

WA Health Cancer Services Framework

October 2005



Developed by the WA Health Cancer Services Taskforce

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Foreword

Each year, cancer affects thousands of people in Western Australia both directly and indirectly, with around 3500 people losing their lives to the disease. One of the top priorities of the health reform agenda and a key strategy in 'Delivering a Healthy WA' is to ensure that coordinated, high quality cancer services are available in this State.

The WA Health Cancer Services Framework is a comprehensive document outlining initiatives that have been widely supported by the community and key stakeholders. These strategies have been endorsed by the Minister for Health, Jim McGinty MLA as a plan for Cancer Services in WA. There is also significant support by the State Government to advance and expand cancer services already provided in this State, demonstrated by its funding commitment to this process.

I'd like to commend the excellent work of the Western Australian Cancer Services Taskforce, which convened in January 2005 and was chaired by Professor Christobel Saunders to examine the provision of cancer services in this State, and subsequently undertook the task of developing this Framework for improving services over the next five years.

Thank you also to all those who participated in the consultation process in developing this Framework. The depth and breadth of input received has been, and will continue to be, an extremely valuable resource to guide us in the establishment of a Cancer Network and the implementation of these key cancer initiatives.

The State Cancer Network is to be the first official clinical network established under the leadership of Dr Simon Towler, Executive Director of the Health Policy and Clinical Reform Division. The role of the clinical networks includes the promotion and building of partnerships with key stakeholders, facilitating communication and collaboration, establishing patient pathways and guidelines for evidence-based care, and incorporating a multidisciplinary whole-of-health team approach in patient care.

The Director of the Cancer Network will play a lead role in implementing the initiatives in this Framework. The Network itself will establish Tumour Collaboratives that will involve formalising communication and planning with each specific cancer group. The purpose of these Collaboratives will be to define standards and ensure effective coordination and delivery of all aspects of care - from diagnosis through referral, to treatment and follow-up.

I know the Cancer Network will be fully committed to the continuing involvement of clinicians, the community and key stakeholders in the development and implementation of cancer initiatives to ensure high quality health care is consistently provided.

WA Health Cancer Services Framework

Palliative Care and Haematology services will be established as sub-networks to coordinate and plan for statewide services to address cancer and non-cancer related conditions. These sub-networks will also utilise the support of the Cancer Network to improve the coordination of their services across Western Australia.

I am confident this Framework, and the work to be carried out through the Cancer Network, will significantly enhance cancer services in this State through improved communication, referral pathways and service provision that all patients deserve to experience.



Dr Neale Fong
Director General
Executive Chairman, Health Reform Implementation Taskforce

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Executive Summary

Background: In 2003, the Health Reform Committee (HRC) chaired by Professor Michael Reid examined cancer service delivery in Western Australia. During this process a review was conducted by Professor James Bishop, resulting in the "Review of Cancer Services for the Health Review Committee of Western Australia". In January 2005, the Western Australian Cancer Services Taskforce (WACST) was convened by the Executive Chairman of the Health Reform Implementation Taskforce Dr Neale Fong. Professor Christobel Saunders was co-opted as the Chair of the WACST.

Purpose: The WACST was convened to examine cancer service provision within the State and develop a framework for improvement of services over the next five years. This WA Health Cancer Services Framework will allow improvements in clinical practice with the aim of reducing cancer incidence, increasing survival and care, and enhancing the quality of life of cancer patients. This Framework provides a greater level of detail on the key areas for improvement and outlines an approach to advancing cancer care in Western Australia, which has built on the recommendations in the Bishop review.

Accountability: The WACST, consisting of clinical experts in cancer care and consumer representation, was established in January 2005 to make recommendations for Cancer Services in WA. The recruitment process is underway for the Director of the State Cancer Network, who will have a lead role in implementing improvements in the provision of cancer services.

Scope: The WACST undertook to examine nine key strategic areas, each within sub-groups, and each with a leader from the WACST and additional co-opted members. Palliative care services are not included in this document as they are being reviewed in a concurrent process by a steering group chaired by Professor Linda Kristjanson.

This Framework is for the provision of cancer services in the public sector across the State. It also acknowledges that the private sector currently contributes significantly to cancer care in Western Australia, which is expected to continue. The WACST believes these initiatives, which describe models for delivery of best possible care, will be supported, and can be implemented in collaboration with the private sector.

In May 2005, the building of a comprehensive Cancer Centre commenced at Sir Charles Gairdner Hospital (SCGH). The implementation of services at the Cancer Centre is awaiting the recommendations of the WACST.

Initiative 1: A Director of the Cancer Network for Western Australia is appointed to commence immediately.

Initiative 2: The design brief for a comprehensive Cancer Centre at SCGH is revised to reflect the outcomes of this report.

Initiative 3: A Western Australian (State) Cancer Network Secretariat is initiated under the leadership of the Director of the Cancer Network.

Initiative 4: A Cancer Network Advisory Group is established following the appointment of the Director of the Cancer Network.

Initiative 5: A Cancer Network Lead Nurse role is developed by the Director of the Cancer Network, and the duties and reporting relationships of this position is established.

Initiative 6: The tertiary hospitals develop comprehensive Cancer Centres within area-based models that include access to radiotherapy, day chemotherapy, and supportive care services. Such facilities will care for patients with common malignancies and allocated low incidence disease groups (super-specialities).

Initiative 7: The Director of the Cancer Network proposes appropriate secondary metropolitan and rural hospitals to be developed as accredited Cancer Units.

Initiative 8: Tumour Collaboratives are established to provide formal multidisciplinary links across metropolitan, rural and remote areas of the State.

Initiative 9: Tumour Collaboratives will liaise with General Practitioners (GPs) and include a GP where relevant as part of the Collaborative.

Initiative 10: A preferred streamlined referral pathway is set up by each Tumour Collaborative ensuring patients are referred to the appropriate specialist for each type of cancer.

