast, in spite of significant effort, other programs (particularly in metropolitan Melbourne) were unsuccessful in encouraging GPs to participate in multidisciplinary meetings.

The **challenges** for achieving GP participation in multidisciplinary review meetings included:

- ◇ timing of meetings accommodated acute providers’ needs, rather than GPs’
- ◇ GP distance from meeting venue
- ◇ workload issues or GP working in part-time role
- ◇ the GP nominated had not been the ongoing provider of care for the woman, and felt unable to contribute.

For more information, see *Multidisciplinary care—improving consumer outcomes*—another resource within this learning series.

GP telephone case conference

GP case conferencing, supported by the Enhanced Primary Care (EPC) funding, was trialled across four services within one consortium. The telephone case conferencing was initiated by acute care services, and predominantly coordinated by the breast care nurse. Over six months, 96 case conferences were offered and a total of 66 undertaken, with key participants being the GP, breast care nurse and surgeon.

GPs were unable to participate in 20 out of 30 proposed case conferences because of their workloads (n=13), with other reasons including seeing no benefit and preferring to speak directly with the surgeon. Patient and clinician factors prevented the uptake of other case conferences.

Evaluation of the 66 GP case-conferences that occurred indicated the following **benefits**:

- ★ enhanced two-way, timely transfer of information
- ★ enabled GPs to provide specific input on the woman’s other medical conditions, psychosocial issues and to clarify clinical information
- ★ the role of GP was integrated into the multidisciplinary team
- ★ GPs perceived that it gave women greater confidence in them, and enabled GPs to respond to questions more effectively
- ★ provided GP with clear information about key provider contacts
- ★ increased GPs’ awareness of the breast care nurse
- ★ promoted the breast unit and increased referrals from local GPs.

There should be more of it—it is the first time in 26 years of general practice that I have been kept informed and involved.

General practitioner

Some of the **challenges** identified in the evaluation included:

- ◇ Some surgeons and GPs felt that GPs had a limited role in developing the woman’s management plan.
- ◇ Some surgeons considered it was more beneficial for GPs than them, and felt that GPs were ‘frightened’ to ask questions.
- ◇ Some GPs wanted a greater focus on what was discussed with the woman, rather than on pathology and surgical issues.
- ◇ The organisation of the teleconference added significantly to the workload of the breast care nurse.
- ◇ GPs had limited understanding about the EPC item and how to claim rebates.

Eighteen months after the trial, there were varied levels of continued uptake. In one service, GP telephone case conferencing was routinely offered for all new patients. The lead surgeon’s commitment was significant in achieving this.

At two sites, GP teleconferencing was continued in a more limited way, with one site only organising them for women with complex needs.

At the fourth site, GP case conferencing was discontinued because of the organisational burden. However, this outer metropolitan hospital had close links with the local division of general practice, and surgeons telephoned the woman’s GPs if breast cancer was diagnosed. The breast care nurse also contacted GPs as required.

5.2.2 Learnings about strengthening the general practitioner’s role in the multidisciplinary team

- ✓ GPs play an important and valued role in the multidisciplinary team and can influence patient outcomes. The GP brings their knowledge of the patient’s other health problems, social setting and family relationships and support. This role needs to be more valued by acute health service providers.
- ✓ Actively engaging GPs as part of women’s multidisciplinary care team may be challenging, particularly in metropolitan areas and in large public providers.
- ✓ Developing or strengthening relationships with local divisions of general practice may be helpful in facilitating communication and in providing GP education programs. It is likely that strategies that increase relationships between individual GPs and local breast care services may lead to stronger communication and collaboration in the future.
- ✓ Stronger relationships with GPs and hospitals appear more achievable in regional areas and with hospital services that serve a more geographically defined local community. Such relationships can be more difficult to develop in large tertiary referral hospitals.

- ✓ There is a lack of clarity about the most effective and efficient ways to work with GPs in different settings and how this impacts on continuity of care as perceived by women.
- ✓ Given the small numbers of women with breast cancer that a GP has in their practice at any one time, it is difficult to know how much general GP educational activities translate into improved continuity of care for individual women with breast cancer.
- ✓ It is likely that the greatest benefits in improving GPs’ participation in multidisciplinary teams will occur when a range of systemwide and sustained approaches are implemented over time.

