Linking cancer care

A guide for implementing coordinated cancer care

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1. Introduction

Care coordination is a comprehensive approach to achieving continuity of care for patients. This approach aims to ensure that care is delivered in a logical, connected and timely manner so that the medical and personal needs of patients are met.

Coordinated care is an important part of management for all patients who require a variety of treatments and care, particularly when care is provided over time and between settings. This is often the case for people with chronic diseases or those who have a range of health problems such as heart disease, diabetes and arthritis. For this reason, there has been a focus by the states and the Australian Government on improving care coordination for patients with a range of chronic diseases.

For cancer patients, it is well known that the treatment journey is complex and challenging. It is not uncommon for these patients to be seen by many health professionals within and across multiple health services and across different health sectors including public, private and community health in both metropolitan and rural regions. Moreover, cancer patients need care over long periods of time – in some cases this may be years.

The demand for coordinated care in the cancer field has been heightened in light of the 2005 Senate Inquiry into Cancer Services. A number of jurisdictions have responded to the need for coordinated care by funding care coordinator positions. However, some health management and nursing experts have expressed concern about this 'default' approach given that this strategy diverts attention from the need for a 'whole-of-system' approach, and potentially creates a dependency and responsibility for care coordination on a limited number of individuals.

The Australian Better Health Initiative, which is a partnership between the states and territories and the Australian Government, aims to refocus the health system to promote good health and decrease the burden of chronic disease. Among its five priorities, the initiative aims to improve the coordination and continuity of care for people with chronic diseases, including cancer. A key aspect of this initiative is improved communication and integration between care services. This relates directly to the development of coordinated care and multidisciplinary care for cancer patients across Victoria.

Many factors need to be considered in developing and implementing a sustainable care coordination model, including current and projected workforce shortages in health care (and specifically in the oncology field) and the projected increase in cancer incidence and prevalence across Victoria.

2. The direction for cancer care coordination in Victoria

Victoria is committed to developing a 'whole-of-system' approach to cancer care coordination, which involves redesigning systems of care to foster and support relationship building between health services, health care providers and patients to ensure continuity of care for cancer patients.

Benefits to patients, health services and multidisciplinary teams

Improving care coordination has numerous benefits, some of which are tangible and evident in the short term, and others that will only become evident over time. Coordination of cancer care can:

- improve patient outcomes (when patients receive the appropriate care at the right time)
- improve use of recommended treatments, including increased referral to appropriate services and patient compliance (when system processes are known and used)
- improve communication between providers (when reliable and trusting relationships are built over time)
- streamline services, decrease duplication and reduce costs (when processes and communication are efficient and monitored or reviewed over time).

Purpose of the cancer care coordination policy

The purpose of this policy is to:

- identify strategic directions for cancer care coordination in Victoria
- promote the development and implementation of activities and initiatives that facilitate the coordination of cancer care at one or more levels of the health and community care system.

Statewide consultation and discussion with Integrated Cancer Services (ICS) has informed the development of this policy. The consultation included:

- the cancer care coordination workshop held in Melbourne in July 2005, organised by Cancer and Palliative Care in the Department of Human Services, Victoria
- the Patient Management Framework consultations held in each ICS in 2005
- meetings and forums within ICS to discuss the implementation of care coordination initiatives
- the Regional Integrated Cancer Services care coordination position paper.

3. Cancer reforms in Victoria

The need for improved delivery of cancer services along with improved outcomes for patients and their families has been identified as a priority by both state and federal governments. It is driven by:

- an ageing population leading to an increase in cancer incidence
- the increasing complexity in the diagnosis and treatment of cancer
- the impact that cancer has on individuals, their families and the community
- the increasing cost of cancer treatment
- · the shift of cancer treatment to the ambulatory care setting
- improved outcomes of current treatment regimes, resulting in increasing survival rates
- the ageing health service workforce.

Victoria has a significant cancer reform agenda that aims to improve the planning and delivery of treatment and support to patients so that appropriate care is provided in a timely manner as close to the patient's home as possible.

The agenda to improve the quality of cancer service delivery and patient care has been supported by:

- · establishing ICS to drive change
- determining a pathway of optimal care for a range of tumour streams (Patient Management Frameworks)
- developing a model for safety and quality in cancer care (Clinical excellence in cancer care: a model for safety and quality in Victorian cancer services)
- identifying four key priorities areas for reform.