Initiative 11: The Director of the Cancer Network will audit current services and develop a plan ensuring patients have access to a range of supports such as allied health, psychosocial, and complementary supportive care. Cancer Nurse Coordinators have a referral role to clinical psychology and other psychosocial support services, liaising closely with the Cancer Helpline and other non-government sources of psychosocial support.

Initiative 12: Increase the number of and access to clinical psychologists and counselling psychologists for public patients. Increase public, specialist and GP awareness of these systems.

Initiative 13: Each Tumour Collaborative has links to a specialist clinical psychology service. The Breast Cancer Clinical Psychology Service could be expanded with additional resources to include all cancer patients.

Initiative 14: All cancer nurses and other cancer care professionals will have access to training in counselling skills, professional supervision, and other advanced cancer care skills supported by the State Cancer Network Secretariat and Area Health Services.

Initiative 15: Assessment of a patient-held record and/or electronic record will be undertaken by the State Cancer Network Secretariat over the next three years.

Initiative 16: A Directory of Cancer Services is developed and published by the State Cancer Network Secretariat within 12 months.

Initiative 17: A plan to increase access to domiciliary services is implemented through consultation with appropriate community service providers by the State Cancer Network Secretariat within 12 months.

Initiative 18: The Cancer Network and Cancer Nurse Coordinators work with the Aboriginal Medical Service (AMS) to improve knowledge of cancer and support available by AMS health workers.

Initiative 19: The Director of the Cancer Network develops a strategy for increasing participation in clinical trials in collaboration with the Western Australian Institute of Medical Research and The Cancer Council Western Australia.

Initiative 20: The Director of the Cancer Network supports the facilitation of regulatory affairs, provision of biostatistical support and data management. Other roles such as management of hospital based data managers, improving pharmacy services to support trials and supporting pathology and radiology input into trials, will be explored.

Initiative 21: The State Cancer Network Secretariat is responsible for documenting and improving patient participation in cancer clinical trials in Western Australia and establishing and maintaining a central register of cancer clinical trials and clinical audits and resulting changes to practice.

Initiative 22: The process of the ethics committee review of clinical trials be examined and streamlined to reduce duplication and delay in protocol activation.

Initiative 23: The State Cancer Network Secretariat undertakes an inventory of all existing individual/institutional cancer registries.

Initiative 24: A single unified hospital-based electronic system, established and run by the State Cancer Network, for recording clinical data, treatments and outcomes, is used by all providers of cancer services. Data collected must comply with the national clinical cancer minimum dataset of the National Cancer Control Initiative (NCCI) and any contractual agreements whereby public patients are treated in the private sector must require the same data to be collected. This State Clinical Cancer Registry will be linked to a cancer bio-specimen database and would be required to participate in data exchange and reconciliation processes with the State (Population-Based) Cancer Registry.

Initiative 25: Data in the State (Population-Based) Cancer Registry will be available by remote access to facilitate care of patients in regional and rural areas.

Initiative 26: The State (Population-Based) Cancer Registry will be funded to collect staged cancer data for all major cancers.

Initiative 27: Cancer Units are developed in some regional centres with formalised links to a Cancer Centre, Cancer Nurse Coordinators, audit and Tumour Collaboratives. A lead clinician at each local site will be identified to run the Unit, supported from identified funds.

Initiative 28: All services undergo accreditation processes as developed by national standards and the Director of the Cancer Network.

Initiative 29: The clinical staff delivering cancer services undergo credentialing as developed by national standards and the Director of the Cancer Network.

Initiative 30: Other regions, in conjunction with the Rural Medical Service, develop Cancer Outreach programs, each with a lead clinician and providers having formal links with a specified Cancer Centre and the relevant Cancer Nurse Coordinators.

Initiative 31: Rural Cancer Nurse Coordinators are set up immediately, reporting to Area Health Services and the State Cancer Network Secretariat.

Initiative 32: The Director of the Cancer Network works with the WA Country Health Service and South West Area Health Service to determine if travel and accommodation support can be improved or better tailored to suit country cancer patients.

Initiative 33: The State Cancer Network acknowledges the importance of skin cancer prevention and endorses efforts by The Cancer Council Western Australia to bring skin cancer prevention opportunities to fruition in WA.

Initiative 34: A (non-cancer specific) State Chronic Disease Prevention Strategy is developed to coordinate the individual risk factor reduction strategies and to link prevention, screening and management.

Initiative 35: The BreastScreen WA program expand to maintain a high level of participation in the face of the rapidly aging population. In the next five years BreastScreen WA consider:

- n relocating and establishing new facilities to meet the demand
- n converting to digital mammographic technology to address manpower and film storage problems
- n improving the attraction and retention of diagnostic radiographers.

Initiative 36: Planning for a Colorectal Cancer Screening program is established immediately to prepare the State for the national program.

Initiative 37: When the proposed Colorectal Cancer Screening program is initiated, consideration is given to co-locating it within an Office of Cancer Screening, along with the BreastScreen WA and WA Cervical Cancer Prevention programs.

Initiative 38: The WA Cervical Cancer Prevention recruitment program is strengthened to increase the cervical screening participation of women in Western Australia.

Initiative 39: The Familial Cancer Program is strengthened to:

- Improve the recognition of the importance of family history in establishing risk within current and planned population screening programs for breast and colorectal cancer; and
- Develop protocols within current and planned population screening programs to identify and refer high-risk patients to specialist services.

Initiative 40: GPs and consumers have access to objective material on the implications of a Prostate Specific Antigen (PSA) test, and support in decision-making.

Initiative 41: The Director of the Cancer Network identifies gaps in workforce in relation to national benchmarks, and include a workforce plan as part of the Statewide Strategic Cancer Plan.