5.3 Patient-held records

Continuity approach: patient-held records facilitated women’s understanding of the treatment pathway, facilitating informational continuity.

Three consortia developed patient-held records.

These three resources had significant commonality in their purpose, although there was diversity in their scope, development, design and evaluation processes.

The different titles reflect some of the differences:

- patient-held record
- personal care record
- personal breast cancer journey.

For an example, see www.whg.org.au/breastcancer/journal.htm

Each resource was developed with both clinical input and consumer involvement. Two resources were developed with very strong consumer input from the outset.

The three records aimed to empower women, facilitate their active involvement in care and provide women with an aide de memoire, with one having a stronger emphasis on facilitating communication between service providers.

All three resources provided contact details for key members of the team, appointment pages, test and treatment record pages and notes pages for the woman’s own comments. One record included clinical pathways.

Two resources were presented in similar A5 (book-sized) formats, while the third was developed as A4 sheets that could be photocopied, placed in clear plastic envelopes and bound in-house.

All three resources were very favourably received by women. Women indicated that they most valued the resource at diagnosis and early treatment, using it less as they became familiar with the system and treatment information.

I could not have done without it—I needed it as my reference because I was so overwhelmed at the time.

Consumer

Initially I used it extensively, but as the six months proceeded I needed it less often.

Consumer

Breast Cancer Network Australia has developed a patient-held record as part of the *My Journey* kit. This resource replaces locally developed resources, but health professionals may still need active encouragement to assist women to complete and use it.

Other key findings across all three projects included:

- Women were more likely to record information than health professionals. Some women were reluctant to ask service providers to complete it.
- Health professionals relied on women presenting the record for completion, rather than proactively asking for it.

Women need to be given it at diagnosis and encouraged to use it. A very useful tool. However, it gets forgotten.

Clinician

I didn't bother asking health professionals to write in it—not enough time.

Consumer

5.3.1 Learnings about patient-held records

- ✓ Strong local ownership by both health care professionals and consumers can assist in the development of a patient-held record.
- ✓ A local champion within each service is needed to facilitate the record's effective introduction.
- ✓ A patient-held record provides consumers with an important reference document to aid them through treatment and navigate the health system.
- ✓ Further time and encouragement are needed to maximise the active use of the record by health professionals to support their communication with consumers.
- ✓ Given the focus of the three records, their value in aiding communication between health professionals was not tested.
- ✓ Ongoing sustainability of the resources was facilitated by one being placed on a local website, accessible to women. Another resource can be readily produced in-house. Following initial development costs, the unit cost of externally reprinting one record was estimated to be \$10 to \$15.
- ✓ The learnings from the patient-held records are readily transferable to the development of similar resources for other cancer patients.
- ✓ There were many similarities in the content of the patient-held records. Consideration could be given to the development of an agreed core component in the development of new patient-held records. Specific local information and branding could then be added to this.

Continuity approach: information management systems may facilitate information transfer between service providers and enhance informational continuity.

5.4 Information management systems

For one regional consortium, the availability of a region-wide IT health network provided an opportunity to develop a data system that facilitated both data collection for audit purposes and access to patient information to all regional services and service providers.

This was an ambitious and complex project. At the end of 2004, the data system was established within the regional cancer centre, but individual clinicians had not started to access the data themselves. Further work was also needed to make the link with the regional IT network to enable information access wherever women would be seen within the region.

The **critical success factors** included:

- ✓ very committed and IT knowledgeable program staff
- ✓ a strong vision of what was possible
- ✓ the infrastructure of the regional health information network.

The major **challenges** were:

- ◇ time and competing demands on program staff
- ◇ the complexity of the project.

The future achievement of the full project scope depends on the commitment of major stakeholders within cancer services, health service executives and information technology.

5.4.1 Learnings about information and data management systems

This project was one of several data projects developed across several consortia. It was the only one that was developed with the dual purpose of data collection and the facilitation of timely access to patient information across the region.