Integrated Cancer Services (ICS)

In 2004, eight ICS were established with funding to support the development of integrated care and defined referral pathways for the populations they serve. The ICS are the platform through which improvements in cancer service delivery and patient care is being implemented.

Patient Management Frameworks

The Patient Management Frameworks (PMFs) are a guide to the optimal care management of patients in each tumour stream. They are intended to improve patient outcomes by facilitating consistent care based on evidence and best practice across the state. Care coordination is one of the key principles that supports the seven identified steps of the patient journey.

Further information about the PMFs can be found at www.health.vic.gov.au/cancer

Clinical excellence in cancer care

Clinical excellence in cancer care provides a vision for how high-quality cancer services need to be delivered. It describes the key principles and practices necessary for the effective monitoring, management and improvement of cancer services across Victoria. The model incorporates six clinical dimensions that are key to improving the safety and quality of care, one of which is continuity and care coordination.

Further information about Victoria's model for safety and quality in cancer services can be found at www.health.vic.gov.au/cancer

Key priority areas for service improvement

Four key priorities for reform have been identified and are the focus of service improvement initiatives at the ICS and statewide levels:

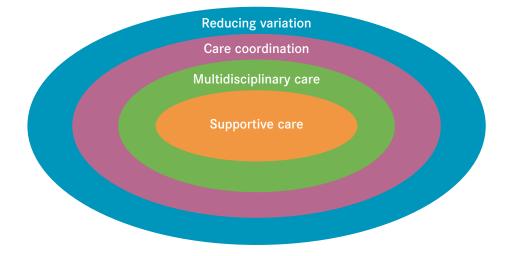
- · multidisciplinary care
- care coordination across the cancer care pathway
- · supportive care
- reducing unwanted variation in practice.

The four priority areas are integrally linked to each other with some initiatives impacting on more than one priority area (see Figure 1).

In the context of cancer, care coordination encompasses multiple aspects of cancer care delivery including multidisciplinary team meetings, supportive care assessment and the provision of required care, referral practices, data collection, development of common protocols, information provision and individual clinical treatment.

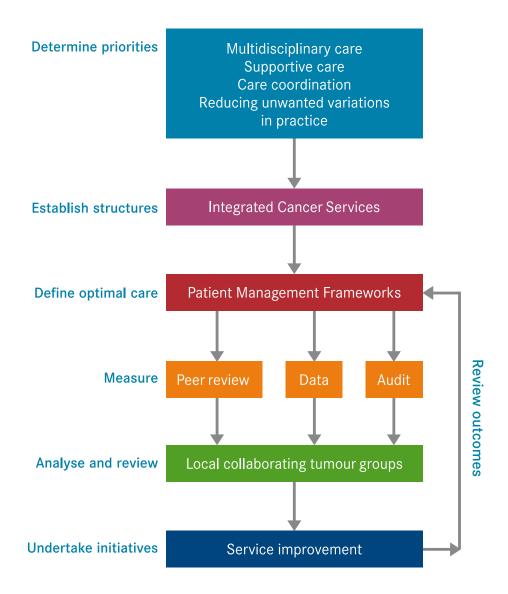
Multidisciplinary care is a key aspect of care coordination and further information on this area can be found at www.health.vic.gov.au/cancer. The interface between multidisciplinary care and care coordination are the processes and relationships between providers and between providers and patients.

Figure 1: The interface between the four key priorities for reform



The relationship between the various structures and components of the cancer reforms is depicted in Figure 2.

Figure 2: Systematic approach to quality in cancer services



4. Defining coordination in cancer care

Care coordination is a complex concept that health professionals have been grappling with in recent years due to the increasing sub-specialisation of the health workforce. The relationship between care coordination and continuity of care is often not clear – the two terms mean different things in different settings and are often used interchangeably.

It is important to clarify that **care coordination** *is a multi-faceted approach to achieving continuity of care*¹ *and that* **continuity of care** *is best viewed as an* **outcome of care** *as experienced by the patient*².

Ideally, a patient should experience their care as connected and coherent³ – that is, to have their care delivered in a logical and timely fashion, consistent with their medical and personal needs. Continuity of care is achieved for patients when a provider knows what has happened in the past, different providers agree on the management plan and a provider who knows them will care for them in the future⁷.