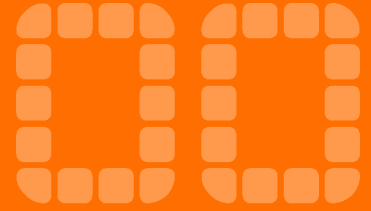
Initiative 42: The State Cancer Network supports and provides a structure for workforce planning, career path and recruitment, including training programs and ongoing education for all health care professionals.

Initiative 43: Review of access to allied health, other supportive care services, and complimentary therapies is undertaken by the State Cancer Network Secretariat to ensure appropriate screening of patients and referral to services.

Initiative 44: A structure of accreditation of individual health care professionals and multidisciplinary teams are developed and monitored through the Director of the Cancer Network.

Initiative 45: Review multidisciplinary workforce issues in the development of rural cancer services.

WA Health Cancer Services Framework



1. Background

1.1 The Burden of Cancer in Western Australia

New cases of cancer in 2003

There were 8653 new cases of cancer recorded in Western Australia in 2003, with 55% of recorded cases of cancer occurring in males. Age-standardised rates were 354 per 100,000 males, and 268 per 100,000 females, for 2003. The estimated lifetime risk of cancer to age 75 years was 1 in 3 for males, and 1 in 4 for females, which has essentially remained unchanged over the past five years.

Cancer-related deaths

Among Western Australians, there were 3318 deaths due to cancer in 2003 (males accounting for 55% of deaths). Mortality rates for 2003 were 126 deaths per 100,000 males and 87 per 100,000 females. The most common causes of cancer-related death in males were lung, colorectal and prostate cancers, while breast, lung and colorectal cancers were the most common in females.

Common cancers

The most common occurrences of cancers in males in 2003 were prostate cancer, melanoma of the skin, colorectal cancer and lung cancer. Breast cancer predominated among females, followed by colorectal cancer, melanoma and lung cancer. These patterns have changed very little in recent years.¹

1.2 National Initiatives

National initiatives relevant to the development of a comprehensive cancer service are:

Cancer Australia

The Federal Government will establish a single new national agency, Cancer Australia. This decision addresses a recommendation of the Government's current policy advisory body, the National Cancer Control Initiative, that there is a National Taskforce on Cancer to ensure that the entire spectrum of cancer care services throughout Australia are evidence-based and consumer-focused.

Cancer Australia, which is accountable to the Federal Minister for Health, will:

- Provide national leadership in cancer control
- Guide improvements to cancer prevention and care, to ensure treatment is scientifically based
- Coordinate and liaise between the wide range of groups and providers with an interest in cancer
- Make recommendations to the Federal Government about cancer policy and priorities and
- Oversee a dedicated budget for research into cancer.²

¹ Cancer Registry 2005

² Strengthening Cancer Care Australian Liberal Party

The Western Australian Cancer Services Taskforce (WACST) supports the Federal Government's commitment to the establishment of Cancer Australia as a national body to provide a link between multiple national cancer agencies and implementation of the recommendations in the National Service Improvement Framework for Cancer.

Senate Inquiry

The WACST made a submission in March 2005 to the Cancer Care Senate Inquiry into service and treatment options for persons with cancer. The submission addressed the terms of reference in the inquiry that related to the key areas being undertaken by the WACST in the development of a statewide framework for improving cancer services (See Appendix 1). Following the submission there was a request for evidence to be presented to the Community Affairs References Committee on 31st March 2005. The final report of the inquiry into services and treatment options for persons with cancer is available on the internet at:

http://www.aph.gov.au/senate/committee/clac_ctte/cancer/report/a01.pdf - 127k

2. Introduction

In 2003, the Health Reform Committee (HRC) chaired by Professor Michael Reid examined cancer service delivery in Western Australia. During this process a review was conducted by Professor James Bishop which resulted in the "Review of Cancer Services for the Health Review Committee of Western Australia" in October 2003 (the Bishop review). The Health Reform Implementation Taskforce (HRIT) has been established to implement the recommendations of the HRC. The Executive Chairman of HRIT is Dr Neale Fong, Department of Health Director General.

In January 2005, the Western Australian Cancer Services Taskforce (WACST) was convened by Dr Neale Fong. Professor Christobel Saunders was co-opted to chair the WACST, and administrative support was provided by the HRIT (Ms Liza Houghton, Senior Project Coordinator and Mr Kingsley Burton, Project Director). Extensive contributions were made by clinicians and other stakeholders throughout the process.

The outcome of the WACST has been the development of this WA Health Cancer Services Framework 2005-2010.

2.1 Funding for the Proposed Initiatives

The initiatives contained in the WA Health Cancer Services Framework will be supported by State Government funding committed during the development process.

The State Government has undertaken to fund a series of initiatives in Cancer Control. These include a \$30 million commitment over four years, with:

- \$16 million for specific cancer prevention and care strategies:
 - Cancer Nurse Coordinators; 10 rural/10 metropolitan - \$4.8 million
 - Country Cancer Medical Services upgrade - \$4 million
 - Improved access to specialised cancer services - \$4 million
 - Improving clinical practice program - \$2 million
 - Establishing Office of Director Cancer Network - \$1.2 million
- \$4 million for improving Palliative Care and Support services particularly to the rural areas
- \$6 million to ensure that cancer research is rapidly and directly applied to clinical practice
- \$1.2 million to expand the Statewide Skin Cancer Prevention Program
- \$2.8 million to implement necessary infrastructure to enable the introduction of a statewide colorectal screening program.

PLUS

- \$12 million for two additional radiation therapy machines as phase 1 of the State Cancer Centre.
- A verbal commitment to build a comprehensive State Cancer Centre once requirements for this type of facility are identified by WACST.

It is recommended that these initiatives are led by the Director of the Cancer Network. The timeframes for implementation of these initiatives begin with the recruitment of the Director of the Cancer Network and are all expected to commence in the 2005/06 financial year.