The following learnings draw on the experiences of all the data and information management projects across all consortia.

- ✓ The development of data and information systems are complex projects that require:
 - clarity of purpose
 - strong clinical leadership
 - significant IT knowledge
 - systems change
 - change management
 - time
 - resources.

- ✓ Strong clinician interest and enthusiasm in data collection does not necessarily translate into the day-to-day commitment needed to develop and establish effective and sustainable data systems that facilitate information transfer for patient benefits.
- ✓ Stronger central coordination is needed to ensure data systems are based on common questions, data definitions and the development of minimum data sets, and that links are made with the Victorian Department of Human Services’ HealthSmart strategy.

6 Improving continuity and coordination —the breast care nurse role

Key messages

- Women’s access to breast care nurses was substantially improved through the development of new positions, the extensions of established positions and strengthening of breast care nurse skills and referral processes.
- The breast care nurse role has evolved and been strengthened.
- Innovative models of breast care nurse practice were introduced, which trialled breast care nurses working across sub-systems within a service, and across public and private system boundaries, and regional or state boundaries.
- The scope of the breast care nurse role depends on the context in which they practice, with some breast care nurses working at only specific points on the pathway.
- A number of strategies were developed to support breast care nurses in their roles, in a variety of contexts. These in turn strengthened referral and coordination of care and improved continuity for women. Strategies included:
 - regional network meetings
 - the establishment of regional breast care nurse coordinator positions
 - a breast care nurse database
 - skills development in psychosocial assessment and referral.
- Some gaps in services remain, in both access to breast care nurses within the initial diagnostic and treatment pathway, and across the care continuum. These and other issues provide challenges for the future.

As part of their broader role, the breast care nurse plays an important part in ensuring continuity of care for women with breast cancer. However, achieving this continuity depends on:

- the context within which the role is practised
- the skills and experience of the breast care nurse
- their links to other breast care nurses and to community services
- the organisational and professional support offered to them.

This section considers:

- the context of breast care nurse practice
- improving access to breast care nurses
- working across boundaries
- supporting professional practice
- the learnings for improving continuity of care.

Underpinning this section is the complex relationship between the breast care nurses’ role in providing ‘interpersonal continuity of care’ and ‘coordination of care’.

Continuity approach: breast care nurses provide information and support to women enhancing interpersonal and informational continuity.

6.1 The context of breast care nurse practice

The scope of the breast care nurses’ work is influenced by the service setting and the resources available for the role.

6.1.1 Service settings

In some settings, a range of diagnostic and treatment modalities are provided within one service site, or within very close geographic locations. This provides the opportunity for women to link with the breast care nurse at different points in the treatment pathway. It also enables the breast care nurse to offer a service to women referred from other services for a specific treatment modality.

In other settings, one treatment modality is offered. For example, surgery alone is often provided in some small public and private hospital, with women referred elsewhere for other treatment. Breast care nurses provide care at this specific point in the treatment pathway, and may have limited ongoing contact or only disjointed contact with women as they go between treatment modalities.

In community settings—particularly in rural Victoria—all or most treatment may be undertaken at larger regional or metropolitan centres. Rural community nurses with or without formal breast care nurse qualifications provide ongoing supportive care to women within their local communities.

6.1.2 Role resources

There is considerable variation in the availability of dedicated breast care nurse resources, regardless of the setting and patient volume. For example, an 0.2 EFT breast care nurse role was available at one health service hospital providing the full treatment range. Care was only provided at the surgical breast clinic, and with the coordination of a local support group. Over time, the volume of patients at this service increased to approximately two-thirds of that seen at another hospital within this same health service. At this second site, a full-time breast care nurse position has been available for many years.

For some breast care nurses, the role is integrated into a broader role, for example, stomal therapy, community nursing or a management position.

When the Program commenced, it was clearly identified that improved and consistent access to breast care nurses was needed to facilitate continuity.

