Towards better care for all cancer patients in Victoria

Ministerial Taskforce for Cancer – Leading the way to a better approach to cancer

Action plan 2005-06

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Contents

Improving Victoria's approach to cancer

Cancer is the leading cause of death in Victoria, accounting for 28.9 per cent of all deaths in 2002[1]. It is a complex disease to diagnose and treat, and represents a significant burden to patients and their families, the health system, and the community at large. Cancer directly affects one in three men and nearly one in four women under the age of 75. Prostate, bowel, breast and lung cancer are the most common forms of cancer and cancer deaths.

Cancer treatment has changed dramatically over the past decade, with improvements in medical technology and a focus on early identification through increased public awareness and screening programs. This has resulted in more people being cured of cancer and a longer life for those who are not cured. However with the ageing of the population, the number of people being diagnosed with cancer is growing, and meeting the current and future demand for high quality care is a key issue for our community.

In 2000-01, the annual health expenditure due to cancer in Australia was estimated to be $2.76 billion[2], which represented about 5.5 per cent of the annual health care budget for Australia. Cancer also presents a significant financial burden to many families, which can impact on treatment choices and quality of life.

Many initiatives are taking place at both a state and national level to ensure that people with cancer have timely access to high quality services and treatment options, that care is coordinated, and that the social and emotional needs of patients and families are met.

The Victorian Government is working to make changes to our state based systems that will provide best possible cancer treatment and care to all Victorians, no matter where they live.

An ambitious agenda for change

The Victorian Government has developed a vision for an improved cancer system in its *Fighting Cancer Policy*[3] (launched November 2002) and the *Cancer Services Framework for Victoria*[4] (launched November 2003). Together, these documents provide a blueprint for the restructure, coordination, integration and development of cancer services and research across the state.

To help achieve these reforms, the government has formed the Ministerial Taskforce for Cancer. The Taskforce provides advice and leadership on how the government's vision can best be implemented.

The Taskforce provides a forum where the clinical community, government and people who have experienced cancer can work together to plan and implement effective, workable reforms to the cancer system.

A group of key minds from the cancer community

The Taskforce includes doctors, nurses, researchers, scientists and educators who have extensive expertise in cancer research and treatment, as well as people who have experienced cancer.

Together the group brings a wealth of knowledge and expertise in all aspects of cancer control to provide strategic leadership to the rest of the cancer community and the government.

They are people with a strong commitment to improving cancer care, and to ensuring that the reforms in Victoria are achievable.

Leading the way to a better cancer system

The Taskforce's role is to lead the way to improving cancer outcomes in Victoria by:

- advising on how to improve patient care, including the integration of cancer services across the state and improving the quality and accessibility of services
- forging better links between government, national cancer bodies, and cancer initiatives in other states
- advising on processes to coordinate cancer research and translate its results into better treatment, including investigating the benefits of an organisation that could help achieve this
- strengthening the collection of information on cancer and the results of cancer treatment that will help us to improve treatment and research.

A partnership with government

The Taskforce works closely with the Department of Human Services and the Department of Industry, Innovation and Regional Development. The Department of Human Services has primary responsibility for the implementation of the cancer reforms and works in collaboration with the Department of Industry, Innovation and Regional Development on the cancer research agenda.

The Department of Human Services has established a Cancer Coordination Unit to facilitate the coordination of cancer related initiatives across the department. The Unit provides secretariat support for the Ministerial Taskforce for Cancer.

Our vision is that anyone who has cancer should have access to best practice treatment and care, no matter where they live in Victoria

Our vision

We want to improve the results and outcomes for cancer patients, including:

- preventing secondary cancers and recurrence of cancer, wherever possible
- promoting appropriate management at diagnosis and during treatment to ensure the maximum number of years of healthy life for cancer survivors
- minimising preventable pain, disability and psychosocial distress for those living with, through and beyond cancer
- ensuring that cancer survivors and their families get the support they need to cope with their disease.

The Taskforce's objectives are that:

- anyone who has cancer should have access to best practice treatment and care, no matter where they live in Victoria
- services should have a strong evidence base for action, and should be centred on meeting the needs of patients and their families
- everyone involved in cancer treatment, care and research works together to develop the best treatment, and to plan and carry out relevant research that will enable ongoing improvements to treatment and extend our knowledge about cancer.

The challenges

Improve cancer services

There are many strengths of cancer services in Victoria, including innovative approaches to radiotherapy in regional Victoria, a track record of improving breast cancer services based on patients' needs, and a strong network of clinical expertise through the Victorian Cooperative Oncology Group (VCOG). However there are also opportunities for further improvement in the areas of coordination of cancer services, adherence to established clinical practice guidelines, referral to appropriate treatment centres, and better planning at both a local and statewide level to meet the needs of cancer patients[4].

