

A CLINICAL SERVICE  
FRAMEWORK FOR

# Optimising Cancer Care in NSW

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2003

*‘to provide optimal  
cancer management  
for all patients  
requiring care’*

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# Foreword

Cancer is a major cause of morbidity and mortality in NSW. Incidence rates for cancer have increased by almost 25% between 1980 and 2000. In NSW in 2000, there were 28,889 new cases of cancer diagnosed, and 12,185 deaths from cancer.

Patients suffering from chronic and complex conditions such as cancer are entitled to high quality best-practice standards of care, and to care that is well coordinated throughout their cancer journey. For this reason, we are pleased to endorse *A Clinical Service Framework for Optimising Cancer Care in NSW*.

The framework builds upon the significant achievements of the NSW Health Optimising Cancer Management Initiative, including the *Cancer Care Model for NSW* introduced in 1999 for implementation across all Area Health Services. The framework is an important recommendation of the NSW Chronic and Complex Care Report *Improving health care for people with chronic illness – A blueprint for change 2001-2003*. It incorporates the aims of the Chronic Care Program to achieve more integrated, coordinated and patient-focused approaches to address the health care needs of people with chronic illness.

We commend the work of the Clinical Expert Reference Group for Cancer and the Special Interest Group for Cancer co-chaired by Associate Professor Paul Harnett and Dr Tom Acheson, the Newcastle Institute of Public Health, the Centre for Health Research and Psycho-oncology, and numerous affiliated health professionals throughout the NSW Health system. Their combined knowledge and expertise have contributed to the development of this framework.



Professor Ronald Penny AO  
**Co-Chair, CCCICG**



Robyn Kruk  
**Director-General**



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# Executive summary

## Background

There is global consensus that health services for people with chronic and complex conditions such as cancer need to be configured to provide more integrated, coordinated and patient-focused approaches across all health sectors and stages of care. It is also recognised that there should be equity of access to all appropriate services.

'A Cancer Care Model for NSW' was developed as part of the NSW Department of Health's Optimising Cancer Management Initiative in 1999. The document outlined an organisational model for optimal delivery of cancer services in NSW, comprising population health services, Cancer Units and Comprehensive Cancer Centres linked by formal networks and strategic alliances. This clinical service framework gives form to the Cancer Care Model and sets clear standards for cancer service delivery.

The framework has been developed as one of various initiatives being undertaken by the NSW Chronic Care Program, established in 2000 to improve the quality of life for people with chronic and complex conditions and their carers and families. Other initiatives include a personal health record and a number of Priority Health Care Programs in Area Health Services developing improved models of care.

## Structure of the framework

This framework outlines seven broad topics, each with key objectives and standards (Section 2). Further information that may be helpful in implementing the standards is included in each section. Timeframes for compliance are specified for each standard. Methods for monitoring the implementation of the framework are outlined in Section 3.

## Key objectives

The foundation standards in this framework have been developed to achieve the following key objectives:

### Standard 1 – Implementation, monitoring and review of standards for cancer care in NSW

To ensure that *A Clinical Service Framework for Optimising Cancer Care in NSW* is implemented across NSW, and is regularly reviewed and updated.

### Standard 2 – An Area-wide approach to optimising cancer care

To establish an effective management group for cancer services in each Area Health Service, with clear leadership, membership and scope of activities.

### Standard 3 – Patient-centred care

- To ensure that cancer patients and their carers have access to the level of information and support they require to assist them through their cancer journey.
- To ensure that cancer patients receive care that is coordinated throughout the continuum of care.
- To minimise the physical and psychosocial impact of cancer on patients.
- To provide care that is tailored to meet specific physical and psychosocial issues identified by cancer patients and their carers through a process of routine assessment.

## **Standard 4 – Access to appropriate clinical services**

- To ensure access to the full range of appropriate treatments, whilst minimising anxiety and stress, and delays in investigation, diagnosis and treatment of cancer.
- To ensure that cancer services are managed and organised effectively to support high quality care.

## **Standard 5 – Multi-disciplinary care**

- To ensure that all patients have access to a multi-disciplinary care approach throughout the continuum of care.
- To ensure that designated specialists work effectively together in teams to make multi-disciplinary recommendations to primary treating clinicians regarding the diagnosis, treatment and care of individual patients.

## **Standard 6 – Communication between primary, secondary and tertiary services**

- To ensure effective communication between all levels of care through the development and implementation of
  - Clear local arrangements for smooth and timely progression of patients and their carers between all care settings.
  - Mechanisms to ensure information about individual patients is shared by all involved in that patient's care.

## **Standard 7 – Education, training and continuing professional development**

- To ensure that all health care professionals in the cancer workforce maintain high quality skills and competencies in oncology.
- To ensure that mechanisms are in place for all health care professionals in the cancer workforce to participate in multi-disciplinary continuing professional development irrespective of geographical location.
- To provide opportunities for health care professionals not in the cancer workforce to:
  - enhance core skills and competencies in cancer and cancer related complications and
  - understand the pathways for entry into the cancer care program.

## **Assessing progress**

Compliance requirements for implementing the standards are clearly stated in this framework, and will be monitored in a systematic manner. As progress is made in meeting compliance requirements for the foundation standards, further work will be undertaken by the NSW Health Cancer Clinical Expert Reference Group and Area Directors of Cancer Services to identify new objectives and develop further standards.

## **Conclusion**

The success of this framework in meeting its key objectives depends on the strong and demonstrated commitment of the NSW Department of Health and each Area Health Service. This will involve supporting implementation of the framework, and active participation of the cancer workforce, in both hospital and community settings, to improve service provision for all patients with cancer in NSW. Close collaboration and firm commitment by all participants in the process of providing cancer care will ensure that NSW progresses further towards its goal *'to provide optimal cancer management for all patients requiring care'*.

# I. Introduction

Cancer is the second most common cause of disease burden in males and females in NSW (after cardiovascular diseases). It accounts for just under one-fifth of years of healthy life lost due to premature death, disease and injury. In NSW in 2000, there were 28,889 new cases of cancer (54% in males), and 12,185 deaths from cancer (56% in males). Between 1980 and 2000, the incidence rates for all cancers rose by almost 25% (20% in males and 25% in females) (Public Health Division, 2002).

The increase in incidence rates for all cancers in NSW over the last 30 years is due to a range of factors including earlier diagnosis of some cancers from increased screening, a real rise in new cases of some cancers, and improved notification of cancer cases. Reduced death rates for all cancers over the last decade reflect successful treatment of some cancers, and the cumulative effect of small decreases in deaths for others.

The key stages of cancer control and management include prevention, screening, diagnosis, treatment, rehabilitation, survivorship and palliative care. In NSW cancer services are delivered by public, private and community organisations in a range of settings including hospitals, doctors' rooms, general practice, community health centres and the home environment.

There are often insufficient links between diverse service providers in cancer care. This compromises coordination, continuity, convenience and cost-effectiveness of patient care. Some of the problems experienced by people with cancer include having to repeat their medical history every time they see a new health care provider, having tests repeated because the results of tests performed by other service providers are unavailable, having difficulty in accessing relevant and reliable information, and travelling long distances to access services.

Various reports state that service provision for people with cancer needs to improve. This is to ensure that consistent and high standards of cancer care and evidence-based best practice are available to all NSW residents regardless of geographical, socio-economic or cultural considerations (NSW Health, 2001a; NSW Health, 1999a).

## Optimising Cancer Management Initiative

The reference point for a statewide clinical service framework for cancer is the Optimising Cancer Management (OCM) Initiative in NSW (NSW Health, 1999b). This Initiative originated from a recommendation of the Cancer Expert Advisory Group in 1995, which was to provide optimal cancer management for all patients requiring care.

Strategies under the OCM Initiative were grouped into four streams:

1. Integration and coordination of cancer services
2. Promotion of patient-centred care
3. Development of information systems for monitoring quality and outcomes in cancer care
4. Development and implementation of clinical practice guidelines.

A *Cancer Care Model for NSW* (NSW Health, 1999) was developed as part of the OCM Initiative. This outlined an organisational model for the delivery of cancer services in NSW. The model was designed to support best practice for cancer patients throughout the continuum of care. The model proposed a reconfiguration of key service delivery components comprising population health services, Cancer Units (Level 4, district metropolitan or major non-metropolitan referral hospitals) and Comprehensive Cancer Centres (Level 6, major metropolitan referral or principal referral hospitals) (NSW Health, 2002).

# I. Introduction

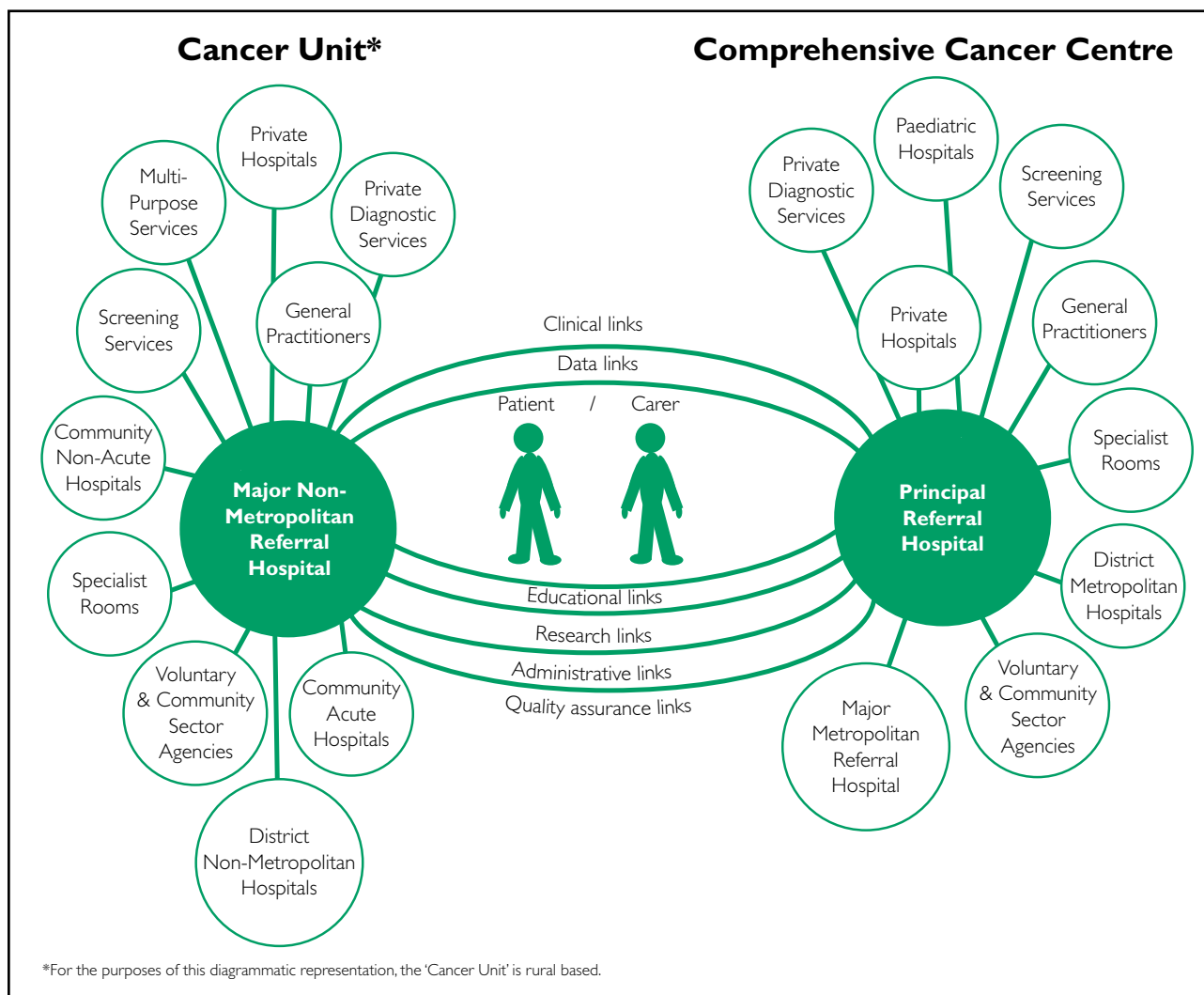
The model recommended the setting up of formal networks and strategic alliances between and within Area Health Services. These would ensure a population-based approach for planning, delivery and evaluation of cancer services, and provide a framework for disseminating information and approved technology.

A number of Area Health Services have since developed Cancer Service Plans. These draw on the NSW Health service planning and development requirements that promote the implementation of the Cancer Care Model. Networking with other Areas, where services are not provided locally, is a requirement for the plans.