3. Western Australian Cancer Services Taskforce

3.1 Purpose

The Western Australian Cancer Service Taskforce (WACST) was convened and chaired by Professor Christobel Saunders to examine cancer service provision within the State and develop a framework for improvement of services over the next five years. This Framework will allow improvements in clinical practice with the aim of reducing cancer incidence, increasing survival and care, and enhancing the quality of life of cancer patients. This Framework provides a greater level of detail of the key areas for improvement and outlines an approach to advancing cancer care in Western Australia, which has built on the recommendations in the Bishop review.

The main objectives of the Bishop review were:

1. To develop a framework for cancer, which is likely to substantially improve outcomes for patients, taking into consideration the current limitations of care.
2. To develop high-priority initiatives most likely to achieve the desired changes and outcomes.
3. To describe how a Director of the Cancer Network and a State Centre for Cancer Coordination will help achieve these aims.

3.2 Terms of Reference

The WACST role was to assist in improving the coordination, integration and delivery of cancer services in Western Australia. In particular, the WACST was to consider and advise on:

- a. The development and implementation of a comprehensive statewide framework for cancer services.
- b. Long-term service deployment to ensure equitable access and to promote integrated models of care.
- c. Resource priorities for cancer services to ensure appropriate coordination, optimal mix and distribution of services.
- d. A continuing commitment to quality and appropriate standards of cancer care including benchmarks, accreditation and credentialing.
- e. Workforce, education, and training required by medical and other health personnel to support the framework.
- f. Maximum collaboration with government and the non-government sectors.
- g. How clinical research and audit should be integrated into clinical care.
- h. Other relevant matters.

3.3 Accountability

The WACST consisting of clinical experts in cancer care and consumer representation was established in January 2005 to make recommendations for cancer services in WA. The position of the Director of the Cancer Network will be recruited in the near future, to take on the lead role of implementing improvements in the provision of cancer services in this State.

3.4 Scope

The WACST undertook to examine nine key strategic areas, each within sub-groups, and each with a leader from the Taskforce and additional co-opted members. Palliative care services are not included in this document as they are being reviewed in a concurrent process by a steering group chaired by Professor Linda Kristjanson.

Further development of the comprehensive Cancer Centre at Sir Charles Gairdner Hospital (SCGH) is awaiting the outcomes of this report.

This Framework is for the provision of cancer services in the public sector across the State. It also acknowledges that the private sector currently contributes significantly to cancer care in Western Australia, which is expected to continue. The WACST hopes that these initiatives, including models of care and the development of the Tumour Collaboratives, will be supported, and can be implemented in collaboration with the private sector.

3.5 Membership

The WACST members appointed by the Executive Chairman, Health Reform Implementation Taskforce (HRIT) include:

Professor Christobel Saunders (Chair) - Professor Surgical Oncology, School of Surgery & Pathology
UWA, RPH, SCGH

Dr David Joseph - Director, Department of Radiation Oncology, SCGH

Mr Steve Archer - General Surgeon, Department of General Surgery, RPH

Dr Henrietta Bryan - General Practitioner, Shenton Park

Dr Michael Byrne - Consultant Oncologist, SCGH

Dr Paul Cannell - Consultant Haematologist, RPH

Dr Barry Cassidy - Radiation Oncologist RPH, Perth Radiation Oncology Centre

Ms Rhonda Coleman - Chief Radiation Therapist, SCGH

Mr Clive Deverall - Consumer Representative

Professor Michael Millward - Director, Western Australia Clinical Oncology Group WACOG, Professor
Clinical Cancer Research, SCGH, UWA

Dr Marianne Phillips - Consultant Paediatric & Adolescent Oncologist, PMH

Mr Cameron Platell - Surgeon, Department of General Surgery, FH

Ms Violet Platt - Clinical Nurse Manager Medical Oncology, SCGH

Ms Susan Rooney - Chief Executive Officer, The Cancer Council WA

Dr Margaret Stevens - Executive Director Population Health, Department of Health WA

Ms Liza Houghton - Health Reform Implementation Taskforce Senior Project Coordinator,
Department of Health WA

The co-opted members who contributed to at least one sub-group include:

Dr Peter Barratt - Senior Clinical Advisor, Department of Health WA

Dr Evan Bayliss - Medical Oncologist, RPH

Dr Martin Buck - Medical Oncologist, Mount Hospital

Dr Phil Claringbold - Medical Oncologist, FH

Ms Lynley Coen - Coordination of Promotion, BreastScreen WA

Ms Sue Eslick - Manager Health Strategies, WA Country Health Service

Ms Julia Fallon Ferguson - Manager of Women's Cancer, The Cancer Council WA

Clinical Professor Ian Hammond - Gynaecologic Oncologist & Director of Gynaecology, KEMH

Mr Paul Katris - Executive Officer WACOG, The Cancer Council WA

Ms Amanda Leigh - Director Cancer Services, The Cancer Council WA

Dr Yee Leung - Gynaecologic Oncologist, KEMH

Ms Susan Kay - Program Manager Health Service Development, SWAHS

Ms Cynthia Leal - Business Manager, BreastScreen WA

Ms Sue Leivers - Senior Policy Officer, Population Health, Department of Health WA

Dr John Lindsay - Physician, Albany, WA Country Health Service

WA Health Cancer Services Framework

Ms Gillian Mangan - Cervical Cancer Prevention Program, Department of Health WA

Dr Martin Phillips - Respiratory Physician, SCGH

Dr James Trotter - Medical Oncologist, RPH

Dr Merran Smith - Information Services, Department of Health WA

Mr Terry Slevin - Director Education and Research, The Cancer Council WA

Dr Liz Wylie - Medical Director, BreastScreen WA

4. WA Health Cancer Services Framework 2005 - 2010

In this WA Health Cancer Services Framework, 45 initiatives are presented within nine major strategic areas with outcomes to be achieved over the next five years. The strategic areas include:

- 4.1 Director of the Cancer Network
- 4.2 Structure of the Cancer Network
- 4.3 Cancer Centres
- 4.4 Models of Care: Tumour Collaboratives
- 4.5 Patient Support and Cancer Nurse Coordination
- 4.6 Clinical Trials and Cancer Data Collection
- 4.7 Rural Cancer Services
- 4.8 Prevention and Screening
- 4.9 Workforce Planning

The overall guiding principles of the Framework are based on:

- Safety and quality in cancer care
- Patient focussed care with appropriate information and transparency
- Accessibility and timeliness of care
- Addressing all elements of the patient pathway including partnerships with patients, carers and families
- Ensuring multidisciplinary care
- Addressing issues of facilities and workforce
- Supporting staff education and development
- Linking research to care and providing opportunities for enhanced data collection and
- Evidence-based therapy.