Work together more effectively

A major issue we face is that care is not always fully integrated and there are gaps. Fragmentation of services, the lack of clear referral pathways, clinicians practising in isolation in both the public and private sector, and the absence of support services in many parts of Victoria all contribute to suboptimal care for some cancer patients[4,5].

We need to develop a greater sense of unity, and improve coordination and collaboration across the cancer sector, so that we are working together to improve cancer treatment and outcomes.

The *Cancer Services Framework for Victoria* outlines a plan for structural change to achieve this, by creating networks of integrated services based on specified geographical areas. These Integrated Cancer Services will ensure that people with cancer are diagnosed and treated promptly, and that general practitioners, hospitals and community health services work together to deliver optimal care to the populations they serve.

Improve consistency and quality of care throughout the state

We need to ensure access to best practice care throughout Victoria by introducing consistent standards, creating better links between services, and by identifying and closing gaps in services.

We need to ensure that treatment is patient centred and based on evidence, and that health services, general practitioners and patients understand which cancers can safely be treated locally, and when it is important to receive more highly specialised care in a larger hospital.

This can be achieved by:

- ensuring care is delivered in accordance with national and international guidelines for the management of different types of cancer[6,7,8,9,10]
- adopting a systematic approach to monitoring performance, and by having clear role designation for hospitals which describes the types of treatment they can offer[4].

We need to identify a set of minimum standards for cancer treatment at all stages of a patient's cancer journey and ensure that these standards of care are met for every cancer patient, no matter where they live[4].

Optimise our research effort

Victoria has a distinguished record in cancer research, including a number of excellent research institutes, outstanding scientists, a commitment to fostering clinical trials through VCOG and a range of cancer research consortia, and the highest number of patients on clinical trials across Australia. However more could be done to ensure that the results of our research, and research from around the world, are translated into the better care of patients.

We need to develop and support a strategic direction for our cancer research that will optimise our efforts, and ensure that research across Victoria is well coordinated. This can be achieved through the development of a dedicated support and coordination function to encourage partnerships of all the relevant research groups.

We need to ensure that the experience of people with cancer and their treating clinicians can be translated into research questions in a systematic way, so that research remains relevant to cancer treatment and care.

We also want to improve the translation of research findings into prevention, early detection and treatment of cancer, and further increase the numbers of Victorian cancer patients participating in clinical trials.

Improve cancer data and information management

Understanding and monitoring whether cancer treatment is effective is critical to improving care, and maximising the chance of cure. Currently the Victorian Cancer Registry collects information about all new diagnoses of cancer, and monitors cancer deaths[1], but we are unable to pinpoint with precision which cancer treatments are most effective for different types of cancer.

Advances in information management and technology have revolutionised the options for improving health information. We need to explore new ways to improve the collection of information about cancer management and outcomes so that we know if and when treatment is making a difference.

We also need to support health services in the management of their patients with cancer to ensure that everyone is receiving the highest possible levels of care and support, and that people with cancer don’t have to repeat their stories or attend for unnecessary appointments.

How we are achieving this vision

This action plan has been produced after the Taskforce has been active for approximately one year and has just over 18 months left of its initial term.

This section outlines our priority areas, what we have achieved to date and the key deliverables for 2005-06.

A further plan will be produced in early 2006. The Taskforce will continue until November 2006, however, our agenda is long term and we are focussing on putting in processes that are sustainable over time.

The Taskforce has identified three priority areas: clinical services, research and data/information. Working groups comprising Taskforce members and a small number of other key stakeholders have been established to provide leadership and focus to achieving our goals in each of these three areas.

Summary of activities 2003-04	
Cabinet appointed the Taskforce on 10 November 2003 for three years	
First meeting – 15 December 2003	• Establishment of three working groups in the areas of clinical services, research and data/information
Initial workshop – 9 March 2003	• Terms of Reference confirmed
	• Working groups established priorities and commenced work on various initiatives
Clinical Services Working Group	• Conducted a Patient Management Framework workshop to develop a series of tumour specific frameworks that map a patient's optimal journey through the health care system. The frameworks will be used to guide the development of services in accordance with best practice
	• Developed a proposal to increase and support the involvement of people who have experienced cancer in service reform
	• Instigated a literature review surrounding the evidence for the effect of hospital/clinician volume and specialisation on outcomes in cancer care
Research Working Group	• Conducted inaugural Translational Research seminar and workshop
	• Funding for the Business Case for the STI (Science, Technology and Innovation) grant submission to establish a Tissue Bank for Victoria, as a statewide resource for researchers and clinicians. As understanding of the genetic and molecular bases of cancer is developed, these stored tissue samples can be used to determine future treatment programs for individual patients and groups of patients
	• Development of a survey tool to identify cancer research activities in Victoria
	• Scoping of the role for a Cancer Research Support and Development Agency
Data/Information Working Group	• Completed survey of relevant clinical data collections in hospitals in Victoria
	• Conducted a feasibility study of a clinical data collection system using the National Cancer Control Initiative minimum data set

Strategic priority: Improving clinical services

The Clinical Services Working Group is focussing on improving clinical services to ensure the right treatment and support is provided to all patients as early as possible in their cancer journey, no matter where they live in Victoria.