Progress is continuing in meeting the goals of the Optimising Cancer Management Initiative. This includes establishing Cancer Care Centres

at Nepean and Liverpool Hospitals, and the continued expansion of radiotherapy services within the Cancer Care Model framework in NSW. Other initiatives include the NSW Radiotherapy Information Strategy which is implementing integrated information systems in Radiation Oncology Departments at eleven radiotherapy sites in NSW hospitals. This continues the Radiation Oncology Information, Management and Technology Strategic Plan, 1998. Further details are available at [www.ciap.health.nsw.gov.au/project/radonc/docs/IMTPlan.doc](http://www.ciap.health.nsw.gov.au/project/radonc/docs/IMTPlan.doc). A project to identify and document information needs and functional requirements for medical oncology information systems began in August 2002. A *NSW Clinical Cancer Data Collection for Outcomes and Quality Data Dictionary* was published by NSW Health in 2001 (Public Health Division, 2001).

**Figure 1: Cancer Care Model for NSW** (from A Cancer Care Model for NSW, NSW Health, 1999)



## NSW Chronic Care Program

New and advancing medical technologies, improved longevity and an aging population have significantly changed health service systems in countries such as Australia. The emergence of chronic health problems such as cancer, cardiovascular and chronic respiratory disease and associated increasing health care needs are an example of this change. At the same time, the culture and structure of health service delivery systems in Australia have mainly focused on acute care. As a result, there are often insufficient links between primary, community and acute health care services for people with chronic and complex conditions.

The Chronic and Complex Care Implementation and Coordination Group (CCCICG) was established in 2000 under the Government's Action Plan for Health, based on recommendations made by the NSW Health Council (NSW Health, 2000a) and the Ministerial Advisory Committee on Health Services in Smaller Towns (NSW Health, 2000b).

The NSW Chronic Care Program overseen by the CCCICG has three broad aims to:

1. Improve the quality of life of people with chronic and complex conditions
2. Improve the quality of life of their carers and families
3. Reduce the number of crisis situations and avoidable presentations or Emergency Departments and hospitals.

Evidence-based practice and initiatives have been identified by the CCCICG in conjunction with the Clinical Expert Reference Groups. These include strategies that will best contribute towards the prevention of chronic disease and the way in which care is provided for people with chronic illness, such as the:

- development of evidence-based statewide clinical service frameworks incorporating best-practice standards of care for consistent high-quality chronic and complex disease management. The frameworks cover the continuum of care from prevention, early detection and diagnosis, supported self-care,

management and treatment interventions in the community to acute and palliative care. Further they span the spectrum of illness in terms of severity and progression

- development and implementation of a personal health record, *My Health Record*, for every patient in NSW with symptoms of chronic illness. *My Health Record* will assist patients in monitoring and managing their illness and provide ready access to health related information such as diagnostic test results, current medication regimens, emergency contact details and other important information
- provision of 24-hour contact with health professionals to enable immediate access to acute care services, as well as professional information, education and advice, if and when required.

Recommendations have also been made for the following:

- The need to improve coordination of care and develop closer collaboration between the acute care, and primary and community health care sectors. This includes developing good working partnerships with general practitioners.
- Promoting the use of Medicare Benefits Schedule Enhanced Primary Care (MBS EPC) items for case conferences and health assessments and developing care plans for people with chronic and complex health care needs.
- Ongoing involvement of clinicians (and patients and carers) in service planning processes to ensure resources target changing health care needs.
- Streamlining admission and discharge planning processes for all patients with chronic and complex conditions.
- Improving workplace practices in Emergency Departments, for example reducing waiting times by the use of fast-track triage systems.
- Education programs promoting patient self-management for patients and health care professionals. The participation of carers in self-management education programs should also be encouraged.

## Clinical Service Framework for Optimising Cancer Care

*A Clinical Service Framework for Optimising Cancer Care in NSW* sits between the Optimising Cancer Management Initiative and the NSW Chronic and Complex Care Program. It draws together evidence and clinical expertise to describe a sound framework to ensure delivery of optimal quality cancer services throughout NSW.

*A Clinical Service Framework for Optimising Cancer Care in NSW* provides further detail on the operation of the Cancer Care Model at an Area Health Service level to optimise care for all cancer patients in NSW.

The framework's goal is to assist Area Health Services and clinicians in optimising cancer care by:

- setting standards of care, both clinical and organisational, for managing patients with cancer
- describing the optimal structure of a cancer service to ensure equitable access to best practice care for all
- establishing initial milestones, goals and performance indicators against which progress within agreed timeframes can be measured
- identifying practical tools to support implementation and monitor progress.

The framework establishes foundation standards for optimal delivery of cancer services in NSW. In doing so, it draws upon and develops many elements from the UK National Health Service Executive *Manual of Cancer Services Standards* (NHS, 2000). As with the Optimising Cancer Management Initiative, the scope of this framework does not include cancer prevention strategies, but rather focuses on optimising care for those who have already been diagnosed with cancer.

This framework complements the recommendations of a recent consultative report *Optimising Cancer Care in Australia* by the Clinical Oncological Society of Australia, The Cancer Council Australia and the National Cancer Control Initiative. The report addresses issues surrounding quality, access and resourcing of cancer services at a national level (NCCI, 2003).

The key objectives of *A Clinical Service Framework for Optimising Cancer Care in NSW* include the establishment of:

- Formal and effective management groups for cancer services in each Area Health Service, with clear leadership, membership and scope of activities (Standard 2).
- Specific initiatives that promote patient-centred care, including provision of information packs and personal health records, development of a consent form, and use of care coordinators for appropriate patients (Standard 3)
- A multi-disciplinary care approach, and development of Area-wide site-specific clinical groups and multi-disciplinary teams (Standards 4 and 5).
- Limits to waiting times and regular waiting time monitoring (Standard 4).
- Processes to encourage and facilitate the involvement of general practitioners at all relevant stages of care (Standard 6).
- Mechanisms to promote continuing professional development for all clinical and non-clinical members of the cancer workforce (Standard 7).

The framework standards require overall compliance by June 2005. A schedule for demonstration of compliance with these standards is in Section 3. Development of standards for the period after June 2005 will be undertaken by the NSW Health Clinical Expert Reference Group with the Area Directors of Cancer Services.

# Standards

## 2. Cancer standards

### Introduction

The following standards for cancer services have been developed following extensive consultation, to facilitate consistency and best practice in the management of people with cancer. An evidence-based approach has been used to integrate best research evidence with clinical expertise and patient values.

These standards are based on a generic cancer services approach rather than dealing with aspects of the service delivery for and clinical management of site-specific cancers. Guidance that is already available in a range of related areas, in documents such as those relating to the Optimising Cancer Management Initiative, the NSW Rural Health Plan, the Department of NSW Health Strategic Plan for Radiotherapy Services and the NSW Palliative Care Framework, has not been duplicated in this framework.

### Standards

The seven topics regarding which standards have been developed are:

1. Implementation, monitoring and review of standards for cancer care in NSW
2. An Area-wide approach to optimising cancer care
3. Patient-centred care
4. Access to appropriate clinical services
5. Multi-disciplinary care
6. Communication between primary, secondary and tertiary services
7. Education, training and continuing professional development.

Within each cancer topic, key objectives are stated as are the specific standards that need to be met to achieve these objectives. For each standard, information is given regarding the activity required to demonstrate compliance, and a recommended time frame within which compliance with each standard is to be demonstrated.

The standards are not meant to substitute for the independent medical judgement of a clinician in relation to the diagnosis and treatment of individual patients.

# 2. Cancer standards

## Standard 1 – Implementation, monitoring and review of standards for cancer care in NSW

The success of this service framework in optimising cancer care will be readily measurable by the extent to which it is implemented across NSW. This will depend upon the active involvement and ongoing commitment of the NSW Department of Health, Area Health Services, clinicians, and patients and their carers.

The aim of this standard is to ensure that the foundation standards in this framework are implemented across NSW, are regularly reviewed and updated, and that further relevant standards are developed.

### Key objective

To ensure that *A Clinical Service Framework for Optimising Cancer Care in NSW* is implemented across NSW, and is regularly reviewed and updated.

Standard	Demonstration of compliance
<b>1.1 NSW Department of Health and the Cancer Clinical Expert Reference Group</b> should ensure that there are standards, based on best available evidence and expert clinical consensus, which define the appropriate and acceptable levels of service provided for cancer patients in NSW.	<b>By June 2003</b> , <i>A Clinical Service Framework for Optimising Cancer Care in NSW</i> will be published and its implementation will commence.
<b>1.2 NSW Department of Health and the Cancer Clinical Expert Reference Group</b> should ensure that uniform and unambiguous measures of compliance and reporting are developed, and that these standards are supported and further standards developed for July 2005 and beyond.	<b>From June 2003</b> , the NSW Department of Health and the Clinical Expert Reference Group will establish mechanisms for the support of the standards, the development of uniform and unambiguous measures of compliance and development of standards for implementation from July 2005.
<b>1.3 NSW Health and all Area Health Services</b> should ensure that there are appropriate systems in place to allow monitoring of compliance with the standards and performance indicators.	<b>From June 2003</b> , at regular intervals, NSW Health and all Area Health Services will participate in ongoing formal assessment of progress with implementation through regular collection of state-wide compliance levels and Area Health Service tracking of the framework's targets (see Section 3: Assessing progress).
<b>1.4 All Area Health Services</b> should ensure that the Area director or coordinator of cancer services has sufficient assistance and resources to ensure compliance with these standards.	<b>By June 2005</b> , and at regular intervals prior to that, each Area Health Service will demonstrate compliance with the framework's standards.

## Standard 2 – An Area-wide approach to optimising cancer care

The standards within this topic aim to ensure that all those who provide cancer care in each Area do so in an integrated and coordinated way, with planning and organisation of services occurring from an Area perspective.

### Key objective

To establish an effective management group for cancer services in each Area Health Service, with clear leadership, membership and scope of activities.

Standard	Demonstration of compliance
<p><b>2.1 All Area Health Services</b> should ensure that there is a named <b>director or coordinator of cancer services*</b> who has responsibility for the development of cancer services across the continuum across the Area Health Service in accordance with the standards outlined in this framework, and with good practice.</p>	<p><b>By December 2003</b>, all Area Health Services will have appointed or nominated the individual who is to be responsible for the development of the Area's cancer services in accordance with the standards of this framework and good practice.</p>
<p><b>2.2 All Area Health Services</b> should ensure that there is an <b>Area Cancer Service management group*</b>, chaired by the director or coordinator of cancer services, with Terms of Reference agreed to with the Area CEO. These terms of reference should include the development of clear specification of the scope of services offered by the Area Cancer Service, regular monitoring of the staffing profile, the activities to be undertaken at specific facilities within the Area (Comprehensive Cancer Centres and Cancer Units as detailed in <i>A Cancer Care Model for NSW</i>), and development of clear arrangements for onward referral of appropriate cases.</p>	<p><b>By June 2004</b>, all Area Health Services will have appointed members of the Cancer Service Management Group.</p> <p><b>By June 2004</b>, all Area Cancer Services will have a clear specification of the scope of services offered by the Area Cancer Service, the activities to be undertaken at specific facilities within the Area and clear arrangements for onwards referral of appropriate cases.</p> <p><b>By June 2004</b>, all Area Cancer Services will be able to monitor their monthly actual staffing profile.</p>
<p><b>2.3 All Area Health Services</b> should ensure that the <b>Area Cancer Service*</b> has a formalised management structure in place that clearly defines the involvement of all service providers, managerial staff, clinicians, patient representatives, volunteer services, and the private sector.</p>	<p><b>By December 2003</b>, all Area Health Services will have documented their Area Cancer Service management structure, including clearly defined authorities.</p>
<p><b>2.4 All Area Health Services</b> should ensure that the Area Cancer Service is aware of the Area's cancer incidence profile and uses this data in planning Area cancer prevention and treatment activities.</p>	<p><b>By June 2004</b>, all Area Cancer Services will be able to demonstrate awareness of their Area's cancer incidence profile and its use in planning Area cancer prevention and treatment activities.</p>
<p><b>2.5 All Area Health Services</b> should ensure that policies and mechanisms are developed to ensure that quality management strategies, minimum data set collection, research and education are planned and where appropriate undertaken on an Area-wide basis.</p>	<p><b>By December 2004</b>, all Area Cancer Services will have developed policies and mechanisms to ensure that quality management strategies, minimum data set collection, research and education are planned and where appropriate undertaken on an Area-wide basis.</p>

\* Denotes terms which are defined in the Glossary.