6.2 Improving access to breast care nurse care

Women’s access to breast care nurses was improved through:

- the establishment of a breast care nurse team within one major metropolitan provider, and a new full-time position within another metropolitan service
- the establishment of a breast care nurse role to trial a model of care that included a psychosocial assessment in the home before treatment, with follow-up home visits after surgery

- new breast care nurse roles were trialled across several public and private services within two large regional centres
- increased hours were achieved for a number of established breast care nurse positions in metropolitan and rural services.

Critical success factors in achieving these positions or increased hours included:

- ✓ project funding was made available to support initial trials of the role within different contexts
- ✓ the development of a successful business case to fund the role within one service, which:
 - brought together the range of best practice evidence
 - aligned the case with the health service’s corporate goals
 - sought executive stakeholder support
 - gained external consumer support for the initiative
- ✓ more informal lobbying by local champions and staff resulted in established roles being extended
- ✓ the identification of unexpected efficiencies (such as reduced postponement of chemotherapy) that facilitated the funding of one breast care team.

The **challenges** in establishing or extending breast care nurse positions, as part of ongoing health service funding, included:

- ◇ lack of executive sponsorship
- ◇ difficulties in mounting a business case in health services with significant financial deficits
- ◇ difficulties in demonstrating cost savings in services with an already below average length of inpatient stay for surgical management.

For more information about sustaining the breast care nurse role, refer to *Supporting sustainable change*—another resource in this learning series.

6.3 Breast care nurses working across boundaries

Within some settings, breast care nurses were able to work across organisational boundaries, facilitating significant continuity of care. Examples included:

- Within health services based on one site, breast care nurses were available at all key points in the patient pathway, while others travelled between health service sites to provide care.
- Breast care nurses trialled service models across public and private services, and within one setting, across state borders.
- In other instances, the breast care nurse role was developed initially within a public service, but agreements were negotiated to provide services to associated individual private providers or local private hospitals. This facilitated continuity of care for women seen in private rooms, but having treatment in the public sector or when specific treatment is provided through a local private service.

The **benefits** of these models of care for both women and services were:

- ★ enhanced continuity of care for women
- ★ provision of a ‘familiar face’, a key point of contact and a consistent advocate
- ★ facilitation of information transfer between providers
- ★ women adequately prepared for the next stage of treatment and able to navigate the system
- ★ streamlining of a range of organisational processes, maximising efficiencies, including:
 - reduced presentation to emergency departments with problems
 - facilitating tests to reduce unnecessary appointments
 - reduced treatment postponement
- ★ coordination of referrals to other services
- ★ supporting end-of-treatment groups to assist women transition from the treatment sector
- ★ in one service, trialling the benefit of home visits. No difference in women’s satisfaction in care was seen as a result of the home visit, but the increased breast care nurse resources reduced the length of hospital stay.

Depending on the setting, **critical success factors** in these ‘across boundaries’ roles included:

- ✓ Health service executives and key clinical stakeholders agreed to support extended service arrangements or support pilot models through some initial funding or in-kind support.
- ✓ The volume of patients across services provided an appropriate critical mass to make different models viable.
- ✓ Conversely, to achieve continuity of care, breast care nurse resources had to adequately match the patient volume. Inadequate breast care nurse resources constrained continuity of care.
- ✓ Full integration of the breast care nurse into the multidisciplinary team.
- ✓ Careful negotiation of role boundaries with other health service providers (such as oncology nurses, allied health or other breast care nurses) working at different points on the pathway. While important within health services, this was crucial for those developing roles across different health services.

However, a number of overlapping **challenges** were also faced:

- ◇ The need for enhanced referral within and across the acute system, and between health sectors.
- ◇ Different breast care nurse resource levels and, at times, suboptimal communication between breast care nurses across settings, resulted in some women being well supported and others poorly supported. Some women received good support at some points on the pathway, but were unsupported at other times. Breast care nurse resources were also predominantly focused on women with early disease, with relatively limited contact with women with advanced disease.