Working to ensure that all patients can access best practice treatment, no matter where they live

Priority areas for the Clinical Services Working Group are:

Developing an integrated approach to cancer care

The *Cancer Services Framework* outlines a model of integrated services that divides the state into eight regions where hospitals, primary and community health services work together to provide integrated care for the communities they serve.

Three metropolitan and five regional Integration Cancer Services (ICS) have been established. Within each ICS, the goal is that services will work effectively together so that patients can access a full range of local services from prevention, screening, diagnosis, treatment, rehabilitation, supportive care and palliative care. ICS will also ensure that the care provided will be multidisciplinary and well coordinated, and that shared service planning will allow for ongoing improvements.

Developing care through ten tumour streams

Clinical treatment and care will be delivered through ten streams (as outlined in the *Cancer Services Framework for Victoria*), with each stream focussing on a particular type of cancer. This will enable us to focus expertise in particular areas, reduce variations in care and promote best practice.

We will develop evidence based standards of care for each tumour stream, to ensure consistency across the state. We will also encourage the ICS to develop shared protocols, to collaborate in service improvement, planning and resource allocation, and to promote a networking approach to cancer care and development through the establishment of tumour groups.

Developing statewide approaches to service improvement

The importance of a multidisciplinary approach to cancer care, the need for mechanisms to ensure coordination of care, and the requirement for appropriate support services for patients and families are strongly emphasised in all the national clinical guidelines as key priorities for improving cancer care. In addition, workforce training and support, mechanisms to ensure early diagnosis and referral, caring for patients with advanced cancer and improving accountability are important areas for service improvement across all tumour streams.

The Working Group is:

- developing Patient Management Frameworks for each tumour stream to guide the development of consistent care across the state
- identifying gaps and priority areas for future service development
- determining how we will develop best practice standards for each stream
- developing options for supporting a statewide approach to networking within and between tumour streams
- exploring the development of a role designation framework to outline which cancers can safely be treated at local hospitals, and when it is important to receive more highly specialised care in larger centres
- developing longer term options for accreditation of cancer services, as outlined in *A Cancer Services Framework for Victoria*[4].

Key deliverables: clinical services

2005

- Workshops held to draft Patient Management Frameworks to improve palliative care, supportive care and haematological cancers
- Draft Patient Management Frameworks available for consultation by cancer community
- Patient Management Frameworks finalised and published
- Process for local and statewide tumour groups and/or networks established
- Priorities and process for developing statewide best practice standards
- Developing ways to increase the participation of people who have experienced cancer

2006

- Develop a role designation structure in conjunction with ICS, to outline where services will be within each ICS
- Referral pathways established for all tumour streams
- Best practice standards developed in priority tumour streams

Strategic priority: Coordinating cancer research

Cancer research is essential to identify how we can improve prevention, diagnosis, treatment, services and management of cancer.

The Cancer Research Working Group aims to provide a strategic approach to research activity across Victoria to optimise the research endeavour and to maximise research outcomes and their translation into better treatment and care.

It is focussing on ways to integrate, coordinate and develop cancer research in Victoria, and to connect research centres and health services to achieve these aims.

Looking at ways to better integrate and coordinate research efforts across the state to maximise results

Priority areas for the Cancer Research Working Group are:

Developing a strategic approach to cancer research

Identifying existing research activities in Victoria, including opportunities for improvement, via a Cancer Research Survey.

Developing a cancer research strategy for Victoria.

Developing and supporting cancer research

Establishing priorities for enhancing cancer research infrastructure in Victoria.

Advising on the establishment of an agency to support and develop cancer research and its translation into better treatment.

Streamlining Ethics Committee processes to facilitate patient and clinician participation in clinical trials.

Translating knowledge from research into care and services

Developing strategies to enable the integration of research and clinical services.

Enhancing the status of Victoria as a national and international leader in translational research.

Key deliverables: research

2005

- Cancer Research Survey finalised and report prepared
- Supportive and psychosocial care research seminar held and report finalised
- Proposal to streamline ethics committees processes for multi centre cancer research in Victoria developed
- Draft Cancer Research Strategy for Victoria developed
- Proposal for the establishment of a Victorian Cancer Research Support and Development Agency prepared
- Report on the seminar and workshop on Translational Research in Cancer finalised

2006

- Cancer Research Strategy for Victoria finalised
- Milestones for establishing a Victorian Cancer Research Support and Development Agency approved and accepted
- Procedures to streamline Ethics Committee approval for multi centre cancer research agreed and approved

Strategic priority: Data/information

Collecting accurate information and using this to inform cancer treatment, service development and research is critical if we are to improve survival and quality of life outcomes for cancer patients.