# 2. Cancer standards

Standard	Demonstration of compliance
<p><b>2.6 All Area Health Services</b> should ensure that there are formalised and documented structures for the establishment and operation of <b>Area-wide site-specific clinical groups*</b> for the common cancer types (breast, lung, colorectal, prostate, gynaecological and haematological) across the cancer continuum from prevention to palliation. These site-specific clinical groups will provide advice relevant to their particular cancer site to the Area Cancer Service Management Group and Area Director. Cancer patients will be managed according to guidelines and protocols endorsed by the relevant site-specific clinical group.</p> <p><i>It is recognised that site-specific clinical groups in rural Areas may need to use different structures and modes of operation to reflect geographical, staffing and other factors specific to rural Areas. Strategies to facilitate the operation of rural site-specific clinical groups may include formal networks with metropolitan Areas to create <b>Virtual Cancer Units*</b>.</i></p>	<p><b>By June 2004</b>, all Area Cancer Services will have formalised structures in place for the operation of Area-wide site-specific clinical groups for at least breast, lung, colorectal, prostate, gynaecological, and haematological cancers, including the development of an Area Directory of Cancer Services which documents the membership of these Area-wide clinical groups.</p>
<p><b>2.7 All Area Cancer Services</b>, where possible, should ensure that there are named <b>lead clinicians*</b> who have responsibility for coordinating tumour specific programs (eg. thoracic oncology, breast oncology etc) across the Area Health Service in accordance with the standards outlined in this framework, and with good practice. These lead clinicians will be accountable to the Area Director of Cancer Services.</p>	<p><b>By June 2004</b>, all Area Health Services, where possible, will have formally appointed lead clinicians with responsibility for coordinating each Area-wide site-specific clinical group (such as thoracic oncology , breast oncology) in accordance with the standards outlined in this framework, and with good practice. These lead clinicians will be accountable to the Area Director of Cancer Services.</p>

## Standard 3 – Patient-centred care

Satisfaction with care has two dimensions. One has to do with technical excellence – the skill and competence of professionals and the ability of equipment, procedures and systems to accomplish what they are meant to accomplish, reliably and effectively.

The other, ‘soft’ dimension relates to subjective experience – the patient’s perception of illness or well-being and their interactions with the health care system. In health care it is the quality of care provided in this subjective dimension that patients experience most directly.

Any health system must address both technical excellence and quality of care to achieve legitimacy in the eyes of those it serves. This can be expressed as ‘patient-centred care’.

### Key objectives

- To ensure that cancer patients and their carers have access to the level of information and support they require to assist them through their cancer journey.
- To ensure that cancer patients receive care that is coordinated throughout the continuum of care.
- To minimise the physical and psychosocial impact of cancer on patients.
- To provide care that is tailored to meet specific physical and psychosocial issues nominated by individual cancer patients and their carers through a process of routine assessment.

Standard	Demonstration of compliance
<p><b>3.1 All Area Cancer Services and health care professionals involved in the care of cancer patients</b> should ensure that all cancer patients have access to appropriate and relevant information regarding their condition and its management at all stages of the cancer journey, and have input according to their need in their care.</p>	<p><b>By December 2003</b>, all new cancer patients undergoing treatment will be offered an <b>information pack</b>* at diagnosis or before definitive treatment begins.</p> <p><b>By June 2004</b>, all Area Cancer Services will develop a checklist of information provided, to be signed by the patient as acknowledgement. The completed form should be filed in the patient’s medical record.</p> <p><b>By December 2003</b>, all Area Health Services will ensure access to resource facilities for the provision of cancer information in a variety of formats to patients, their relatives and carers, and general practitioners.</p>
<p><b>3.2 All Area Cancer Services and health care professionals involved in the care of cancer patients</b> should ensure that processes are in place to ensure that coordination of cancer care occurs for individual patients. These processes will include the use of <b>care coordinators</b>*, <b>specialist nurses</b>*, other staff as required, <b>personal health records</b>*, care plans and <b>nominated points of contact</b>*.</p>	<p><b>By June 2004</b>, all Area Health Services will have in place local protocols/guidelines which define what degree of coordination support is required for individual patients (eg standard requiring only treating clinicians and GP, or complex requiring specialised coordination efforts).</p> <p><b>By December 2004</b>, Area Health Services will ensure that one care coordinator position is available for every 100 cancer patients recognised as needing specialised coordination of care who are treated in the Area Health Service.</p> <p><b>By December 2004</b>, Area Health Services will have protocols in place for those patients needing specialised coordination of care who are primarily treated in another Area Health Service.</p>

\* Denotes terms which are defined in the glossary.



# 2. Cancer standards

Standard	Demonstration of compliance
<p><b>3.3 All Area Cancer Services</b> should ensure that strategies are in place to minimise logistical problems patients may face in attendance for treatment.</p>	<p><b>By June 2004</b>, all Area Health Services will develop facility-specific strategies to deal with locally identified logistical problems for patients in attending for treatment.</p>
<p><b>3.4 All Area Cancer Services and health care professionals involved in the care of cancer patients</b> should ensure that all cancer patients have their psychosocial needs assessed and have access to appropriate psychosocial care.</p>	<p><b>By December 2004</b>, all Area Health Services will establish mechanisms for the routine assessment of patients' psychosocial well-being (eg training of staff, use of questionnaires, establishing psychosocial staffing shortfalls and requirements).</p>

## Key concepts and issues in patient-centred care

### Provision of information

- Information needs vary at different stages of disease and between individuals. Patients should be given appropriate information on diagnosis, treatment options, goals and prognosis with and without recommended treatment prior to commencement of definitive treatment. This should be documented in the medical record. Patients should be asked at key points in the care pathway what information they wish to have.
- Prior to treatment, all cancer patients should be offered appropriate and timely written and verbal information about where to go upon arrival at the hospital, what to bring, visiting hours and ward routines.
- All cancer patients should be offered appropriate and timely written and verbal information about who to contact for post-discharge emergencies, after hours points of contact, medication instructions, date of next appointment, community-based supportive care services available locally and how to access them.
- All cancer patients should be provided with an information pack either at the point of diagnosis or before treatment has commenced.

An information pack should include information on:

- the Cancer Helpline (The Cancer Council NSW)
- resources available from widely recognised organisations such as The Cancer Council NSW, National Breast Cancer Centre, NSW Breast Cancer Institute
- non-mainstream transport services (eg community transport, ambulance services, and patient transport services provided by Area Health Services and Aboriginal Health Services) to and from the treatment centre
- recommended accommodation near the treatment centre
- financial assistance schemes and their eligibility criteria
- the names and description of local support groups
- the names and description of one-to-one peer support networks (eg Breast Cancer Support Service, Prostate Cancer Support Network, Bowel Cancer Support Network)
- an amalgamated guide to clinical services at the cancer facility, including a map and information on facilities such as mode and cost of parking and cafeteria
- a list of reliable cancer websites and books.

- All hospitals should provide access to cancer information in a variety of formats including books, tapes, videos, CD-ROMs and the Internet. Information about how to access information from other sources, such as local libraries and The Cancer Council NSW should also be available.

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- People from culturally and linguistically diverse (CALD) backgrounds, especially those whose English is poor, may require an interpreter. To ensure information is translated accurately, professional interpreters are strongly preferred over the use of family members or others who are not trained in interpreting (NHMRC NBCC, 2000). NSW has health care interpreters who specialise in providing interpreter services (telephone and on site) for the health sector. A telephone interpreter through the Translating and Interpreting Service (TIS) can usually be provided promptly, although giving some notice is preferred. In order for an interpreter from the TIS to be present during the consultation, the interpreter will need to be pre-booked and a specific time arranged.
- Information should be provided to cancer patients in their own language where available.

Existing information sources in other languages include:

- the NSW Multicultural Health Communication Service and website
- cancer information and advice on the Cancer Council's Cancer Helpline, available in Cantonese/ Mandarin, Arabic, Greek and Italian as well as English
- Multicultural Health Units operated by many Area Health Services
- written information booklets available from the National Breast Cancer Centre
- the Multicultural Breast Cancer Information Service (MBCIS), which provides information and support for women with breast cancer in Arabic, Cantonese, Greek, Italian and Mandarin.

- It is important to acknowledge cultural sensitivities among people from culturally and linguistically diverse backgrounds. A study that examined cultural issues relating to breast cancer among Greek, Italian, Arabic and Polish women (Brushin et al, 1997) found that:
  - many women prefer a female medical professional. If that is not possible a female nurse or counsellor should be present during the consultation

- a diagnosis of breast cancer may be viewed as a death sentence whatever the prognosis may be. Reassurance and emphasis on the positive aspects of the diagnosis will be especially important with these women
  - a diagnosis of cancer may be viewed as shameful, so reassurance that having cancer is not the fault of the woman, and is not something to be ashamed of may be required
  - religion may play a fundamental role in the woman's attitude towards her disease and treatment. Spiritual support from her religious group may be important
  - family and extended families have a central role in many cultures. Family members often share rights, responsibilities and decision-making and this may influence choice of treatment.
- People of Aboriginal or Torres Strait Islander (ATSI) backgrounds should have access to appropriate support as needed during their cancer journey. There is very little culturally-specific information written for Aboriginal and Torres Strait Islander people with cancer (Carrick et al, 1996).

**A range of health workers is available to support, interpret, advocate and explain on behalf of Aboriginal and Torres Strait Islander people.**

They can be contacted through:

- Aboriginal Liaison Officers at major hospitals
- Office for Aboriginal and Torres Strait Islander Health Services (OATSIS)
- Aboriginal Health Branches in each state and territory Department of Health
- Aboriginal Health Coordinators in each state and territory area or regional health service
- National Aboriginal Community-Controlled Health Organisations (NACCHO) – there are also state and territory equivalents
- Aboriginal Medical Services (AMS)
- Aboriginal land councils.

# 2. Cancer standards

- People from Aboriginal and Torres Strait Islander backgrounds have a number of cultural sensitivities which include a number of relevant issues, such as:
  - Many people may be concerned about how, and if, their personal information is protected from other health professionals, researchers and members of their own community. Clinicians should not only ensure confidentiality, but also explain how this is achieved.
  - Breast and cervical cancer are considered to be part of the realm of women’s business. Consequently the use of female health professionals would improve acceptability of care. Similarly, prostate cancer would be considered men’s business.
  - The significance of ‘shame’ for Aboriginal people is a sensitive issue and is not well understood.
  - Family and kinship is central to the well-being of Aboriginal and Torres Strait Islander people. Clinicians should be aware that family responsibilities may impact greatly on treatment decisions and that involving family in the decision-making process may increase the acceptability of treatment options as well as completion of, and compliance with, treatment.
  - The concept of ‘support’ is often not well understood; therefore an explanation of social support, including examples of available services and how they can be accessed, should be given to Aboriginal and Torres Strait Islanders.
  - Aboriginal people understand illness in terms of its impact on a person’s ability to fulfil social and spiritual commitments. If treatment is seen to have a negative impact on a person’s social or spiritual role, it is not uncommon for it to be refused or discontinued (Morgan et al, 1997). For example, the death of others at a specific site may impact negatively on others wishing to attend the same place for treatment.

## Acknowledgement of information provided

The following example indicates a practical way in which information provision has been incorporated into routine practice. A Comprehensive Cancer Centre wished to improve its processes for patient information and informed consent, and to measure its success at doing so. To achieve this with minimal additional work, a new form was developed. This form served as a useful tool for quality assurance as it provided a ready checklist for staff and patients to ensure all the relevant actions had in fact been carried out. In addition, the presence of signed forms in the files could be monitored as part of routine clinical process audit.

Provision of information can be acknowledged by individual patients through signing a checklist of information provided. The signed checklist can then be filed in the patient’s medical records.

**Acknowledgement of Information Provided**

I have received the following written information:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

*(to be completed by a treatment team member)*

I know how to contact my treatment team if there are problems.

Name: \_\_\_\_\_ Date: / /

Signature: \_\_\_\_\_

## Logistical problems with attendance for treatment

- All Area Health Services should ensure that strategies are in place to minimise logistical problems patients may face in attendance for treatment.

Strategies to minimise possible logistical problems for patients attending treatment include:

- offering flexible appointment schedules that consider patients' travelling distance and mode of transport
- consolidating appointment times for people from similar areas using non-mainstream transport services to enable more group transport to be provided
- centralising booking systems for all departments to reduce the number of times a patient has to travel to treatment centres
- informing patients of duration scheduled for the consultation
- providing access to parking in close proximity to treatment facilities, for example, a dedicated parking bay for cancer patients receiving treatment coordinated by a booking system
- providing child-friendly waiting rooms.

## Transport needs of rural cancer patients

- Issues regarding the health related transport needs of people in NSW, particularly those living in rural areas, are being addressed under the NSW Transport for Health initiative, as outlined in the NSW Rural Health Plan. Additional funding has been made available to implement this strategy in rural areas, a significant proportion of which will go towards increasing direct service provision.
- One of the ways in which transport needs may be addressed is through the provision of financial assistance under the NSW Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) (NSW Health, 2000c).
- NSW Health participates in a bimonthly national teleconference involving all state and territory coordinators, the aim of which is to share information and resolve any cross border issues in relation to the travel assistance schemes.

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## Standard 4 – Access to appropriate clinical services

Principles underlying this standard include minimisation of system delays in investigation, diagnosis, treatment, rehabilitation and palliation, streamlining of care processes, maximising access to appropriate and specialist services, multi-disciplinary care and encouraging participation in clinical trials.