- ◇ The ability to offer services to an increasing volume of women as a role extends within or across services, within a reasonable but not increasing resource allocation.
- ◇ Role overload as services increasingly expected breast care nurses ‘to fill all gaps’.
- ◇ The need to enhance psychosocial assessment and referral skills.
- ◇ In trialling one breast care nurse service model in several services across state boundaries, implementation was initially constrained by long negotiations to facilitate an appropriate auspice for the role. The original project commitment by local sponsors did not translate readily into the support needed.

For breast care nurses working in low-volume settings, or only at specific points in the treatment pathway, the **challenges** included the need for:

- ◇ increased clinical knowledge and skills
- ◇ improved communication with other breast care nurses and service providers
- ◇ improved understanding of other points in the service system
- ◇ strengthened referral systems.

6.4 Supporting professional practice

The following strategies were developed to support breast care nurses in their practice and strengthen continuity of care for women.

6.4.1 Establishment of local breast care nurse networks

Five regional and one metropolitan program established local breast care nurse networks. Breast care nurses and, in some contexts, other hospital or community nurses, were brought together on a regular basis across a region. The networks were coordinated by program staff, regional breast care nurse coordinators (see Section 6.4.2) or a nominated breast care nurse.

These networks facilitated:

- ★ communication and information exchange between breast care nurses
- ★ the provision of clinical information and skill updates
- ★ the development of agreed care pathways
- ★ improved understanding of care received across the service system
- ★ the development of consistent patient information packages
- ★ increased knowledge about community support services, through the development of regional resource directories, or links with established directories
- ★ the referral of women between breast care nurses across services or regions.

6.4.2 Development of regional breast care nurse coordinators

Three regional breast care nurse coordinator positions were trialled. In two models, this role was combined with the breast care nurse role in a regional centre. In addition to coordinating the regional networks, the regional coordinators:

- ★ provided support and guidance to strengthen the provision of consistent practice within individual services
- ★ provided support and advice to enable local breast care nurses to better support women within their communities
- ★ facilitated the referral of women between breast care nurses in regional services and women’s local communities.

6.4.3 Development of breast care nurse database

A new breast care nurse database was established across several sites within one metropolitan program, and two key sites in a regional program. The database’s aims were broad, but included enhancing continuity of care for women. Components in the database to achieve this included:

- integration of care pathways and key breast care nurse contact points
- patient information summaries that provided an overview of care were placed in the medical history
- recording of what information was given to women
- information on referral sources and responses
- summary reminder sheets of women attending forthcoming services.

Evaluation indicated the database’s important contribution to improving breast care nurse practice overall, and facilitating continuity of care. The database development and implementation also facilitated communication and referral across services.

Some of the **challenges** identified for further enhancing continuity of care included the need to:

- ◇ strengthen referrals
- ◇ ensure more specific documentation of referral actions and outcomes
- ◇ facilitate more direct access to the data by other service providers
- ◇ further enhance psychosocial assessment and referral skills.

More information on the breast care nurse database is available at www.health.vic.gov.au/cancer/

6.4.4 Enhancing psychosocial assessment and referral skills

Given that breast care nurses play a key role in providing information and support to women, several programs developed interventions to strengthen their skills in psychosocial assessment and referral. To varying degrees, these included:

- The use of specific tools, including a simple depression screening tool in one program, and a specifically developed structured, comprehensive psychosocial risk assessment strategy in another.
- Training and education programs provided education and skills development in the use of relevant tools and, in some instances, offered advanced communication skills training.
- Establishment of referral pathways. In one program, referral pathways were developed that linked with a register of local interested psychologists and appropriately trained GPs. In other programs, breast care nurses were encouraged to establish their own referral pathways, and some were provided with referral directories.
- Professional supervision was offered to breast care nurses as part of the psychosocial intervention in some programs (see Section 6.4.5).

The following **benefits** were common findings across all projects:

- ★ The uptake of the psychosocial risk assessment tool with the associated support mechanisms demonstrated the breast care nurse’s capacity to strengthen practice and enhance outcomes for women. The approach was particularly helpful for breast care nurses who provided care across the continuum and built on an already high level of practice.
- ★ Nurses using a psychosocial assessment tool reported greater confidence in their skills, enabling them to provide more individualised, needs-based referrals. Some nurses indicated that they were more likely to refer to a community service directly, rather than referring first to the hospital social worker.