These principles are represented in the following diagram Figure 1.

WA HEALTH CANCER SERVICES FRAMEWORK

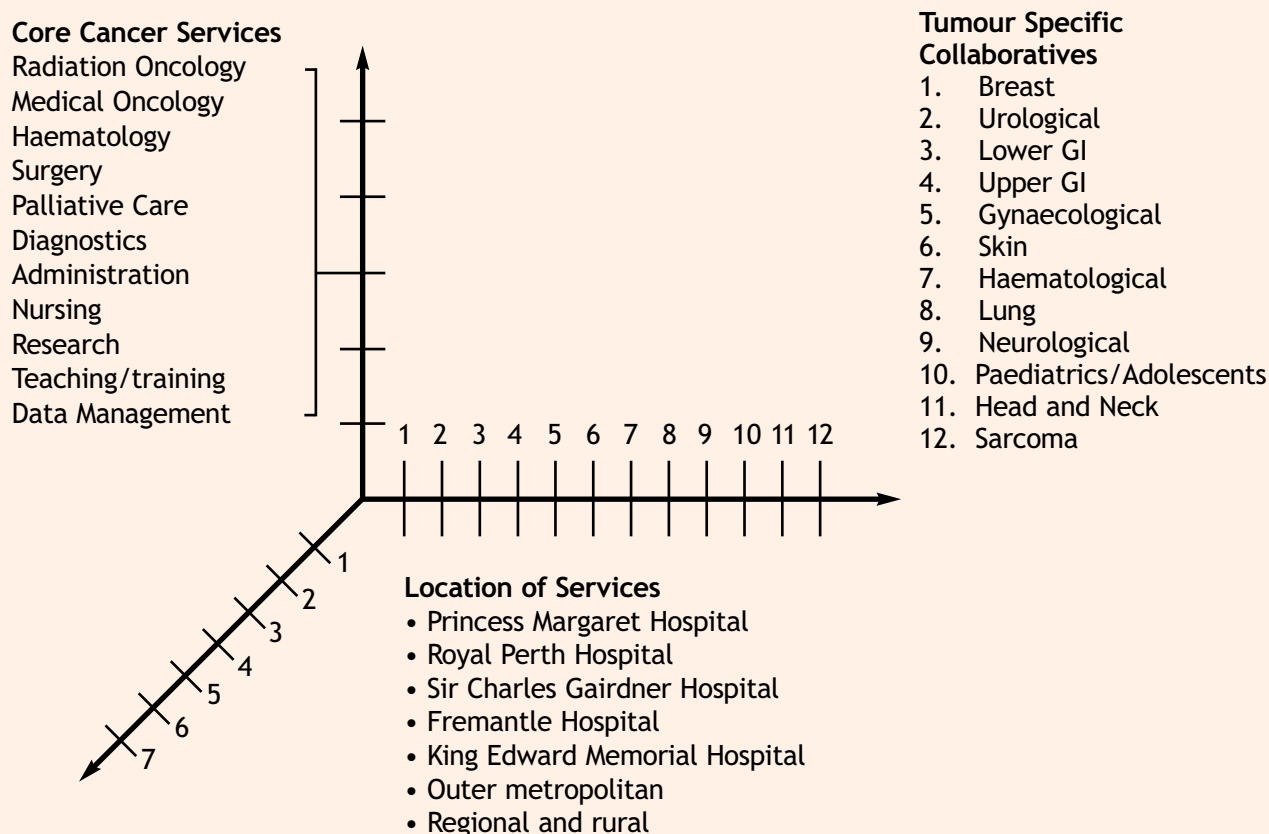


Figure 1: A three dimensional conceptual framework of the interrelationship between Tumour Specific Collaboratives, location of services, and Core Cancer Services in Western Australia.

4.1 Director of the Cancer Network

The key responsibilities of the Director of the Cancer Network will be to direct and lead the State Cancer Network Secretariat, for the purposes of developing and implementing the clinical vision and strategic reform of cancer services throughout the State.

The duties of the Director include:

Strategic Leadership

- Lead the effective implementation of the Framework.
- Lead the development and implementation of a detailed Statewide Strategic Plan for cancer services consistent with principles and directions of the Framework. The plan should address:
 - The determination and implementation of a tiered cancer care service delivery system based on best practice principles.
 - Mechanisms to ensure coordination and integration of cancer services statewide.
 - Training/workforce issues.
 - Performance monitoring including the development of an accreditation and credentialing framework and systems.

- Ensure use of evidence-based therapies.
- Continued quality improvement program.
- Clinical research.
- Resource and budget management.
- The range and mix of cancer services to be funded.
- Outcomes required in the first 12 months.
- Long-term sustainability.
- Ensure partnerships with consumers, carers, community and primary based providers, professional bodies, private and non-government sectors are all appropriately developed and that such groups are actively involved in the planning and reform process.
- Work with the Cancer Network Advisory Group and the Area Health Services to implement cancer reforms.
- Lead scenario planning of areas likely to affect service delivery to allow for contingency to be undertaken as required, for example new drug therapies, workforce shortages, etc.