A care coordination approach needs to take into consideration the whole of the health system so that patients have:

- · access to a range of services
- · dependable service providers who are members of a multidisciplinary team
- · services that are available when they need them
- services that are flexible enough to meet their needs1.

5. Key principles for coordinated cancer care

The following principles have been developed to guide care coordination initiatives implemented at both statewide and ICS levels:

- patients, their families and carers affected by cancer are at the centre of care
- care coordination initiatives should take into consideration the continuum of care including the various health sectors involved in delivering care across tumour streams
- care coordination initiatives should take into consideration rural/regional and metropolitan contexts of care
- enhancing continuity of care across the health sector requires a whole-of-system response, that is, initiatives developed to address continuity of care need to occur across a number of key levels – that of the health system, health service, team and individual
- improving care coordination is the responsibility of all health professionals involved in the care of individual patients and should therefore be considered in their practice
- care coordination initiatives should support and complement the work of ICS and the cancer reform agenda of Victoria.

6. Strategic directions for cancer care coordination

Achieving well-coordinated care for cancer patients is a complex process. Based on the literature and learnings from the Breast Services Enhancement Program and other program areas, Victoria's strategic direction acknowledges the need to redesign systems of care as a way of ensuring care coordination becomes the function and responsibility of the whole health service and multidisciplinary team and not just the role of an individual (care) coordinator. This is to ensure that initiatives implemented address both the process by which care is delivered and the needs of the majority of cancer patients as they move through their pathway of care. This approach minimises the reliance on a single individual health care provider to achieve patient care coordination.

The strategic directions are based on three distinct but overlapping types of continuity described in the health literature. These are:

- strengthening information sharing where links are made between care providers and between health care events (such as electronic information transfer)
- **improving cancer service delivery** where services are delivered in a complementary and timely manner (such as shared treatment protocols)
- building relationships where links are made between past, current and future care³ (such as an agreed key contact for patients).

A variety of initiatives are successful in improving care coordination and these initiatives can be directed at a number of levels within the overall health system. Some initiatives may be directed at the **health system or ICS level**, such as development of referral protocols between a regional ICS and metropolitan ICS or between a metropolitan ICS and a range of community health centres within their region.

Other initiatives could be focused at the **health service level** such as modifying or enhancing a patient booking system or developing supportive care assessment and referral protocols for use by all health care providers caring for cancer patients. Initiatives directed at the **team level** include developing or enhancing multidisciplinary team meetings and treatment protocols for specific tumour streams. Initiatives directed at the **individual patient** or **individual health care provider level**, include developing personal patient records, information provision protocols or appointing case managers for patients with complex needs.

A matrix has been developed depicting the relationship between the levels of the health system and the approaches to continuity (see Appendix 1). This matrix provides some guidance for determining the focus of initiatives for improved care coordination.

Model for coordinated cancer care in Victoria

Victoria's model for coordinated cancer care incorporates the structures established to drive change (the ICS and local collaborating tumour groups) and the models that describe the requirements for optimal delivery of care that is safe, of high quality and consistent with best practice (see Figure 3).

Developing a 'whole-of-system' approach to continuity of care takes into consideration the potential synergy of activities that support the coordination of care for cancer patients across the various health care sectors and throughout their cancer journey.

The following list outlines the enablers and barriers that apply to developing initiatives in one or more of the strategic directions for coordinated cancer care.

Enablers

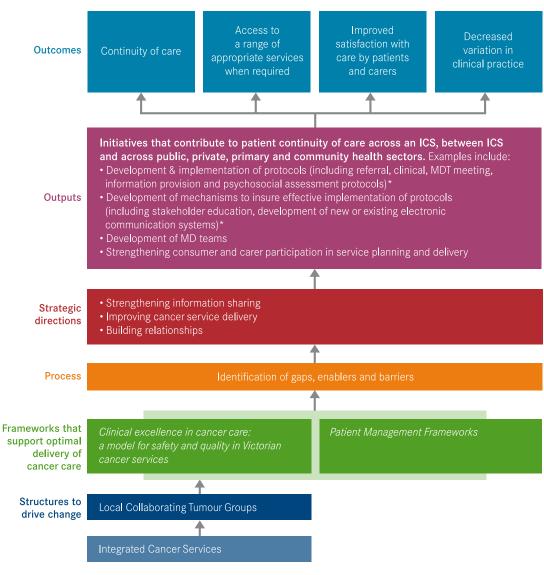
- Developing strong links between metropolitan ICS and regional ICS
- Local collaborating tumour groups
- · Multidisciplinary teams
- Patient Management Frameworks to guide the development of consistent cancer care across Victoria.