### Key objectives

- To ensure access to the full range of appropriate treatment, while at the same time minimising anxiety and stress, and delays in investigation, diagnosis and treatment of cancer.
- To ensure that cancer services are managed and organised effectively to support high quality care.

Standard	Demonstration of compliance
<p><b>4.1 All Area Health Services</b> should ensure that all cancer patients have access to specialist diagnostic and treatment care, according to <b>multi-disciplinary care*</b> principles and relevant guidelines (refer to Standard No 5).</p> <p>Given the distances in NSW, the concept of Virtual Cancer Units may need to be developed.</p>	<p><b>By June 2004</b>, all Area Health Services will develop formal inter and intra Area linkages and collaborations with appropriate facilities and health service providers to ensure that all of their residents have access to the full range of cancer services needed to effectively manage cancer.</p>
<p><b>4.2 All Area Health Services</b> should ensure that patients already under specialist cancer care have after hours access to competent care.</p>	<p><b>By December 2003</b>, all Area Cancer Services will ensure that arrangements are in place for after-hours support and points of contact.</p>
<p><b>4.3 All Area Health Services</b> should ensure that waiting times remain within the following agreed limits for all cancer related services:</p> <ul style="list-style-type: none"> <li>• Time between GP referral and initial specialist consultation is less than 2 weeks.</li> <li>• Maximum acceptable time for results of imaging procedures is 5 days.</li> <li>• Maximum acceptable time for diagnostic and therapeutic endoscopy is 2 weeks.</li> <li>• For surgery, the maximum acceptable time between decision to operate and surgical procedure is 2 weeks.</li> <li>• For radiotherapy, maximum acceptable time between decision to treat and commencing treatment is 3 weeks.</li> <li>• For chemotherapy, maximum acceptable time between decision to treat and commencing treatment is 2 weeks.</li> <li>• For palliative care, maximum acceptable time for palliative care physician consultation is 48 hours for inpatients.</li> <li>• For palliative care nursing, maximum acceptable time before initial contact (eg telephone) is 24 hours, and for a home visit is 48 hours.</li> </ul>	<p><b>By June 2004</b>, all Area Cancer Services will monitor waiting times on a monthly basis.</p>

# 2. Cancer standards

Standard	Demonstration of compliance
<p><b>4.4 All Area Health Services</b> should ensure that within these parameters, all Area Cancer Services will develop priority categories so that cases requiring more urgent attention than the maximum acceptable intervals defined above are appropriately identified and managed.</p>	<p><b>By June 2004</b>, all Area Cancer Services will have developed priority categories which identify and manage cases requiring more urgent treatment than the maximum acceptable limits described above.</p>
<p><b>4.5 All Area Health Services</b> should ensure that where services do not comply with the waiting times indicated above, protocols will be in place to ensure patients can gain access to services that meet standards.</p>	<p><b>By December 2004</b>, where services do not comply with the waiting times indicated above, Area Cancer Services will have written protocols in place to ensure that patients can gain access to services that meet standards.</p>
<p><b>4.6 All Area Health Services</b> should ensure that patients have access to appropriate rehabilitation services as needed.</p>	<p><b>By December 2004</b>, all Area Health Services will develop protocols and strategies to ensure that all cancer patients have access to appropriate rehabilitation services.</p>
<p><b>4.7 All Area Health Services</b> should ensure that patients have timely access to specialist palliative care services as needed.</p>	<p><b>By June 2004</b>, all Area Cancer Services will have in place protocols and strategies which ensure that all patients with advanced cancer have access to specialist palliative care services as outlined in the NSW Palliative Care Framework.</p>
<p><b>4.8 All clinicians involved in cancer care</b> should promote awareness and encourage the participation of patients in appropriate clinical trials for which they are eligible.</p>	<p><b>By June 2005</b>, all Area Cancer Services will document:</p> <ul style="list-style-type: none"> <li>● participation in and accrual (proportion of eligible patients enrolled) to trials approved by <b>Cancer Trials NSW*</b></li> <li>● participation in and accrual (proportion of eligible patients enrolled) to other clinical trials.</li> </ul>

\* Denotes terms which are defined in the glossary.

# 2. Cancer standards

## Key concepts and issues relating to access to appropriate clinical services

### Equitable access to specialist services

- Area Health Services should develop cancer networks, comprising formal inter- and intra-Area linkages and collaborations with appropriate facilities and health service providers, including effective and efficient links with the private sector, to ensure that their residents have access to the full range of cancer services needed to effectively manage common cancers. Where necessary, strategies such as tele-medicine and outreach clinics should be utilised to facilitate access to multi-disciplinary care for all patients. All the health service facilities within each Area Health Service should be involved in the formation of these collaborative links and networks, to ensure equitable access.
- All health service facilities involved in the management of patients with cancer should determine whether there are specific tumour sites or procedures which should not be treated or carried out in their facility but would be more optimally managed at another intra- or inter- Area facility. If any such tumour sites or procedures are identified, formal linkages and agreed referral guidelines should be developed.
- People with advanced cancer should have access to specialist palliative care services at earlier stages of the cancer journey. *The NSW Palliative Care Framework* (NSW Health, 2001) outlines the key elements for effective palliative care, and the different models of care, linkages, formalised networks and referral guidelines that Area Health Services need to develop to ensure equitable access to palliative care for all those who require it. All Area Health Services have developed a palliative care service plan, as required under the *NSW Palliative Care Framework*. The specific linkages and inter-relationships in each Area between specialist providers, generalist providers and support services for palliative care will vary due to geographical location, the available resources and historical factors that have over time influenced service development. Those Area Health Services that do not have the full range of specialist palliative care services must develop linkages with specialist services elsewhere.
- All Comprehensive Cancer Centres should provide access to specialist psychosocial support services. All patients should be assessed to identify the type and level of psychosocial care required, and triaged by the multi-disciplinary team to receive the relevant care. Psycho-oncology specialist services may be included in outreach programs to rural or remote areas and may include telemedicine consultations, programs such as problem-solving skills, communication skills and survivorship programs.
- People of CALD backgrounds should have access to qualified interpreters and people of Aboriginal or Torres Strait Islander backgrounds should have access to health workers as needed during their cancer journey (see *Standard 3: Patient-centred care*).

## Standard 5 – Multi-disciplinary care

Multi-disciplinary care is care provided by a team of various health professionals, using a team approach to make recommendations regarding treatment planning and other aspects of care for individual patients (NHS Executive, 2000). The operation of the multi-disciplinary care approach and the exact configuration of multi-disciplinary teams (MDTs) may vary between and within each Area Health Service, within the limits specified by the following standards.

### Key objectives

- To ensure that all patients have access to a multi-disciplinary care approach throughout the continuum of care.
- To ensure that designated specialists work effectively together in teams to make multi-disciplinary recommendations to primary treating clinicians regarding the diagnosis, treatment and care of individual patients.

Standard	Demonstration of compliance
<p><b>5.1 Area Health Services</b> should ensure that all Area Cancer Services have documented procedures for the development and operation of a <b>multi-disciplinary care*</b> approach.</p>	<p>By <b>December 2004</b>, all Area Cancer Services will have documented procedures for the development and operation of a multi-disciplinary care approach for cancer (at least including breast, lung, prostate, gynaecological, colorectal and haematological cancers).</p>
<p><b>5.2 Area Health Services</b> should ensure that systems are in place to allow all patients access to multi-disciplinary care, regardless of geographical remoteness or size of the institution delivering care.</p>	<p>By <b>December 2004</b>, all Area Health Services will ensure that systems are in place across the Area to allow all patients access to multi-disciplinary care.</p>
<p><b>5.3 All Area Cancer Services</b> will progressively develop <b>multi-disciplinary teams*</b> to:</p> <ul style="list-style-type: none"> <li>• ensure that specialists work effectively together in teams to make multi-disciplinary recommendations to primary treating clinicians regarding the diagnosis, treatment and care of individual patients</li> <li>• provide optimal management in accordance with guidelines and protocols endorsed by the relevant site-specific clinical group (including guidelines for onward referrals)</li> <li>• collect appropriate information to inform clinical decision making and to support clinical governance/audit</li> <li>• establish regular multi-disciplinary case conferences or tumour board meetings to determine management</li> <li>• encourage the participation of patients in their treatment planning where feasible and desirable.</li> </ul>	<p>By <b>June 2004</b>, multi-disciplinary teams (MDTs) in all Area Health Services will keep records of the number of patients who are discussed (prospectively and retrospectively) at MDT meetings.</p> <p>By <b>June 2004</b>, Area-wide site-specific clinical groups will keep records of the number of patients discussed at MDT meetings as a proportion of patients treated for that condition in the Area.</p> <p>By <b>December 2004</b>, Area-wide site-specific clinical groups and MDTs in all Area Health Services will keep records of the proportion of patients managed according to agreed protocols and guidelines.</p>
<p><b>5.4</b> It is recognised that in rural Areas, patient numbers and workforce issues may mean that it is not feasible to establish MDTs for all common cancer sites. Where MDTs are not established, appropriate referral guidelines or other linkages (such as teleconferencing) should be established to ensure the availability of MDT input.</p>	<p>By <b>December 2004</b>, all Area Health Services will be able to demonstrate the establishment of appropriate referral guidelines or other formal linkages for common cancer sites where MDTs have not been established.</p>

\* Denotes terms which are defined in the glossary.

# 2. Cancer standards

## Key concepts relating to multi-disciplinary care

### Rural and remote areas

Geographical remoteness and/or small size of the institution delivering care should not be impediments to the delivery of multi-disciplinary care. Collaborative working links with other Areas, other health service providers including those in the private sector, and, where necessary, strategies such as telemedicine, should be utilised to facilitate access to multi-disciplinary care for all patients. In areas where the number of new cancers is small, formal collaborative links with larger units or centres should give support and foster expertise in the smaller unit.

### Locally adopted guidelines

- A number of evidence-based clinical practice guidelines have been published or are in preparation in Australia. Comprehensive lists of Australian clinical management surveys and clinical practice guidelines for cancer have been compiled by the National Cancer Control Initiative (NCCI) and are to be found in Appendix 3 and 8 of the recent consultative report *Optimising Cancer Care in Australia* by the Clinical Oncological Society of Australia, The Cancer Council Australia and the National Cancer Control Initiative (Clinical Oncological Society of Australia, 2002). These lists will continue to be updated by the NCCI and are available at [www.ncci.org.au](http://www.ncci.org.au). Area Cancer Services and health professionals involved in the care of cancer patients should ensure that evidence-based guidelines are used wherever appropriate.
- Deviation from standard guidelines of care will be necessary in some cases, according to clinical circumstance. However such deviation should occur following discussion by and as a recommendation of the MDT and the reasons should be documented.

### Multi-disciplinary teams (MDTs)

- The composition for a multi-disciplinary team approach may use more than one model of care and may operate over more than one hospital (NHS Executive, 1997). Team composition and function must take into account the different referral, diagnostic and treatment practices associated with individual cancers and individual Area Health Services, which will impact on the aim and purpose of the team.
- The complex nature of cancer care can all too easily lead to coordination lapses, uncertainty and patients feeling 'lost in the system'. All MDTs must have systems in place to ensure appropriate coordination of care for all patients who require it. MDTs should devise triage procedures which separate individual patients on their likely care coordination needs. For example, relatively simple cases may not require more than the individual treating clinicians, their GP and good information packages. More complex cases may require specialised coordination, which may be provided by specialist nurses, or other defined care coordinators.
- A multi-disciplinary team approach should minimally include a core group of all the medical specialists that may be related to the diagnosis and treatment of a particular cancer. This core group is sometimes referred to as a multi-specialty team. As a guide, this will include the disciplines of surgery, medical and radiation oncology, imaging, nursing, palliative care and pathology.
- For each cancer type, specific expertise within the core team(s) will be required. For example:
  - *colorectal cancer*, should include a gastrointestinal surgeon, gastroenterologist, medical and radiation oncologists, nurse specialist and/or care coordinator
  - *lung cancer*, should include a thoracic surgeon, thoracic physician, medical and radiation oncologists, radiologist, histopathologist, nurse specialist and/or care coordinator

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- *breast cancer*, should include a breast surgeon, medical and radiation oncologists and a breast nurse specialist. The latter should ideally be different for early versus metastatic breast cancer, as the skills required to assist patients may be different
- *gynaecological cancer*, should include a certified gynaecologic oncologist, medical and radiation oncologists, nurse specialist and/or care coordinator.
- A **broader MDT approach** may include the general practitioner, palliative care, psycho-oncology and allied health, and other health professionals (some of whom may be off site) such as geneticists, psychiatrists, and nuclear medicine physicians. Palliative care should where possible be provided by a multi-disciplinary team consisting of a nurse with specialist training in palliative care, a palliative care physician, and social worker or psychologist support.
- It is important to acknowledge that there is more than one way to set up a team structure, and that each Area Cancer Service must take its local population needs into account and specify the role and objectives of the team.
- Whilst ideally all new cancer cases should be presented to a MDT, it is recognised that this may not be practical, for example, with high volume low complexity cases for which a management protocol is well established. For patients not presented, systems should be put in place to ensure they have access to the same information and support services that are available to patients actually presented to the team. The overall aim is that eventually all new cases should be presented to the appropriate MDT.