Performance evaluation and clinical governance

- In consultation with relevant clinicians and Tumour Collaboratives develop and evaluate clinical standards and protocols consistent with national guidelines.
- Develop and evaluate an accreditation and credentialing framework and processes in consultation with key stakeholders.
- Audit and accredit all state public cancer services and credential clinical staff directly responsible for delivery of care to cancer patients. This includes developing a publicly available report with the capacity to recommend corrective action for non-complying facilities and services.
- Ensure the development and management of integrated information systems and processes to enable the evaluation of services and outcomes, and the facilitation of cancer research.
- Facilitate increased participation in, and access to, cancer clinical trials.

Cancer Policy

- Act as the State's principal policy adviser on cancer, advising the Director General on cancer issues and areas of required policy development.
- Develop State cancer policies with the active involvement of lead clinicians, consumers, relevant non-government organisations and other key stakeholders.
- Represent the State at Commonwealth level in all matters related to cancer including statutory issues.

Management

- Assume overall management responsibility for the State Cancer Network Secretariat including the staff and resources.
- Oversee the implementation of recommendations made by the Statewide Tumour Collaboratives.

Initiative 1: A Director of the Cancer Network for Western Australia is appointed to commence immediately.

Initiative 2: The design brief for a comprehensive Cancer Centre at SCGH is revised to reflect the recommendations of this report.

4.2 Structure of Cancer Network

WESTERN AUSTRALIAN CANCER NETWORK

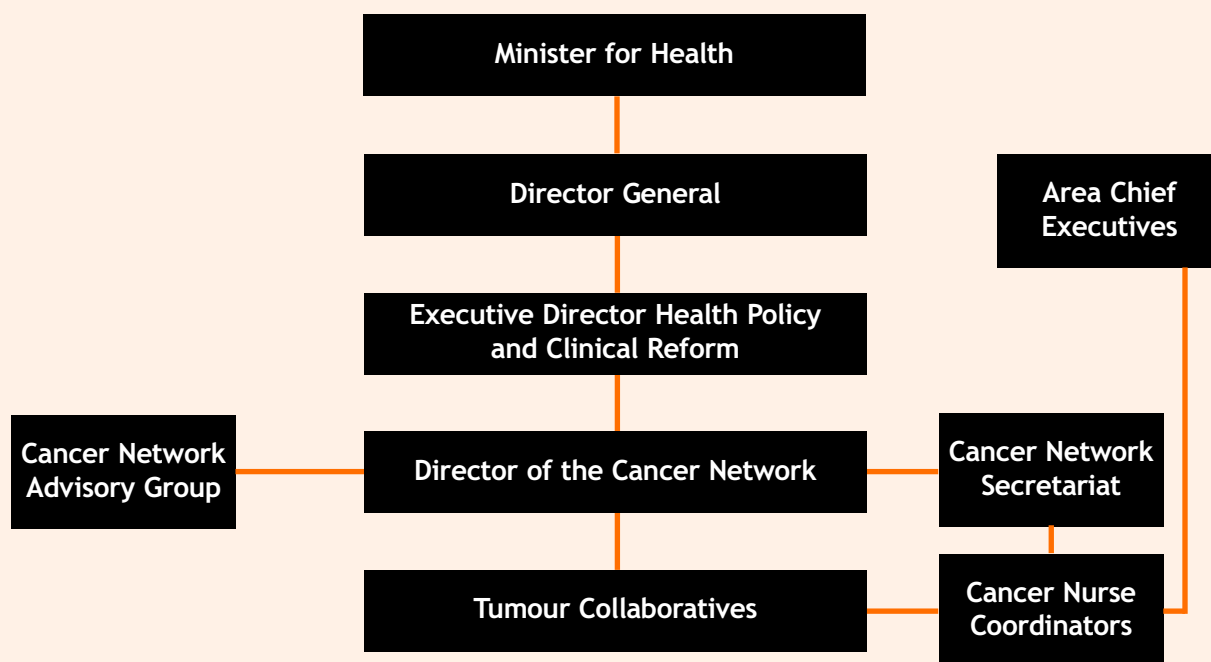


Figure 2: Western Australian Cancer Network (see Appendix 2 for detailed explanations)

The remit of the State Cancer Network Secretariat will be to support the Director of the Cancer Network to:

- Determine and implement a tiered cancer care service delivery system based on best practice principles.
- Ensure coordination and integration of cancer services statewide.
- Review and recommend strategies addressing training and workforce issues.
- Monitor performance including the development of accreditation and credentialing framework and systems.
- Facilitate a continued quality improvement program.
- Facilitate clinical research.
- Manage the resources and budget of the Cancer Network.
- Advise on the range and mix of cancer services to be funded.
- Measure outcomes and report on a 12 monthly cycle.
- Ensure long-term sustainability of the structure of the Cancer Network.
- Support the development of the Cancer Nurse Coordinator roles.
- Utilise consumer groups as reference groups.

To support the Director and to lead nursing initiatives, a Lead Nurse should be appointed within the State Cancer Network Secretariat. A business manager/operational leader will coordinate the process redesign required to ensure the Networks are efficient and effective. Other members of the Secretariat will include administrative support, a project officer and a data manager.

The role of the Cancer Network Advisory Group will be to provide expert advice on strategic issues to the Director of the Cancer Network in the coordination of statewide cancer services. It is recommended that this advisory group be made up of:

- Representatives from senior management from key health services.
- Representatives from key clinical areas from each health service, ensuring that clinicians from the tumour stream groups are represented at executive level.
- Representatives from the private sector, general practice, non-government organisations, and consumer/community.
- Co-opting people with specific skills for key tasks and establishing time limited working groups to address key issues.

Initiative 3: A Western Australian (State) Cancer Network Secretariat is initiated under the leadership of the Director of the Cancer Network.

Initiative 4: A Cancer Network Advisory Group is established following the appointment of the Director of the Cancer Network.

Initiative 5: A Cancer Network Lead Nurse role be developed by the Director of the Cancer Network, and the duties and reporting relationships of this position be established.