The value of introducing an early, more structured approach to psychosocial assessment is demonstrated in Case study 4, below.

Case study 4

Strengthening continuity through early psychosocial assessment

Mary was seen by the breast care nurse before the introduction of the structured psychosocial assessment tool. It was noted that she had good supports. Later, an external service provider contacted the treating clinician because the woman had verbalised suicidal intentions.

At her next appointment, Mary was reassessed using the psychosocial assessment tool. She revealed that she had been seeing a psychologist for work-related issues, but had ceased this following her breast cancer diagnosis.

Mary was referred to the hospital’s liaison psychiatrist, and an ongoing management plan was developed, which included referral back to the psychologist and her GP for ongoing support. Ongoing supportive care was also provided within the breast team and through the liaison psychiatry services.

Some of the **challenges** faced in introducing psychosocial assessment tools or approaches into breast care nurse practice included:

- ◇ Some breast care nurses had difficulty utilising the proposed tool with barriers, including:
 - lack of time, resources, space and executive support
 - the length of one tool
 - the limited ability of nurses to offer care across the pathway
 - the breast care nurse’s own discomfort in asking the questions and concern in their ability to address identified problems
 - concern about women’s privacy.
- ◇ Referral to appropriate psychological and other community services remained challenging in some situations. Factors influencing this included lack of services and women’s reluctance to take up referrals.

For more information on the psychosocial risk assessment approach, see www.health.vic.gov.au/cancer/

6.4.5 Provision of professional supervision

In a number of programs, breast care nurses were offered the opportunity to participate in professional supervision. This is a relatively new practice within acute care services.

The aim of professional supervision is to enable a practitioner to work with another experienced professional in a safe environment, in order to facilitate reflection, skills development and practice enhancement. It is particularly useful when working in autonomous roles, new skill areas and with people with significant psychosocial needs.

Professional supervision was offered as part of strengthening the breast care nurse role within a service or as part of a specific project focused on psychosocial assessment and referral skills. Some breast care nurses were reluctant to take up the offer of supervision.

The breast care nurses who did take up the offer reported that professional supervision:

- ★ facilitated their role development
- ★ gave them specific skills to manage complex situations
- ★ enabled them to manage their boundaries better.

Professional supervision supports and strengthens breast care nurses’ role and skill development.

6.5 Learnings—breast care nurses’ role in improving continuity of care

- ✓ Achieving continuity of care is a team responsibility and requires a systemwide approach. Breast care nurses play a valuable role within this team.
- ✓ The breast care nurse role can provide significant continuity of care for women with breast cancer. Their role is in providing direct care, facilitating communication and coordinating access to services. The role can lead to streamlining of services with resulting efficiencies. However, some significant gaps in women’s access to breast care nurses persist.
- ✓ Where breast care nurses work only at particular points on the pathway, fragmentation occurs. The development of communication mechanisms can facilitate consistency, coordination and continuity of care across systems.
- ✓ The development of innovative models of practice across systems can bring together a critical mass of patients, enabling the appointment of a substantial role in care coordination. This provides greater continuity of care compared with a small number of hours being allocated within individual services.
- ✓ The breast care nurse role predominantly focuses on women with early breast cancer. Their role with women with advanced breast cancer, and the relationship with other specialist nurses and service providers, needs further exploration. It is unclear whether current breast care nurse resources can provide appropriate levels of care to both populations of women.
- ✓ Breast care nurses recognise the need for specific skills in psychosocial assessment and referral, and significant progress has been made in this area. Breast care nurses may also need greater knowledge of community-based resources to facilitate referral.
- ✓ Referrals may remain constrained by the limited access to timely and appropriate community-based psychosocial support services.
- ✓ Through the Program, breast care nurses have significantly contributed to the evolution of the role. Given constraints within health care systems, there is increasing recognition of the need to balance direct care provision with service and care coordination, in order to ensure that all women experience continuity of care across the system. Examining a range of models of care coordination may provide opportunities for future role evolution.