- **Specialist cancer nurses** are integral members of the multi-disciplinary team, providing essential health services for people diagnosed with cancer in inpatient, outpatient, and extended care hospice and community settings. They may also take on the role of the patient's care coordinator.

The broad range of cancer services provided by nurses include:

- implementation of national cancer screening programs
- administration of specialised cancer treatments.
- monitoring of patients' progress and response to treatments to ensure early identification of health needs
- providing education and support to prevent and overcome cancer related physical and psychological problems
- teaching and coaching patients and family members to promote effective self care
- delivery of palliative care interventions to promote quality of life (Cancer Nurses Society of Australia, 2002).

There is clear evidence of the ability of specialist cancer nurses to reduce unplanned admissions, to reduce patient attendances at Emergency Departments and to improve the quality of life of patients and their carers. Several studies have documented their cost-effectiveness.

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## Standard 6 – Communication between primary, secondary and tertiary services

Effective coordination between the primary health team, the hospital team and patients and their families is important for optimal cancer care (NHS Executive, 1997).

By ensuring effective communication, it is expected that patients will move through their cancer journey more efficiently, reducing the burden on patients and their carers. Effective communication across the different levels/sites of care should also provide a better information base on which to base care decisions, resulting in better outcomes for patients.

### Key objectives

To ensure effective communication between all levels of care through development and implementation of:

- clear local arrangements to enable smooth and timely progression of patients and their carers between all care settings
- mechanisms to ensure that information about individual patients is communicated effectively to all those involved in that patient's care.

Standard	Demonstration of compliance
<b>6.1 Area Cancer Services</b> should ensure that processes are in place to ensure effective communication between different service providers, including the use of personal health records, care coordinators, specialist nurses, and an Area Directory of Cancer Services.	<p><b>By December 2003</b> and on an ongoing basis, personal health records will be offered to all cancer patients whose coordination support requirements are deemed to be complex.</p> <p><b>By June 2004</b>, all Area Cancer Services will have developed and distributed an Area Directory of Cancer Services (as per Standard 2.6).</p> <p><b>By December 2004</b>, all Area Health Services will have in place local protocols/guidelines which define what degree of coordination support is required for individual patients (eg standard requiring only treating clinicians and GP, or complex requiring specialised coordination efforts, as per Standard 3.2).</p> <p><b>By December 2004</b>, Area Health Services will ensure that one care coordinator position is available for every 100 cancer patients recognised as needing specialised co-ordination of care who are treated in the Area Health Service (as per Standard 3.2).</p>
<b>6.2 Area Cancer Services and clinicians</b> should encourage and facilitate the involvement of general practitioners at all relevant stages of care.	<p><b>By December 2003</b>, general practitioners will be contacted within 24 hours of admission and discharge for every cancer inpatient, and a copy of the discharge summary will be given to the patient.</p> <p><b>By December 2004</b> all Area Cancer Services will, in collaboration with local Divisions of General Practice, implement mechanisms to facilitate ongoing involvement of GPs while patients are in hospital (eg case conferences, GP visiting rights).</p>

## Key concepts and issues

### Personal health records

All patients should have records of their cancer diagnosis and care to ensure continuity of care during their cancer journey. In cases where a patient has a personal health record (PHR), members of the MDT should complete the relevant sections at each care point, to ensure that the patient has an appropriate record of care.

NSW Health has developed and distributed copies of a personal health record to general practitioners and to Area coordinators of the Chronic and Care Programs, for use by patients with chronic and complex conditions including cancer. *My Health Record* is in a folder format that can be adapted to the specific needs of cancer patients for coordination of their care, and can be updated throughout periods of care. Copies of *My Health Record* are available from the Better Health Centre on (02) 9816 0452.

### Care coordinators

Each cancer patient should have a care coordinator to facilitate continuity of care, ranging from a treating clinician or general practitioner in standard cases to a specialised coordinator in more complex cases. The care coordinator should be aware of all consultations, treatment plans and treatment outcomes. The identity of the care coordinator should be clearly known to both the patient and the treating team.

The responsibilities of the care coordinator would include:

- coordinating the scheduling of procedures
- guiding the patient to information and services
- participating in multi-disciplinary team meetings and communicating outcomes to the patient's general practitioner (if the care facilitator is not the general practitioner)
- coordinating the implementation of the patient care plan including provision of information and referral to appropriate support services
- monitoring the implementation of care against the patient care plan.

### Care coordinators – A clinical scenario

A 47 year old woman with rapidly progressive ascites from ovarian cancer had been returning to the Emergency Department (ED) approximately every 10 days with severe abdominal pain from tense ascites. Given the pressures of work in the ED, the ascites was often not drained until the following morning.

With the use of a care coordinator, the patient now rings the coordinator who arranges immediate ascites drainage by an experienced radiologist at the local private radiology practice. This course of action now provides immediate relief of symptoms, a procedure done by experienced personnel under optimal imaging circumstances, improved patient satisfaction, reduced pressure on ED resources and hospital admission is avoided.

### Area Directory of Cancer Services

Area Health Services should prepare and regularly update a Directory of Cancer Services detailing what services they provide and their location, key personnel and contact details. Relevant services provided by the private sector should also be included. The directory should be disseminated to primary health care providers serving the populations of the relevant catchment area.

Access to information for new patients, their families and health practitioners should also be available via both an internet address and a free-call phone number, which is disseminated by comprehensive cancer care centres, GPs, screening units and others involved in the diagnosis and management of cancer.

The NSW Department of Health should maintain a central contact point for up-to-date information about cancer services and resources, such as a NSW Directory of Cancer Services, which is updated annually and to which all Area Health Services and other groups contribute information.

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An Area Directory of Cancer Services should include:

- Area Cancer Service key contacts
- membership of the Area-wide site-specific clinical groups
- lists of available MDTs, the core members and their referral details
- radiotherapy and medical oncology departments – description and contact details
- palliative care services and specialist pain services
- voluntary and support groups for patients and carers, with referral contact points
- referral guidelines and processes for referral of patients with suspected cancer.

## Discharge planning

The majority of cancer care is undertaken on an outpatient basis. However, for those cancer patients who require hospitalisation, development of a detailed discharge plan prior to the patient leaving hospital is essential in facilitating their continuity of care and in helping to maintain the patient's and carer's overall health and well-being.

Consultation by hospital-based staff with the general practitioner forms an important part of this process. A discharge case conference with the patient, carer and family, members of the hospital multi-disciplinary team, the general practitioner and community care providers to discuss the ongoing care needs for the patient is recommended. This will help to organise and to coordinate what support services are required.

In recognition of the need to improve discharge planning performance in NSW public hospitals, NSW Health circulated *Shared Responsibility for Patient Care between Hospitals and the Community – An Effective Discharge Policy* (July 2001).

Further development of this document has been undertaken and an *Effective Discharge Planning Framework for NSW Health* will be circulated and supported by an implementation process in 2003.

A key component of the framework is the need for a discharge risk screen to be completed for all patients admitted to hospital, occurring at pre-admission for booked patients and within two days of admission for emergency patients. An Estimated Date of Discharge (EDD) is also

to be completed on all patients, to provide a focus for the discharge planning process. The patient/carer/family are to be included in discussions about the patient's hospital length of stay. The EDD is to be revised if the patient's clinical condition alters.

An electronic medical discharge referral is being trialed in a number of Area Health Services, and it is hoped to include in it a referral for community health services. Further development will include referrals to community service providers.

The discharge planning process should include the following:

- discharge risk screen and follow-up assessment by health professionals
- expected date of discharge – recorded and reviewed
- communication with the patient/carer/family, GP, community health and service providers
- case conference and planning for services as required
- medical discharge referral to the GP
- referral to community health providers
- referral to community service providers
- discharge medications and prescriptions
- patient education about medications and clearly written medication list with instructions
- requirements and arrangements for consumables such as wound care and continence aids
- requirements and arrangements for equipment such as walking frames, electric beds, hoists etc.
- names and contact numbers of the arranged services to be provided to the patient, GP and community health and service providers
- patient education and information
- name and contact number for the patient after discharge.

## Facilitating the involvement of general practitioners

- Involvement of the patient's GP is integral to good ongoing care following their patient's discharge from hospital. There are systems in place such as DocFax/DocMail which will notify the GP of their patient's admission and discharge dates.

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- The patient's GP should be provided with a copy of the medical discharge referral. For complex cases it is recommended that the GP be contacted by phone as well. The medical discharge referral represents the formal transfer of responsibility for patient treatment and care to the GP. The discharge referral may be faxed where security arrangements can be met, on the day of discharge or within 48 hours following, and a copy provided to the patient.
- When the case is complex and the patient and/or the family might benefit from direct involvement of the GP while the patient is in hospital, cancer centres should facilitate this. Area Health Services should consider different means of encouraging GP attendance, which may include that all GPs have a hospital ID card if they wish with some form of accreditation with limited rights to their local hospital. These rights can be noted on the ID card, such as visiting, writing in notes and participating in case conferences.
- Since most cancer patients spend the majority of their time in the community, the GP or primary health care team is integral to the provision of patient care. Written communication from the specialist team to the patient's GP should include information on diagnosis, clinical findings, test results and recommended future tests, treatment options, likely side effects and prognosis. Other alternatives, such as the patient taking a note back to the GP from the MDT, should also be considered to increase the efficiency and timeliness of communication back to the GP.

## Clinical scenario

A 39 year old mother with a young family was an inpatient receiving treatment for painful bone metastases. Her disease was progressing rapidly, such that every time one clinical problem was dealt with, another occurred, causing multiple delays in discharge. The patient and her husband had not felt able to discuss the grave prognosis with their children.

The patient's GP was contacted by the hospital team and visited the patient in hospital. Since the GP knew the family well over several years and in particular was known to the children, the GP played a vital role in conducting a family conference in hospital and dealing directly with the children outside hospital as well.

GPs usually know the family as individuals, over an extended period, and are uniquely placed to offer specialised support.

The medical discharge referral should be clearly written and legible, and should include:

- patient demographics
- name of medical consultants
- presenting problem
- diagnosis
- alerts and allergic reactions
- major interventions
- potential side effects of the treatments and recommendations for management
- discharge medications and reasons for changes
- GP advice for follow-up
- information relayed to the patient about treatment
- medical specialists/consultant appointments
- community health contacts
- community service provider contacts.

## Clinical scenario

A medical oncology department wished to increase GP involvement in care coordination. For all new cases, patients were given a second copy of chemotherapy information in addition to one for themselves and a brief summary note. The chemotherapy information and summary note were delivered by the patient to the GP the next working day.

This form of communication almost always reached the GP before a dictated letter, and in the opinion of many GPs surveyed, replaced the need for such a typed letter. GPs reported feeling more able to deal with acute side effects of chemotherapy in general practice and reduced referrals of patients back to the hospital.

# 2. Cancer standards

## Standard 7 – Education, training and continuing professional development

The principle underpinning these standards is that continuing professional development enhances patient care, workforce competence and professional satisfaction.

### Key objectives

- To ensure that all health care professionals in the cancer workforce maintain high quality skills and competencies in oncology.
- To ensure that mechanisms are in place for all health care professionals in the cancer workforce to participate in multi-disciplinary continuing professional development irrespective of geographical location.
- To provide opportunities for health care professionals not in the cancer workforce to enhance core skills and competencies in cancer and cancer related complications and understand the pathways for entry into the cancer care program.

Standard	Demonstration of compliance
<p><b>7.1 All members of the cancer workforce</b> should participate in a range of continuing education and quality assurance activities. This should include non-clinical members such as clerical/reception staff as well as clinical staff.</p> <p><b>7.2 All Area Cancer Services</b> should ensure that policies and mechanisms are in place for all health care professionals in the cancer workforce to participate in training and continuing professional development, and support and resources are provided for primary care professionals to participate in relevant continuing professional development activities.</p>	<p><b>By June 2005</b>, all Area Cancer Services will monitor cancer workforce participation in training and continuing professional development. Such training and professional development will include clinical and non-clinical staff/services.</p>

### Key concepts and issues

- All Area Health Services should have a formal policy regarding training and continuing professional development of its staff. The policy should include:
  - the minimum level of continuing professional development per annum for different types of staff
  - the institutional support to be given to assist staff to undertake training and professional development
  - strategies for notifying staff of relevant training and professional development opportunities
  - strategies for remediating those who do not meet minimum standards.
- Each Area Cancer Service should undertake training needs assessment, at least three yearly, with health professionals involved in cancer care to identify continuing professional development needs and priorities. Results should be made available in a training needs assessment document.
- All health care professionals involved in the care of cancer patients should participate in a range of continuing education and quality assurance activities, with formal documentation of their participation by the treatment centre.
- Regular (at least bi-annual) communication skills training for clinical and non-clinical staff should be part of the accreditation process associated with cancer care.