4.3 Cancer Centres

The concept of coordinating cancer care across the State is important, and therefore four models of existing Cancer Centres were considered throughout the process (Outlined in Appendix 3).

There is a lack of comprehensive data available to accurately measure the quantity of work, particularly ambulatory cancer services, that currently takes place in WA. This makes planning for service provision difficult. It would appear that around 90% of cancer services are ambulatory, but the precise breakdown of service delivery needs to be confirmed through accurate data collection.

Although many of the features of the State Cancer Centre described in the Reid report were relevant and essential, the concept of a single Cancer Centre providing all ambulatory cancer services for the State would not appear to be the best option in the current environment. In addition, an upgrade of radiotherapy ambulatory services at Sir Charles Gairdner Hospital (SCGH) is currently underway, but further planning is pending a decision about the size of the facility required and the outcomes of this report.

Recommended key features of cancer care in WA include:

- Inpatient facilities at all tertiary hospitals - this is in agreement with the recommendations of the Reid report.
- Ensuring continuity of care, convenience for patients and efficient ambulatory care facilities, available at the sites of inpatient care.
- Super-speciality units should be designated and patients triaged appropriately.

After consideration of the four proposed Cancer Centre models (See Appendix 3), Model 4 was selected because it accounted for the large volume of cancer services that are provided in WA; it considered the inconvenience to patients travelling to a single centre, potentially further from their home; and, it incorporated the inefficient use of time for specialist clinicians to travel to one centre for ambulatory work and another for inpatient work.

Model 4 (Preferred Option) Specifications

- Ambulatory and inpatient facilities at all tertiary hospitals.
- Designation of super-specialty units at one designated tertiary site.
- Oversight and clinical support by tertiary cancer coordinating centre and the State Cancer Network Secretariat.
- Cancer Units in rural and regional settings linked through Tumour Collaboratives to tertiary Cancer Centres.

The advantages of this preferred model are varied, and include:

- Patient focussed, not centre focussed;
- Better access for patients;
- More efficient use of staff;
- No disruption of non-cancer services provided by members of the multidisciplinary team e.g. surgical services;
- Credentialing of staff and accreditation of facilities ensures standards of care are uniform;
- Community and rural health care providers would have access to multidisciplinary expertise in the tertiary comprehensive Cancer Centres and through Tumour Collaboratives;
- Patients have access to a range of clinical trials;
- Staff have access to biological research and academic opportunities;
- Research, both basic and clinical, are considered a core service; and
- Improved patient access to allied health professionals and supportive care services that are co-located with the Cancer Centres.

Low incidence malignancies should be dealt with at super-specialty units. Such units may be located at one tertiary hospital where other members of the multidisciplinary team are located. Examples include Gynae-oncology, Neuro-oncology, Adolescent/transition, Sarcoma, Allogenic/complex transplants, and Paediatrics.

In addition to Cancer Centres (Level 6 according to the definitions used in the WA Health Clinical Service Framework-Appendix 4) the concept of Cancer Units needs to be developed. These will be at secondary metropolitan and regional hospitals with a limited scope of services. The Clinical Services Framework identifies two tertiary Cancer Centres and four cancer treatment centres at secondary hospitals. It is proposed that up to 65% of ambulatory care could be delivered at Cancer Units. This concept is a significant shift from the tertiary focus initially proposed by Reid. The scope and size of Cancer Units needs to be carefully considered by the Cancer Network in conjunction with the Tumour Collaboratives. It is important that these Units do not undermine the initial aims of a single ambulatory Cancer Centre (as proposed by Reid) such as the development of expertise for less common malignancies and facilitation of multidisciplinary care. Workforce requirements across six sites must also be considered.

Cancer Units will include ambulatory care for a defined group of conditions, access to palliative care, surgery deemed appropriate by Tumour Collaboratives, allied health and supportive care, and rehabilitation. It is suggested that initially there be a phased introduction of Cancer Units at Level 4-5 facilities only (See Appendix 4). These services will be accredited by the Director of the Cancer Network and the Tumour Collaboratives.

Initiative 6: The tertiary hospitals develop comprehensive Cancer Centres within area-based models that include access to radiotherapy, day chemotherapy, and supportive care services. Such facilities will care for patients with common malignancies and allocated low incidence disease groups (super-specialities).

Initiative 7: The Director of the Cancer Network proposes appropriate secondary metropolitan and rural hospitals to be developed as accredited Cancer Units.

4.4 Model of Care: Tumour Collaboratives

The establishment of Tumour Collaboratives will take place in the following tumour groups (which may be expanded over time):

- Lower Gastrointestinal
- Upper Gastrointestinal
- Lung
- Breast
- Skin
- Haematological
- Paediatric and Adolescent
- Urological
- Gynaecological
- Head and Neck
- Neurological
- Sarcomas - bone and soft tissue

The aims of the Tumour Collaboratives will be

- To achieve best practice and outcomes for all patients diagnosed with cancer.
- To develop outcome benchmarks for the various groups, which can be monitored throughout the state by the Director of the Cancer Network.
- To establish the resources needed to achieve these outcomes and lobby for their provision.
- To ensure standards by all providers - both staff and institutions - are maintained. Formal accreditation and credentialing processes are being developed by the Australian Cancer Network and these will form part of the future plans of the Tumour Collaboratives.
- To measure agreed outcomes for all patients, e.g. mortality, morbidity, QOL.
- To act as a communication forum and facilitate multidisciplinary care.
- To develop management guidelines for particular tumours and audit adherence to these.
- To act as an educational focus/forum.
- Address the special needs of patients from rural areas and act as a resource for rural practitioners.

These activities will occur across all sites in the public sector and when treating cancer patients and will be applicable across all disciplines.

Endpoints of the Collaboratives will be to

- Define standards of care and develop treatment guidelines.
- Improve survival and other defined outcomes for specified tumours.
- Become a resource for all aspects of care from diagnosis to treatment and follow up.