7 Improving continuity and coordination —the impact of multiple interventions

Key message

Multiple interventions focusing on different points in the system facilitated the strengthening of continuity of care for women within a service.

Enhancing continuity of care across the health sector requires a whole-of-system response.

A clear learning from the Program was that a number of strategies came together to improve continuity of care within specific services. For example, within different programs, continuity of care was strengthened through:

- ★ developing a multidisciplinary meeting and strengthening breast care nurse access and skills across one multi-site service
- ★ bringing GPs into the multidisciplinary meeting, or through GP case conferencing blended with improving the breast care nurse roles across the region and implementing a patient-held record
- ★ establishing a regional breast care nurse coordinator role, multidisciplinary meetings and other specific strategies within a region, such as consistent information packages, and improved referral across breast care nurses and other allied health workers.

Within one high-volume service provider, a range of service redevelopment and quality improvement initiatives were implemented which strengthened continuity of care. Some initiatives preceded the Program and set the scene; other initiatives were planned within the Program; some arose opportunistically. This resulted in significant strengthening of service delivery and enhancing of care. Case study 5 reflects this experience.

Case study 5

Enhancing continuity of care in a high-volume health service

Where we started

Our health service has three major sites for acute care services. From the early 1990s, the health service has been one of the key breast screening and assessment services within metropolitan Melbourne. At the same site as the screening service, the health service provided surgical care and day oncology services and auspiced a radiotherapy centre. The oncology outpatient clinic was based at another site. A small volume of breast surgery was also undertaken at a third health service site.

Before the Breast Services Enhancement Program, we had no designated breast care nurses and limited access to lymphodema services.

What we did

Through the Breast Services Enhancement Program we undertook some specific activities to strengthen our services. This included:

- development of a breast care nurse team model to provide services across all acute sites and with a regional focus
- development of a multidisciplinary lymphodema service at the main site
- development and trial, then implementation of a patient-held record.

With the opportunity of some service reconfiguration across the health service, we were finally able to negotiate that women with breast cancer should be seen in a multidisciplinary clinic, rather than having to go to the general oncology clinic at a different site. The availability of Program staff resources supported this initiative and made it happen.

What we have achieved

- All screening, diagnostic and treatment services are provided at one site. Only a small number of women have surgery at another site, which is visited by the breast care nurses.
- A multidisciplinary clinic, with a prior multidisciplinary meeting, has been established for all women diagnosed with breast cancer.
- The establishment of a breast care nurse team supported by a social worker. The breast care nurses:
 - provide care for all women along the treatment pathway
 - prepare women for the next stage of treatment
 - have streamlined processes
 - reduced women’s presentation at emergency department with problems
 - maximised the efficiency of outpatient appointments
 - act as co-facilitator with the social worker in an end-of-treatment group to assist women make the transition away from the treatment sector
 - implemented a model of care recognised by the organisation as both improving care and improving efficiencies, thereby offering basis for translation to other tumour streams.
- The lymphodema service provides both preventive and therapeutic services.
- The patient-held record enabled women to maintain an accurate record of their acute care.
- Established a consumer reference group, with a designated support worker. Group now well established and well placed to help organisation engage better with consumers in other tumour streams.

When we started with BSEP, I thought that we had a pretty good service. I couldn't see how we could make a difference. But now, I can't tell you how much it has improved.

Clinician

From this case study the following **critical success factors** were identified, many of which are shared with other programs:

- ✓ The unit head provided strong clinical leadership, a clear vision and a willingness to champion change.
- ✓ The clinical coordinator was fully engaged in all aspects of the program, provided significant on-the-ground support and promoted agreed initiatives.
- ✓ There was a strong breast services team committed to service improvement.
- ✓ Given its volume, the breast unit had a very high profile within the health service, enabling some of the more structural change to happen.
- ✓ The Program provided resources that allowed service providers time to think, develop ideas, explore possibilities and challenged them to aim high to further improve services.
- ✓ Resources for social work support for breast care nurses meant that problem areas identified by them could be researched, and improvement plans made and implemented. For example, the exploration of a depression screening tool (still to be implemented) and the end-of-treatment group are both initiatives with wider application to other tumour streams.