- Area Cancer Services should provide support and incentives for staff to participate in relevant continuing professional development activities. These may include:
  - provisions for study leave
  - assistance with HECS and other course fees for nurses to overcome the financial barriers nurses face in undertaking postgraduate cancer nursing courses
  - establishment of conjoint academic-clinical appointments in cancer nursing and other clinical areas.
- Internal and external training and continuing professional development programs should:
  - include proven strategies for achieving change such as using performance-based learning, providing feedback to participants and undertaking periodic assessment of skills
  - where possible, be available in formats that are suitable for different sub-groups (such as satellite broadcasts for those in non-metropolitan areas)
  - include participants from multi-disciplinary backgrounds to facilitate a better understanding and appreciation of the contribution of the different specialties to improving cancer care.
- The level of participation in recognised continuing professional development should be a formal component of periodic performance reviews of all health professionals involved in cancer care.
- Area Cancer Services should provide support and resources for primary care professionals to participate in relevant continuing professional development activities. These may include:
  - targeted education sessions
  - directories of cancer services and contact details
  - guideline summaries
  - care coordinators providing targeted information packages.

## Medical specialists

In Australia, formal continuing professional development programs are available for clinicians and are managed by the respective medical colleges. However, participation in these programs is voluntary except for those provided by the college of surgeons, obstetricians and gynaecologists and emergency medicine (Peck et al, 2000). All programs encourage self-directed learning and allow for different learning styles and practice environments (RACP, 1999).

## Medical students

Two useful resources are now available to assist medical schools in the revision of their cancer education curriculum to increase the likelihood that medical graduates will possess core skills and competencies in oncology:

- The National Breast Cancer Centre's model curriculum for medical students on breast cancer (CAMEO-B) (NBCC, 1999).
- The Ideal Oncology Curriculum for Medical Students, which is based upon and expands the CAMEO project. This was developed by the Oncology Education Committee of the Australian Cancer Society (Oncology Education Committee, 1999) and can be accessed via [www.cancer.org.au/documents/Ideal Oncology Curric H1.pdf](http://www.cancer.org.au/documents/Ideal%20Oncology%20Curric%20H1.pdf)

# 2. Cancer standards

## Specialist cancer nurses

Studies in Australia and overseas indicate that specialist cancer nurses can reduce psychological morbidity associated with cancer, enhance early recognition of support needs and provide continuity of care (NBCC, 2000; NHMRC NBCC, 2000). The *Australian Standards for Specialist Cancer Nursing Education Programs* is a useful resource developed by the Cancer Nurses Society of Australia (CNSA, 1999) which recommends that specialist cancer nursing education programs:

- promote professional practice in cancer nursing
- develop the nurse's understanding of the dynamic nature of the cancer experience through comprehensive knowledge of pathophysiology and epidemiology of the malignant process as well as the individual's/family's experiences of diagnosis, treatment, palliation and survivorship.
- prepare the nurse to understand the use of contemporary and emerging treatment modalities across the illness trajectory, and the impact of these on individuals/families
- prepare the nurse to understand the effective use of detection, intervention and information technologies relevant to cancer control
- prepare the nurse to facilitate effective symptom management
- develop the attributes necessary for the nurse to communicate effectively
- prepare the nurse to support the individual and family as they respond to cancer.

## General practitioners

Cancer-related training needs have been identified by Australian GPs. For example, a survey of GPs treating breast cancer patients indicated that at least half had a moderate or high need for training to address the medical information, provider interaction, psychological and social needs of their patients (Girgis et al, 2000b). A moderate or high need for training in psychological, social and interpersonal, physical and daily living needs was reported by significantly more urban than rural GPs (Girgis et al, 2000b). There is also evidence that GPs have unmet needs for professional development across a range of cancer sites, with over one-fifth of GPs indicating a high unmet need for information on the detection of breast, cervical, colorectal, skin, prostate and testicular cancer (Hancock & Sanson-Fisher, UER 2002). Urban GPs were more likely than their rural counterparts to express high unmet need in at least one issue for breast, colorectal, prostate and testicular cancer (Hancock & Sanson-Fisher, UER 2002).

Australian research has reported that postgraduate training in interactional skills is recognised as a need among GPs, surgeons and physicians (Girgis et al, 2001). In particular, over four-fifths of Australian surgeons surveyed identified a need for formal training in preparing patients for surgical procedures and breaking bad news to patients about their diagnosis/prognosis (Girgis et al, 1997). This is further supported by research reporting that a low number of surgical trainees demonstrate an ability to meet established guidelines for breaking bad news and preparing a patient for a potentially threatening surgical procedure (Perkins et al, 1998).

# Progress

## 3. Assessing progress

### The Framework Implementation Plan

The Implementation Plan for this Clinical Service Framework is essentially described by the specified dates by which compliance with the standards is required. The following table provides a summary of the compliance dates for each standard.

Standards	2003		2004		2005
	By June	By Dec	By June	By Dec	By June
1. Implementation, monitoring and review of standards for cancer care in NSW	1.1	1.2 1.3 1.4	1.3 1.4	1.3 1.4	1.3 1.4
2. An Area-wide approach to optimising cancer care		2.1 2.3	2.2 2.4 2.6 2.7	2.5	
3. Patient-centred care		3.1	3.1 3.2 3.3	3.2 3.4	
4. Access to appropriate clinical services		4.2	4.1 4.3 4.4 4.7	4.5 4.6	4.8
5. Multi-disciplinary care			5.3	5.1 5.2 5.3 5.4	
6. Communication between primary, secondary and tertiary services		6.1 6.2	6.1	6.1 6.2	
7. Education, training and continuing professional development					7.1 7.2

# 3. Assessing progress

The following table provides a more detailed chronological listing of the compliance requirements and those responsible for implementation of each standard.

Std	Demonstration of compliance	Responsibility
<b>To be achieved by June 2003</b>		
<b>1.</b>	<b>Implementation, monitoring and review of standards for cancer care in NSW</b>	
1.1	Publication of standards	NSW Health/Cancer Clinical Expert Reference Group
<b>To be achieved by December 2003</b>		
<b>1.</b>	<b>Implementation, monitoring and review of standards for cancer care in NSW</b>	
1.2	Establishment of mechanisms for support of the standards, monitoring of compliance, and review	NSW Health/Cancer Clinical Expert Reference Group
1.3	Participation in ongoing formal assessment of progress with implementation	NSW Health/ Area Health Services
1.4	Demonstration of compliance with framework's standards at regular intervals	Area Health Services
<b>2.</b>	<b>An Area-wide approach to optimising cancer care</b>	
2.1	Nomination or appointment of an Area director or coordinator of cancer services	Area Health Services
2.3	Documentation of Area Cancer Service management structure, including clearly defined authorities	Area Health Services
<b>3.</b>	<b>Patient-centred care</b>	
3.1	Information pack offered to all new cancer patients at diagnosis or before definitive treatment begins; and access to resource facilities in a variety of formats for patients, relatives and GPs	Area Cancer Services Area Health Services
<b>4.</b>	<b>Access to appropriate clinical services</b>	
4.2	Arrangements in place for after-hours support and points of contact	Area Cancer Services
<b>6.</b>	<b>Communication between primary, secondary and tertiary services</b>	
6.1	Personal health records offered to all cancer patients whose coordination support requirements are deemed to be complex	Area Cancer Services
6.2	General practitioners contacted within 24 hours of admission and discharge for every cancer inpatient, and discharge summary given to patient	Area Cancer Services

# 3. Assessing progress

Std	Demonstration of compliance	Responsibility
<b>To be achieved by June 2004</b>		
<b>1.</b>	<b>Implementation, monitoring and review of standards for cancer care in NSW</b>	
1.3	Participation in ongoing formal assessment of progress with implementation	NSW Health/ Area Health Services
1.4	Demonstration of compliance with framework's standards at regular intervals	Area Health Services
<b>2.</b>	<b>An Area-wide approach to optimising cancer care</b>	
2.2	Membership of Area Cancer Service management group determined; clear specification of the scope of services offered by the Area Cancer Service, activities undertaken at specific facilities, arrangements for onwards referral for appropriate cases, and monthly monitoring of staffing profile	Area Health Services/ Area Cancer Services
2.4	Demonstrated use of Area's cancer profile in Area cancer prevention and treatment activities	Area Cancer Services
2.6	Formalised structures in place for operation of Area-wide site-specific clinical groups, and development of an Area Cancer Directory	Area Cancer Services
2.7	Appointment of lead clinicians responsible for coordinating each Area-wide site-specific clinical group	Area Health Services
<b>3.</b>	<b>Patient-centred care</b>	
3.1	Development of a checklist of information provided to be signed by the patient and filed in the patient's medical record.	Area Cancer Services
3.2	Local protocols/guidelines in place which define degree of coordination support required for individual patients (eg standard requiring only treating clinicians and GP, or complex requiring specialised coordination efforts)	Area Health Services
3.3	Development of facility-specific strategies to deal with logistical problems for patients in attending for treatment	Area Health Services
<b>4.</b>	<b>Access to appropriate clinical services</b>	
4.1	Development of formal inter- and intra-Area linkages and collaborations with appropriate facilities and providers to ensure access to the full range of cancer services required	Area Health Services
4.3	Monthly monitoring of specified waiting times	Area Cancer Services
4.4	Development of triage categories within waiting time parameters to identify and manage more urgent cases appropriately	Area Cancer Services
4.7	Protocols and strategies in place to ensure access to specialist palliative care services for patients with advanced cancer	Area Cancer Services
<b>5.</b>	<b>Multi-disciplinary care</b>	
5.3	Records kept of number of patients discussed at multi-disciplinary team (MDT) meetings, number of patients discussed at MDT meetings as a proportion of patients treated for that condition in the Area.	Multi-disciplinary teams/Area-wide site-specific clinical groups
<b>6.</b>	<b>Communication between primary, secondary and tertiary services</b>	
6.1	Development and distribution of an Area Directory of Cancer Services	Area Cancer Services

# 3. Assessing progress

Std	Demonstration of compliance	Responsibility
<b>To be achieved by December 2004</b>		
<b>1.</b>	<b>Implementation, monitoring and review of standards for cancer care in NSW</b>	
1.3	Participation in ongoing formal assessment of progress with implementation	NSW Health/ Area Health Services
1.4	Demonstration of compliance with framework's standards at regular intervals	Area Health Services
<b>2.</b>	<b>An Area-wide approach to optimising cancer care</b>	
2.5	Policies and mechanisms developed to ensure quality management strategies, minimum data set collection, research and education are planned and, where appropriate, are undertaken on an Area-wide basis	Area Cancer Services
<b>3.</b>	<b>Patient-centred care</b>	
3.2	Appropriate number of care coordinators are available for those cancer patients treated in the Area with specialised coordination needs, and protocols are in place for those needing specialised coordination of care who are primarily treated in another Area Health Service	Area Health Services
3.4	Establishment of mechanisms for the routine assessment of patients' psychosocial well-being	Area Health Services
<b>4.</b>	<b>Access to appropriate clinical services</b>	
4.5	Where services do not comply with the waiting time limits specified, written protocols are in place to ensure patients can gain access to services that meet Standards	Area Cancer Services
4.6	Protocols and strategies are in place to ensure access to appropriate rehabilitation services	Area Health Services
<b>5.</b>	<b>Multi-disciplinary care</b>	
5.1	Documented procedures for development and operation of a multi-disciplinary approach for cancer	Area Cancer Services
5.2	Systems are in place across the Area to ensure all patients have access to multi-disciplinary care	Area Health Services
5.3	Records kept of proportion of patients managed according to agreed protocols and guidelines	Multi-disciplinary teams/ Area-wide site-specific clinical groups
5.4	Establishment of appropriate referral guidelines or other formal linkages for common cancer sites where MDTs have not been established	Area Health Services
<b>6.</b>	<b>Communication between primary, secondary and tertiary services</b>	
6.1	Development of local protocols/guidelines defining degree of coordination support required for individual patients; establishment of care coordinator positions for cancer patients needing specialised coordination of care	Area Health Services

# 3. Assessing progress

Std	Demonstration of compliance	Responsibility
<b>To be achieved by June 2005</b>		
<b>1.</b>	<b>Implementation, monitoring and review of standards for cancer care in NSW</b>	
1.3	Participation in ongoing formal assessment of progress with implementation	NSW Health/ Area Health Services
1.4	Demonstration of compliance with framework's standards at regular intervals	Area Health Services
<b>4.</b>	<b>Access to appropriate clinical services</b>	
4.8	Documentation of patient participation in and accrual to trials approved by Cancer Trials NSW and to other clinical trials	Area Cancer Services
<b>7.</b>	<b>Education, training and continuing professional development</b>	
7.1/ 7.2	Monitoring of cancer workforce participation in training and continuing professional development	Area Cancer Services

A standardised reporting proforma is to be developed by NSW Health in consultation with the Clinical Expert Reference Group for Cancer, to facilitate reporting of compliance with the requirements for each standard by the Area Health Services.