The Data/Information Working Group is focussing on developing mechanisms to support the development of cancer data collections. These data are required for quality improvement, performance monitoring and reporting, benchmarking for clinical practice, and research. The data need to be timely, accurate, based on consistent definitions and available on a regular basis, at both hospital level and statewide level. They also need to support the coordination of patient care, and be linked into existing and future hospital administration systems.

Collecting quality data is critical if we are to improve treatment and services

Priority areas for the Data/Information Working Group are:

Improving data collection and information management

Improving the range and quality of data collected in local settings and then aggregated across the state.

Improving data and information collected at various stages of treatment so that different aspects of care can be monitored and coordinated.

Exploring data ownership and privacy issues which impact on our ability to provide integrated care.

Promoting the collection of the National Control Cancer Initiative (NCCI) Core Clinical Cancer Dataset, which has been agreed at a national level as the minimum clinical data requirement in cancer.

Developing better reporting structures

Creating a culture of reporting on the quality of treatment and care, so that services can be reviewed and improved to ensure all patients receive optimal care.

Establishing benchmarks to lead best practice

Developing mechanisms to collect and monitor appropriate performance indicators and standards of care, which will be developed across tumour streams.

Identifying potential benchmarks for surgical oncology, chemotherapy, palliative care and supportive care to ensure best practice across the state.

Key deliverables: data/information

2005	2006
• Promote collection of the NCCI Core Clinical Cancer Dataset	• Develop a proposal for ongoing statewide data collection systems
• Pilot the collection of the complete NCCI data set at a small number of hospitals	• Propose mechanisms to collect and monitor performance indicators developed in a number of tumour streams
• Scope the data collection and information management issues that impact on care coordination within and across health services	• Identify benchmarks for surgical oncology, chemotherapy, palliative care and supportive care

How the cancer reforms make a difference

What will this mean for cancer patients?

Cancer patients will be referred to services that have the right skills and resources to treat their particular type of cancer, as close to their homes as possible. Hospitals and community based health services in the same area will work together to provide coordinated care and support for patients. Networks of cancer services across Victoria will ensure that specialist care is available to all cancer patients, and that consistent high standards of care will apply to all cancer services.

Meeting the needs of cancer patients and their families will be given a high priority. All Integrated Cancer Services will work with patient advocates and consumer representatives in the community to ensure that patients and families are well supported throughout their cancer treatment, through living with cancer, and in the later stages of cancer.

What will this mean for cancer clinicians?

Doctors, nurses and all health professionals involved in the treatment and care of cancer patients will work in supportive networks (tumour streams) with other clinicians treating the same cancers, and across specified geographic areas (Integrated Cancer Services).

Cancer clinicians will be able to better coordinate the treatment and care of their patients, and to more closely monitor the results of treatment.

Cancer clinicians will have the opportunity to share expertise, ideas, protocols, and quality improvement approaches. There will also be opportunities for collaborative projects and participation in clinician lead research initiatives and multicentre clinical trials.

What will this mean for cancer research?

Cancer research in Victoria will be well coordinated and positioned to participate in international research projects and trials. There will be a core infrastructure for developing and supporting research, including the commercialisation of Victorian innovations.

Researchers will be provided with opportunities to work alongside clinicians in planning and carrying out a range of research activities. This will enable research to be more rapidly translated into clinical practice, and will ensure that research remains relevant to current cancer management issues.

Get involved

The Taskforce is committed to broad community involvement in the reform process.

We seek the participation of health services, clinicians, people who have experienced cancer, researchers and others involved in cancer in our community – both formally through working parties and informally through networks – to ensure that the best possible outcomes are achieved for people with cancer in Victoria, both now and in the future.

For more information about the Ministerial Taskforce For Cancer, please contact: 03 9616 2135 or visit www.health.vic.gov.au/cancer. This website is regularly updated with information about progress and initiatives, and contains a current listing of Taskforce members.

Taskforce activities are also featured in the quarterly newsletter *Cancer Bulletin*, which is produced by the Cancer Coordination Unit, Department of Human Services. Please contact the Cancer Coordination Unit on 03 9616 2136 to subscribe.

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The Ministerial Taskforce for Cancer provides strategic advice and leadership to improve cancer services and research throughout Victoria.

Our vision is that anyone who has cancer should have access to best practice treatment, no matter where they live in Victoria.

That everyone involved in cancer treatment, care and research works together to develop the best treatment available, and to plan and carry out relevant research that will enable ongoing improvements to treatment and extend our knowledge about cancer.

This action plan reports on our activities and achievements to date and our plans for the remaining term of the Taskforce.

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