For more information on the sustainability of these initiatives, refer to *Supporting sustainable change*—another resource in this learning series.

However, while this service made substantial improvements in improving continuity of care, key challenges were related to the sustainability of the lymphoedema service and the breast care nurse team.

8 Learnings across continuity and coordination of care initiatives

The following summarises the broad learnings from across the range of Program initiatives to facilitate continuity of care for women with breast cancer.

- ✓ A systemwide, multifaceted approach is needed to improve continuity of care. Improvements may require action at various levels:
 - at the level of the individual client
 - at the team level
 - at the service level
 - at a whole-of-system level.
- ✓ Further service mapping—particularly of community-based services and the examination of the patient pathway from the patient’s perspective—may facilitate a systemwide approach to enhancing continuity of care.
- ✓ Significant Program achievements were identified in improving continuity of care for women focused at the level of the individual client and at team levels, which sometimes were supported by improvements developed at the broader service level. These broader service level improvements sometimes required significant executive support. A few initiatives had links with whole-of-system improvements (for example, the Enhanced Primary Care scheme).
- ✓ The capacity to further improve continuity for the individual sometimes depends on whole-of-system improvements. For example, service providers indicated that timely access to appropriate psychosocial support was constrained by the limited resources available within the acute and community sectors.
- ✓ Much of the work of the Program focused on improving the cancer journey for women with early breast cancer within the acute sector. Some achievements were gained facilitating coordination across the acute, primary and community health sectors. Only one initiative was commenced to strengthen coordination across the acute and palliative care sectors.
- ✓ Further work is needed to achieve substantial gains in continuity across acute care, the primary health sector, and community and palliative care sectors. Mechanisms to integrate and value the role of the general practitioner better into the multidisciplinary team is crucial.
- ✓ As part of the team, the breast care nurse plays a significant role in care coordination for women with breast cancer, particularly early breast cancer. Care coordination for women with advanced breast cancer requires further exploration.
- ✓ The breast care nurse role has evolved and strengthened over the last five years. However, one role cannot fill all system gaps, and challenges for the future remain. The experiences of the breast care nurse role in care coordination, along with those of other care coordinators in cancer or chronic illness, may inform the development of future cancer care coordinator roles.
- ✓ Given that continuity is a patient outcome, mechanisms to measure continuity in cancer care need to be explored. The consumer feedback tool currently being trialled within Victorian breast services may provide insight into how women’s perspectives on continuity of care can be assessed.

9 Useful resources

Unless otherwise indicated, the following resources and tools are available at www.health.vic.gov.au/cancer

Resources and reports

North Eastern Metropolitan Breast Services Enhancement Program. 2004. *The C-CARE Psychosocial assessment in the clinical practice of breast care nurses. Summary report of the multi-centre trial.* Victorian Department of Human Services.

Loddon-Mallee Breast Services Enhancement Program: *Multidisciplinary care guidelines for women with breast disease. A resource package for health professionals.* Available at www.breastservices.lmha.com.au/info/guidelines.

Final reports on specific Breast Services Enhancement Programs

Learning series resources

The following resources are part of this learning series:

- *Multidisciplinary care—improving consumer outcomes*
- *Building partnerships with consumers to improve service delivery.*
- *Supporting sustainable change*

The National Health Services Modernisation Agency (UK) has developed a series of Improvement Leader Guides on various aspects of organisational change to improve the patient’s journey through the health system. This series is available from: www.modern.nhs.uk/improvementguides

Other useful websites

Primary care partnerships (PCPs). PCPs are a major Victorian government reform program to improve the way primary care and community support services sector provide support services to the community. There are 31 primary care partnerships across Victoria, bringing together a range of local organisations.

www.dhs.vic.gov

PCPs have developed a comprehensive web based human services directory.

This is accessible on <http://humanservicesdirectory.vic.gov.au>

General Practice Divisions Victoria (GPDV). GPDV is the peak body for the 30 Divisions of general practice in Victoria. Some individual GP Divisions have local resource directories on their websites.

www.gpdv.com.au

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