Barriers

- Limited capacity by health services to provide a full range of therapeutic services to all cancer patients, including supportive care
- Workforce constraints experienced by health care providers who need to manage volume and direct clinical care demands. This issue is prominent in rural cancer services where health care providers often take on a number of roles to meet the needs of their health services
- Lack of common protocols for both referral and clinical care domains across and between ICS leading to variation in referral pathways and care
- · Variation in knowledge of appropriate referral patterns or practices
- The culture of health services and health disciplines that influences referral practices
- · Lack of technology to support linkage between teams and health services
- Limited opportunity and capacity for multidisciplinary case conferencing to support care coordination
- Limited experience of the benefit of multidisciplinary care and in particular multidisciplinary team meetings
- Issues of distance and linkage of rural, regional and metropolitan sites
- Knowledge, accessibility and timeliness of available transportation for cancer patients
- The absence of clear links between public/private acute health and community sectors
- · Lack of consumer and carer participation in service planning and quality improvement processes
- The competitive nature of the current health care environment that challenges the development of a culture of shared responsibility and working across services

Historically continuity of care has focused on individual patient management rather than
taking a systemic approach that benefits the greater number of patients. This 'case management'
role is familiar to many in the health system and is perceived to be an all encompassing role
that can manage the coordination of individual patient care as well as manage the coordination
of activities that support the patient's journey through the system. This might include organising
multidisciplinary meetings, preparing discharge summaries or referrals to other health care providers.

Figure 3: Victoria's model for coordinated cancer care



^{*} Aspects of these care coordination initiatives are part of the Australian Better Health Initiative: A joint Australian, State and Territory government initiative

6.1 Strengthening information sharing

Informational continuity or the transfer of patient information between one provider and another and between care events is important at a number of levels. At the individual patient level it helps to minimise duplication (whether that be repetition of a person's medical and social history, or duplication of clinical services such as pathology investigations). At the team level, information sharing can support the development of an appropriate treatment plan that takes into consideration individual patient need. At a service level, sharing information between providers can assist timely access to services for patients and, for the providers, clinical databases can support clinical audit processes.

The **process** by which information is shared is equally important to the **content** of information shared and both need to be considered carefully in the context of strategies developed for improved care coordination.

The following box outlines a number of initiatives that support information sharing at various levels of the health system.

Initiatives to support information sharing include:

- comparing mapping data and information collected from ICS service mapping to the Patient Management Frameworks to enable identification of areas where improved information sharing between health providers and between health providers and patients is required
- developing multidisciplinary teams within ICS that include general practitioners
 and other relevant health care providers to facilitate continuity of care, consideration of
 supportive care needs in treatment planning as well as communication to patients and their
 carers
- developing multidisciplinary team meeting and treatment protocols to facilitate consistency of care delivered
- **developing referral protocols** that include agreed referral pathways, criteria for referral, mechanisms for referral and minimum information required for referral completion
- **developing documentation protocols** that include discharge documentation to facilitate transition between health care providers
- **developing information provision protocols** to ensure consistent information and communication to patients and between health care providers.

6.2 Improving cancer service delivery

Improved planning and delivery of cancer care is a key component of the Victorian cancer reforms. Efficient clinical management and care processes can assist patients to access timely and appropriate care as close to home as possible.

Two key components related to continuity of care are **comprehensiveness** and **accessibility**. This relates to patients receiving the appropriate range of treatments at the appropriate time in their cancer journey. Agreement between cancer services and providers on clinical treatment protocols and referral pathways (and developing relevant referral mechanisms) can help to streamline care. Developing multidisciplinary care and multidisciplinary teams and team meeting protocols can support such processes, as does establishing local collaborating tumour groups.

The **systems** and **processes** utilised for care are the focus of this strategic direction.