## 4. Conclusion

*A Clinical Service Framework for Optimising Cancer Care in NSW* has been developed to provide clear direction for ongoing service improvement for patients with cancer across NSW. It builds upon the structure, initiatives and recommendations of *A Cancer Care Model for NSW* (1999), and the Optimising Cancer Management Initiative as a whole.

The framework is supported by various other initiatives being undertaken under the NSW Chronic Care Program, including thirteen Priority Health Care Programs for cancer being undertaken by Area Health Services, and the development and recent dissemination of personal health records to facilitate better coordination of patients' care.

Work being undertaken in a range of areas by NSW Health and others, such as the development of an electronic health record, and various primary and rural health initiatives, may also beneficially influence future service delivery for patients with cancer, and would need to be considered for inclusion in further versions of the framework.

The success of this framework in meeting its key objectives depends on the strong commitment of the NSW Department of Health and Area Health Services in supporting its implementation. As well, it depends on the active participation of the cancer workforce, both in the hospital setting and in the community, in effecting meaningful change to improve service provision for all patients with cancer in NSW. Close collaboration between all the participants in the process of providing cancer care will ensure that NSW progresses further towards its goal '*to provide optimal cancer management for all patients requiring care*'.

# 5. Acknowledgements

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- Dr Martin Berry, Area Director of Cancer Services, South Western Sydney Area Health Service
- A/Professor Bill Kricker, CCOPE, South Western Sydney Area Health Service

# Glossary

## 6. Glossary

Key term	Definition
<b>Area Cancer Service</b>	A formally constituted organisational structure, established by the Area Health Service, comprising the services that are provided specifically for cancer across the cancer continuum from population health to palliation within the Area Health Service, organised and managed on an Area-wide basis, under the directorship of the Area Director or Coordinator of Cancer Services with the assistance of the Area Cancer Service Management Group.
<b>Area Cancer Service Management Group</b>	<p>A group established by the Area Health Service, chaired by the Area Director or Coordinator of Cancer Services, comprising appropriate representatives of the Area Cancer Service's workforce (eg nursing, allied health etc), who meet regularly (eg weekly or fortnightly) to provide input regarding the operation of the Area Cancer Service.</p> <p>The group's Terms of Reference should include:</p> <ul style="list-style-type: none"> <li>● the development of a cancer service delivery plan for the Area which is in accordance with the standards outlined in this framework and with good practice</li> <li>● the development of clear specification of the scope of services offered by the Area Cancer Service and the activities to be undertaken at specific facilities within the Area</li> <li>● the development of clear arrangements for onward referral of appropriate cases through identification of services that are not available within the Area</li> <li>● ensuring, through advice from Area-wide site-specific clinical groups, that site specific pathways and service provision apply uniform standards of care across the Area</li> <li>● regular monitoring of the cancer service staffing profile, and of waiting times and other patient throughput issues</li> <li>● ensuring that there is coordination and uniformity across the Area for quality management strategies, minimum data set collection, research and education.</li> </ul> <p>The group is recognised as the primary source of advice to the Area Health Service on cancer services for the Area.</p>
<b>Area Coordinator or Director of Cancer Services</b>	<p>The individual nominated or appointed by the Area Health Service who has leadership responsibility for the development of cancer services across the continuum across the Area Health Service, in accordance with the standards outlined in this framework and with good practice.</p> <p>The Area Director/Coordinator has responsibility to:</p> <ul style="list-style-type: none"> <li>● provide leadership to the Area Cancer Service Management Group</li> <li>● ensure that Area-wide site-specific clinical groups are established and their work commissioned and coordinated.</li> </ul>

Key term	Definition
<b>Area-wide site-specific clinical groups</b>	<p>A limited group of experts for each cancer site (at least including breast, lung, colorectal, prostate, and gynaecological cancers) who are the agreed source of the Area's clinical opinion on matters relating to their particular cancer site.</p> <p>Each site-specific clinical group is to be coordinated by a named lead clinician, and to have agreed clinical guidelines and protocols as well as referral guidelines (the indications for referral of a patient to a given level of care, from primary care to Cancer Unit, Comprehensive Cancer Centre, or care outside the Area Health Service).</p>
<b>Cancer Care Model</b>	<p>An organisational model for the delivery of cancer care services within NSW. The Model was developed as part of the NSW Health Department's Optimising Cancer Management Initiative in 1999 (NSW Health, 1999a), and consists of a reconfiguration of the existing organisational elements comprising population health services, Cancer Units and Comprehensive Cancer Centres.</p> <p>The Model recommended that this service structure should be supported by the formation of strategic alliances within and across Area Health Services.</p> <p>Other mechanisms recommended by the Model for the promotion of integration and coordination of care include the use of care coordinators, patient care plans, shared care models of service delivery and patient held records.</p>
<b>Cancer Trials NSW</b>	<p>A collaborative network organisation that supports and promotes cancer clinical trials and related research in NSW. <i>Cancer Trials NSW</i> operates under the auspices of The Cancer Council NSW and its aims include:</p> <ul style="list-style-type: none"> <li>• funding of staff for trials coordination, data management and consultative statistical support</li> <li>• development of a comprehensive website including a database registry of all cancer clinical trials</li> <li>• provision of access to information about clinical trials in cancer therapies to assist cancer patients</li> <li>• support of locally initiated trials.</li> </ul> <p>Further information regarding <i>Cancer Trials NSW</i> is available at <a href="http://www.cancer council.com.au">www.cancer council.com.au</a></p>
<b>Cancer Unit</b>	<p>A facility which provides access to diagnostic (Role Delineation Level 4 Pathology and Imaging, Level 3 Nuclear Medicine), treatment (Level 4 surgery, medical oncology, radiation oncology), palliative care (Level 2 or 3), rehabilitation (Level 2 or 3) and support services (physiotherapy, social work, occupational therapy, dietetics, speech therapy, interpreters) for the management of patients with cancer (NSW Health, <i>Guide to the Role Delineation of Health Services</i>, 3rd Ed. 2002).</p> <p>A Cancer Unit may be located at a major non-metropolitan referral hospital or district metropolitan hospital, with formal network links to a Level 6 service provider (Comprehensive Cancer Centre).</p>
<b>Care Coordinator</b>	<p>A nominated professional who facilitates patient-centred and integrated cancer care, and continuity of care across the continuum of care. The care coordinator may be a treating clinician or general practitioner in standard cases or a specialised coordinator in more complex cases. The care coordinator liaises with and coordinates service providers, provides patient and carer education and acts as a point of contact for all. Care coordinators' roles may be filled by specialist cancer nurses, or other health professionals.</p>

# 6. Glossary

Key term	Definition
<b>Comprehensive Cancer Centre</b>	<p>A centre which is normally located in a major metropolitan referral or principal referral hospital and incorporates one or a number of sub-specialty medical oncology, radiation oncology, surgical oncology, palliative care and rehabilitation streams. It also provides access, on a consultative basis, to a range of generalist (non cancer specific), clinical sub-specialty (eg psychiatry) and support services at Role Delineation Level 5 (imaging) and Level 6 (pathology and nuclear medicine), incorporates a multi-disciplinary approach to service delivery by staff with specific training and/or expertise in cancer care and plays a major role in teaching, research and quality assurance.</p>
<b>Information pack</b>	<p>A recommended pack of information which should be provided to all cancer patients at the point of diagnosis or before definitive treatment has commenced, including information on:</p> <ul style="list-style-type: none"> <li>● the Cancer Helpline (The Cancer Council NSW)</li> <li>● resources available from widely recognised organisations such as The Cancer Council NSW, National Breast Cancer Centre, NSW Breast Cancer Institute</li> <li>● non-mainstream transport services (eg community transport, ambulance services, and patient transport services provided by Area Health Services and Aboriginal Health Services) to and from the treatment centre</li> <li>● recommended accommodation near the treatment centre</li> <li>● financial assistance schemes and their eligibility criteria.</li> <li>● the names and description of local support groups</li> <li>● the names and description of one-to-one peer support networks (eg Breast Cancer Support Service, Prostate Cancer Support Network, Bowel Cancer Support Network)</li> <li>● an amalgamated guide to clinical services at the cancer facility, including a map and information on facilities such as mode and cost of parking and cafeteria</li> <li>● a list of reliable cancer websites and books.</li> </ul>
<b>Lead clinician</b>	<p>A clinician member of an Area-wide site specific clinical group who takes on the responsibility for the Group's coordination and operation. This clinician need not necessarily be the most professionally or academically senior member of the group. It is also recognised that there are many examples of where this coordination role has been successfully performed by individuals without a clinical background, but with strong leadership skills.</p>
<b>Multi-disciplinary care</b>	<p>Comprehensive care provided by a team of various health professionals, using a care team approach to decision-making regarding treatment planning and other aspects of care for individual patients.</p>
<b>Multi-disciplinary teams (MDTs)</b>	<p>Teams of designated health professionals who work together to make multi-disciplinary recommendations to primary treating clinicians regarding the diagnosis, treatment and care of individual patients. The core team comprises all the medical and other specialists relevant to the diagnosis, treatment and care of a particular cancer site or type.</p> <p>Core MDTs should meet at an agreed frequency to discuss the planned management of individual cancer patients, and should agree on specified Area-wide clinical guidelines, protocols and referral guidelines with the Area-wide site-specific clinical group for that cancer site.</p> <p>Fully developed MDTs will include input from the general practitioner, palliative care, psycho-oncology, allied health and other health professionals such as geneticists, psychiatrists and nuclear medicine physicians.</p>

Key term	Definition
<b>Optimising Cancer Management Initiative (OCMI)</b>	<p>The aim of this NSW Health initiative, which started in 1996, was to optimise cancer management in NSW by developing a framework for the integration of cancer services and programs incorporating evidence-based practice (NSW Health, 1999). The Initiative coordinated a range of major strategies in four streams:</p> <ol style="list-style-type: none"> <li>1. Integration and coordination of cancer services</li> <li>2. Promotion of patient-centred care</li> <li>3. Development of information systems for monitoring quality and outcomes in cancer care</li> <li>4. Development and implementation of clinical practice guidelines.</li> </ol>
<b>Personal health record</b>	<p>A patient-held record which provides patients with regularly updated information regarding their disease and its ongoing management, and provides immediate access by all appropriate health service providers to key information such as diagnostic test results, current medication regimens and treatment plans, emergency contact details and other relevant information.</p> <p>NSW Health has developed and distributed copies of a personal health record to general practitioners and to Area coordinators of the Chronic Care Programs, for use by patients with chronic and complex conditions including cancer. <i>My Health Record</i> is in a folder format that can be adapted to the specific needs of cancer patients for coordination of their care, and can be updated throughout periods of care. Copies of <i>My Health Record</i> are available from the Better Health Centre on (02) 9816 0452.</p>
<b>Points of contact</b>	<p>A resource for patients that provides 24-hour access to appropriate services, professional information, education and advice when required.</p>
<b>Specialist cancer nurses</b>	<p>Nurses with specific training and expertise in cancer care, who are integral members of multi-disciplinary teams, and play an important role in reducing psychological morbidity associated with cancer, enhancing early recognition of patient and carer support needs and providing continuity of care.</p> <p>Relevant education programs for cancer nurses are detailed in Australian Standards for Specialist Cancer Nursing Education Programs (Cancer Nurses Society of Australia, 1999).</p>
<b>Virtual Cancer Units</b>	<p>The physical linking of remote service providers through existing technologies such as Teleconferencing, Telehealth and e-mail for administrative, clinical (multi-disciplinary assessment and treatment planning), educational, research and quality assurance purposes. The resulting entity is capable of providing the services provided by a Cancer Unit, through the use of technologies as well as formal linkages with larger centres.</p>