The following box outlines a number of initiatives that support the improvement of cancer service delivery at a number of levels.

Initiatives to support improvements in cancer service delivery include:

- strengthening governance and management structures within ICS to enable the examination of barriers and challenges around process requirements and support for care coordination initiatives
- developing and implementing initiatives that support the inclusion of the patient and carer experience to inform the planning, development and implementation of initiatives related to the cancer reform agenda
- using the PMFs in collaboration with knowledge of current cancer service delivery to identify current gaps and quality improvement initiatives required
- using funds allocated to the ICS to implement new or improved process and practice models for coordinated care that benefit the majority of cancer patients
- developing and implementing agreed treatment protocols across an ICS to support consistency in cancer care
- developing and implementing agreed referral pathways across an ICS and between ICS to support access to a range of appropriate services in a timely manner
- education, engagement and consultation with key stakeholders in service planning and development activities
- implementing *Clinical excellence in cancer care: a model for safety and quality in Victorian cancer services* to support the development of an ongoing quality improvement approach to cancer care.

6.3 Building relationships

Developing relationships between one provider and another and between providers and patients impacts positively on the planning and delivery of cancer care and is critical to strengthening information sharing. Good communication is an important part of the relationship-building process and helps to foster trust and patient participation in care decisions and implementation.

Dedicated care coordination roles are often perceived as the only mechanism through which care is coordinated. It is acknowledged that such roles already exist in a range of settings and that in cancer service settings the interpretation and implementation of current care coordinator roles varies widely based on location, volume and institutional focus.

The increasing subspecialisation of oncology nurses (such as breast care nurses or breast care nurse coordinators) adds to the complexity of defining and delineating the role of cancer care coordinators and distinguishing these roles from specialist cancer nursing roles that also have a coordination component.

Many of the functions required for coordination are not clearly or exclusively nursing roles and have a major administrative and communication component. This is evident in certain health care fields that place the general practitioner or even a family member/carer in the role of care coordinator.

The following box outlines a number of initiatives that support the improvement of cancer service delivery at a number of levels.

Initiatives to support the building of relationships include:

- establishing local collaborating tumour groups (with clinical leadership) into functional groups that inform and support the implementation and evaluation of care coordination initiatives within ICS
- developing multidisciplinary teams within ICS and between ICS
- developing multidisciplinary team meeting and treatment protocols to facilitate consistency of care
- clarifying and documenting the coordination components of health care providers' roles to support a team approach for achieving continuity of care for all cancer patients
- increasing use of technology for real-time intervention and decision making.

Appendix 1: Continuity of care matrix

The continuity of care matrix brings together the three approaches to continuity of care and the four levels within the overall health system. It provides a framework for identifying initiatives or activities that could be implemented at each level for each of the three approaches to continuity.

	Informational	Management	Relational
System	Links occur between one provider and another and between health care events across and between the ICS and are inclusive of primary and community care	Services are delivered in a complementary and timely manner between and across the ICS and are inclusive of primary and community care	Care is linked between past, current and future care events and between and across the ICS (inclusive of primary and community care)
	Electronic patient records	MoU between providers for delivery of specified services	Development of standards
Service	Links occur between one provider and another and between health care events throughout a health service and are inclusive of all health providers or disciplines	Services are delivered in a complementary and timely manner throughout a health service and are inclusive of all health providers or disciplines	Care events are linked along the continuum of care and between health services (inclusive of all health providers or disciplines) Service coordinators
	Enhanced documentation through medical records and letters between providers	Referral pathways and mechanisms	
Team	Links occur between one provider and another and between health care events across all disciplines involved in the care of cancer patients	Services are delivered in a complementary and timely manner across all disciplines involved in the care of cancer patients Agreed and shared	Multidisciplinary teams (or all disciplines involved in the care of patients with cancer) are informed about patients' care events along the continuum of care
	GP case conferencing management protocols	Recording and disseminating information	
Individual	Links occuring between one provider and another and between health care events are addressed at the individual health care	Services are delivered in a complementary and timely manner at the individual health care provider and individual	Individual patients or individual health care providers are informed about care events along the continuum of care
	provider and individual patient level Consumer information	patient level Patient involvement in management planning	Agreed key contact for patient at different phases of patient journey

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