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# Service models

Service Model I – Providing multi-disciplinary care in a Comprehensive Cancer Centre	
<b>Location</b>	Department of Gynaecological Oncology, Westmead Hospital
<b>Team members</b>	<ul style="list-style-type: none"> <li>● Gynaecological oncologists</li> <li>● Medical oncologists</li> <li>● Radiation oncologists</li> <li>● Junior medical officers</li> <li>● Pathologist</li> <li>● Clinical nurse consultant</li> <li>● Clinical psychologist</li> <li>● Social worker</li> </ul>
<b>Structure</b>	<ul style="list-style-type: none"> <li>● Agreed protocols of treatment for each gynaecological malignancy               <ul style="list-style-type: none"> <li>- Developed with input from medical oncologists, radiation oncologists and gynaecological oncologists from most centres in NSW and reviewed 1-2 times per year.</li> <li>- For most cases, the gynaecological oncologist proceeds to operate.</li> <li>- For cases where there is uncertainty, multi-disciplinary discussion occurs before surgery.</li> </ul> </li> <li>● Weekly tumour board meeting               <ul style="list-style-type: none"> <li>- Attended by all members of multi-disciplinary team as listed above.</li> <li>- Upon receipt of pathology following surgery, the case is presented by the lead clinician for that case, discussed by the multi-disciplinary team and a treatment plan developed and documented.</li> </ul> </li> <li>● Joint consultation               <ul style="list-style-type: none"> <li>- For some cases (eg cervical cancer), a joint assessment is done by the gynaecological oncologist and radiation oncologist in the operating theatre while the patient is under anaesthetic and appropriate treatment determined.</li> </ul> </li> <li>● Weekly ward meeting               <ul style="list-style-type: none"> <li>- Attended by nurses, palliative care representatives, social worker, clinical psychologist, gynaecological oncologist to discuss the care of patients on the ward.</li> </ul> </li> <li>● Psychosocial support               <ul style="list-style-type: none"> <li>- Unit clinical psychologist and social worker who provide counselling and facilitate two educational-support groups for women with early stage or advanced stage cancers.</li> <li>- The Clinical Nurse Consultant undertakes routine psychosocial screening of every patient attending the pre-admission clinic with early referral to clinical psychologist or social worker as needed. Ongoing psychosocial assessment occurs during admission incorporating discharge planning, monitoring of needs and referral.</li> <li>- Patient information sessions and yoga program.</li> <li>- Relaxation tapes.</li> <li>- Lending library of resources.</li> </ul> </li> </ul>
<b>Throughput</b>	330 new patients per year

<b>Service Model 2 – Providing coordinated care: lung cancer multi-disciplinary team</b>	
<b>Location</b>	Newcastle Mater Hospital
<b>Team members</b>	<ul style="list-style-type: none"> <li>● Respiratory physician</li> <li>● Thoracic surgeon</li> <li>● Medical oncologist</li> <li>● Radiation oncologist</li> <li>● Pathologist</li> <li>● Radiologist</li> <li>● Palliative care</li> <li>● Lung cancer resource nurse</li> </ul>
<b>Structure</b>	<ul style="list-style-type: none"> <li>● Fortnightly multi-disciplinary team meeting                             <ul style="list-style-type: none"> <li>- Cases with suspected stage IIIA, IIIB,IV cancer, complex cases and mesothelioma cases are presented and discussed by the team to confirm diagnosis and recommend best practice treatment.</li> </ul> </li> <li>● Lung cancer resource nurse                             <ul style="list-style-type: none"> <li>- Coordinates and organises multi-disciplinary team meetings.</li> <li>- Notifies patient's general practitioner of management plan options within 24 hours of case being presented at multi-disciplinary team meeting.</li> <li>- Notifies hospital social worker of patients with a new diagnosis. Social worker contacts patient and offers assistance.</li> <li>- Provides written information to patients about the disease, diagnostic process and treatment procedures.</li> <li>- Serves as a central point of contact for patients and their general practitioner to obtain further information or re-entry to the system.</li> </ul> </li> <li>● General practitioner                             <ul style="list-style-type: none"> <li>- Participates in the management of common side effects of treatment and on-going care. The GP is provided with written information based on best practice of management of potential side effects of treatment for lung cancer.</li> </ul> </li> </ul>
<b>Throughput</b>	Currently only more complex cases with a view to including all 250 lung cancer patients per year in the Area.

Hunter Health in conjunction with the Mater Hospital is trying to improve the processes involved in the delivery of lung cancer services. This is being achieved through the provision of better information to patients and providers about the disease process and treatment options, improved coordination in the diagnostic process through a multi-disciplinary team approach to the diagnosis and treatment of lung cancer and through the involvement of the General Practitioner in the management of common side-effects of treatment and on-going care.

The multi-disciplinary team consists of representatives from respiratory medicine, thoracic surgery, medical oncology, radiation oncology, histopathology, radiology and palliative care. The team is coordinated and organised by a Lung Cancer Resource Nurse. The team meet fortnightly. At this stage patients with suspected stage IIIA, IIIB, IV, problematic patients and patients with mesothelioma are presented. However a mechanism is currently being developed to ensure that all patients diagnosed with lung cancer are registered with the team.

The multi-disciplinary team approach is designed to:

- provide more consistent and streamlined management of patients diagnosed with lung cancer
- provide the patient with written information about the disease, diagnostic process and treatment procedures
- provide a central point of contact for the patient and GP.

#### Benefits for patients from the MDT

- reduction in the length of time patients wait between diagnosis and treatment
- provision of information about the disease and treatment phases
- increase in quality of life and satisfaction as patient moves through the system more quickly and in a more coordinated way
- decrease in the number of crisis attendances to Emergency Departments.

#### Benefits for GPs from the MDT

- notification within 24 hours of your patient's presentation at MDT meetings and treatment options for that patient
- written information based on best practice of management of potential side effects of treatment for lung cancer
- central point of reference to obtain further information, or re-entry to system via MDT.

### Service Model 3 – Providing cancer services in a large non-capital city via resident specialists

<b>Location</b>	Border Medical Oncology, Albury-Wodonga
<b>Team members</b>	<ul style="list-style-type: none"> <li>● Medical oncologists</li> <li>● Medical oncology registrar</li> <li>● Radiation oncologists</li> <li>● General surgeons</li> <li>● Specialist surgeons</li> <li>● Oncology pharmacists</li> <li>● Oncology nurses</li> <li>● Palliative care nurses</li> <li>● Research nurses</li> </ul>
<b>Structure</b>	<ul style="list-style-type: none"> <li>● Local cancer treatment                             <ul style="list-style-type: none"> <li>- Resident specialists provide a range of cancer treatment specialities including medical oncology, radiation oncology and surgical oncology. Links established with Royal Melbourne Hospital to provide ongoing support to resident oncologists and to deal with complex or high risk cases.</li> <li>- Specific types of tumours treated on-site. Sarcoma, acute leukaemia, paediatric oncology referred to specialist units in city.</li> <li>- Specific surgical oncology procedures performed on-site. Thoracic surgery, neurosurgery, gynaecology oncology, breast reconstruction referred to specialist unit in city.</li> </ul> </li> <li>● Monthly multi-disciplinary clinics.                             <ul style="list-style-type: none"> <li>- Involves medical oncologists, radiation oncologists, general surgeons and specialist surgeons.</li> <li>- Conducted in breast, gynaecology, head and neck and urology cancers.</li> </ul> </li> <li>● Palliative care service.</li> <li>● Outreach clinics to Finley and Wangaratta.</li> <li>● Clinical trials unit.</li> </ul>
<b>Throughput</b>	750 new patients per year

Source: *Cancer in the Bush: Optimising Clinical Services (COSA, 2001)*

Service Model 4 – Providing cancer services in rural communities via outreach clinics	
<b>Partners</b>	Prince of Wales Hospital (provider) Tamworth Base Hospital (recipient)
<b>Team members</b>	<ul style="list-style-type: none"> <li>● From Prince of Wales Hospital               <ul style="list-style-type: none"> <li>- Consultant medical oncologist</li> <li>- Consultant radiation oncologist</li> </ul> </li> <li>● From Tamworth Base Hospital               <ul style="list-style-type: none"> <li>- General surgeons</li> <li>- Specialist surgeons in breast, colorectal and gastro-intestinal</li> <li>- Haematologist</li> <li>- Clinical nurse consultant</li> <li>- Palliative care nurse</li> </ul> </li> <li>● From New England Area Health Service               <ul style="list-style-type: none"> <li>- General practitioners</li> <li>- Community health centre</li> </ul> </li> </ul>
<b>Services</b>	<ul style="list-style-type: none"> <li>● Weekly outreach clinic at Tamworth Base Hospital provided by consultant medical oncologist and radiation oncologist visiting from Prince of Wales Hospital on different days.               <ul style="list-style-type: none"> <li>- Consultant oncologists provide expert opinion on treatment, develop patient management plans, perform clinical review of patients.</li> <li>- Cases are presented by the medical oncologist at the weekly Prince of Wales Hospital multi-disciplinary team meeting and further treatment decisions made by the team.</li> <li>- Treatment decisions documented and sent to patient's surgeon and general practitioner.</li> <li>- Day to day management of outreach clinic and care coordination provided by Clinical Nurse Consultant. Day to day management of patients in-between visits from the consultant oncologists is provided by nurses and general practitioners.</li> </ul> </li> <li>● General surgery for less complicated cases as well as specialist surgery for breast, colorectal and gastro-intestinal cancer performed at Tamworth Base Hospital.</li> <li>● Haematology service provided at Tamworth Base Hospital by resident haematologist with peer support provided by haematologists at Prince of Wales Hospital via videolink.</li> <li>● Palliative care provided by dedicated palliative care ward at Tamworth Base Hospital with expertise provided by Newcastle Mater Hospital via telephone.</li> <li>● Psychosocial support/counselling provided by Clinical Nurse Consultant (palliative care), general practitioners and community health centre. Remote tele-psychology service proposed between Prince of Wales Hospital and four local Tamworth centres.</li> </ul>
<b>Throughput</b>	40-50 patients per day (outreach clinic)

<b>Service Model 5 – Providing cancer services in rural and remote communities via telehealth</b>	
<b>Partners</b>	Royal Adelaide Hospital Cancer Centre (provider) Royal Darwin Hospital (recipient)
<b>Team members</b>	<ul style="list-style-type: none"> <li>● From Royal Adelaide Hospital               <ul style="list-style-type: none"> <li>- Medical oncologists</li> <li>- Radiation oncologists</li> <li>- Palliative care clinicians</li> <li>- Pathologists</li> <li>- Radiologists</li> <li>- Nurses</li> </ul> </li> <li>● From Royal Darwin Hospital               <ul style="list-style-type: none"> <li>- General physicians</li> <li>- Surgeons</li> </ul> </li> </ul>
<b>Services</b>	<ul style="list-style-type: none"> <li>● Videoconferencing link between Royal Adelaide Hospital and Royal Darwin Hospital.               <ul style="list-style-type: none"> <li>- Facilities at Royal Adelaide Hospital include a purpose-built 30-seat videoconferencing theatre, adjacent clinic room and remote cameras. Royal Darwin Hospital has a portable videoconferencing unit.</li> <li>- The pathology slides and medical images of cases are sent from Darwin and reviewed by the appropriate specialists in Adelaide prior to discussion at weekly multi-disciplinary meetings.</li> <li>- General physicians and surgeons in Darwin present the cases via videoconferencing to a multi-disciplinary meeting of specialists at the Royal Adelaide Hospital, treatment recommendations are made and the treating physicians in Darwin convey the opinion of the meeting to their patients. Patients are informed in advance that their case will be discussed via videoconference link.</li> <li>- For continuing education purposes, clinicians in Darwin can remain on-line to participate in the presentation of the local Adelaide cases.</li> <li>- Weekly videoconferences supplemented by clinician visits at least annually.</li> </ul> </li> <li>● Patients can receive chemotherapy from general physicians in Darwin in accordance with the chemotherapy guidelines of the medical oncology unit in Adelaide and with the support of the associated medical oncologists.</li> </ul>

Source: Olver N, Selva-Nayagam S. Evaluation of a telemedicine link between Darwin and Adelaide to facilitate cancer management. *Telemedicine Journal* 2000;6:213-18.

# Membership of Cancer Clinical Expert Reference Group and Special Interest Group for Cancer

## Co-Chairs of Cancer Clinical Expert Reference Group and Special Interest Group for Cancer

<b>A/Prof Paul Harnett</b>	<b>Director of Cancer Services, Western Sydney and Wentworth Area Health Services</b>
<b>Dr Tom Acheson</b>	<b>GP Director, Hornsby-Ku-ring-gai-Ryde Division of General Practice</b>

## Cancer Clinical Expert Reference Group

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Ms Sally Crossing	Consumer Representative, Cancer Voices NSW
Dr Peter Davidson	General Practitioner, Cowra NSW
Ms Mary Hicks	Clinical Nurse Consultant, Tamworth Base Hospital
Ms Aspasia Iosifidis	Social Worker in Charge, Wollongong Hospital
Dr Shanti Kanagarajah	Head, Geriatric Medicine, Port Kembla Hospital
Prof John Kearsley	Professor Cancer Services, St George Hospital
Dr Karen Luxford	Evidence Based Medicine Manager, National Breast Cancer Centre
Ms Halina Nagiello	Senior Planner, Royal North Shore Hospital
Dr Andrew Penman	Chief Executive Officer, NSW Cancer Council
Dr Michael Smith	Palliative Care Unit, Mt Druitt Hospital

## Special Interest Group for Cancer

### All Cancer Clinical Expert Reference Group members (as above)

Ms Gilli Appleby	Director, Integrated Care Hunter AHS
Dr Rodney Aroney	Medical Oncologist, Gosford Hospital
Dr Robert Arthurson	Chairperson, Cancer CRG Southern AHS
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