Structure of the Tumour Collaboratives

The multidisciplinary Collaboratives will be responsible directly to the Director of the Cancer Network.

Each Tumour Collaborative will have a Clinical Leader who will use the support of the Director of the Cancer Network and the Cancer Network Secretariat to establish the Tumour Collaborative. This position will rotate each 12-24 months and may come from any discipline within the Collaborative.

The Clinical Leader will chair Tumour Collaborative meetings and lead the development of the Collaborative. Each Tumour Collaborative will establish their own executive team from within the Collaborative group to support the clinical lead and ensure the initiatives of the Tumour Collaborative are implemented. The structure of each Collaborative will vary according to need, but each will represent the full multidisciplinary team, including nursing, allied health, and consumer representation.

The Collaboratives will build upon the existing Western Australian Clinical Oncology Group (WACOG) committees where appropriate, including clinicians from within these groups. It is envisaged that there will be eventual merger of the functions of WACOG and the Tumour Collaboratives.

Each tertiary hospital will support services for most complex adult malignancies. However there will be a small number of low volume, rarer malignancies treated at a single super-specialist site (for example a single soft tissue sarcoma unit). Gynaecological malignancies are currently managed in a geographically fragmented manner outside a tertiary cancer centre (surgery occurring at King Edward Memorial Hospital, radiation and medical oncology being provided by Royal Perth and Sir Charles Gairdner Hospitals). Gynae-oncology services should be considered for alignment with other adult malignancies at a tertiary hospital and be integrated in the future with provision of other gynaecological services.

Paediatric and Adolescents/Young Adults (AYA) are a distinct separate group deserving of specialised health service provision. The overall long-term survival for all malignancies in the paediatric group is now more than 70%, and clinical trial enrolment occurs in more than 90% of eligible patients. It is recommended that paediatric cancer treatment continue to be provided in the specialist multi-disciplinary, high-volume treatment centre at Princess Margaret Hospital (for children up to 19 years). Survival outcomes for AYA patients remain below 40% for most tumour types. The significant reduction in outcomes for this patient group is due to a lack of access to equivalent resources and their limited clinical trial participation, despite clinical trials for most paediatric type malignancies being open to patients from AYA age groups. There is increasing

published peer reviewed data demonstrating that many AYA cancer patients treated with the paediatric oncology approach achieve better outcomes compared with those treated on adult cooperative group trials. It is recommended that care for the majority of cancers in this age group be provided by a multidisciplinary team, in an age-appropriate environment, with adequate long-term surveillance. Thus these patients should:

- receive age-appropriate state of the art care,
- by fully skilled age-appropriate multidisciplinary teams,
- on evidence-based age-appropriate collaborative clinical trials,
- in age-appropriate facilities,
- with appropriate long-term follow-up, and
- planned transition for older adolescents/young adults.

Initiative 8: Tumour Collaboratives be established to provide formal multidisciplinary links across metropolitan, rural and remote areas of the State. Most Collaboratives will be functional within 12 months and staged implementation of the others will be over 24 months.

Initiative 9: Tumour Collaboratives will liaise with General Practitioners (GPs) and include a GP where relevant as part of the Network.

Initiative 10: A preferred streamlined referral pathway is to be set up by each Tumour Collaborative ensuring patients are referred to appropriate specialists for all cancers.

4.5 Patient support and Cancer Nurse Coordinators

A number of key gaps in cancer care are identified including access to psychosocial support, General Practitioner liaison, how public health system services fit in with those provided by non-government organisations (NGOs), special needs of Aboriginal and Torres Strait Islander cancer patients, the role of Cancer Nurse Coordinators and rural special needs.

Gaps in Psychosocial support

- There is a recognised under-provision of psychosocial support services including liaison psychiatry in the public sector and the expense of providing this in the private sector makes access inequitable.
- There is a lack of training of cancer nurses at all levels in psychosocial support, counselling and in knowledge of available services.
- A few tumour groups (e.g. the breast cancer tumour group) have good support services but this is not the case across all tumour groups nor for all patients within the public sector, particularly those treated outside tertiary hospitals.
- There is limited documentation of available services.

Gaps in General Practitioner access and liaison

- Referral patterns are not always appropriate, for example to the 'best' specialist service, nor are they streamlined.
- Communication of cancer treatment plans and follow up plans is sometimes inadequate.
- General Practitioners are not always equipped to have an 'interpreter' role.

Gaps in Interaction with community services

- There is a lack of domiciliary care in many instances with gaps in Silver Chain provision in metropolitan and rural areas. It is acknowledged that The Cancer Council WA and the WA Clinical Oncology Group (WACOG) have excellent links with cancer service providers. There is a new service providing more than 65 subsidised counsellors statewide, credentialed by The Cancer Council (in 30 localities) and accessible to cancer patients and families through the Cancer Helpline.

Gaps in Special needs of Aboriginal and Torres Strait Islander cancer patients

- Aboriginal and Torres Strait Islander cancer patients experience poorer survival outcomes and suffer from lack of support and unmet communication needs.
- Providers of cancer care are not trained in the needs of Aboriginal and Torres Strait Islander patients.

Gaps in Care Coordination

- Many patients experience confusion and lack of information during their encounter with cancer care services delivered by multiple carers and often in multiple sites (geographic as well as public/private).
- Many patients experience lack of adequate support and unmet information needs.
- Many patients do not access appropriate care.
- There is an acute lack of support for rural patients with malignancies (other than breast groups) and for some patients treated outside specialist centres.

The best model for Cancer Nurse Coordinators (CNC) is yet to be established and will almost certainly vary between locations, the nurses involved and tumour groups (See Appendix 5 for proposed model of CNC). These positions will liaise with all other members of the multidisciplinary team including the patient's GP. Cancer Nurse Coordinators will be supported through the State Cancer Network Secretariat and report through specific Area Health Services.

Co-locating complementary therapies within Cancer Centres is becoming more common and accepted practice throughout the world and is increasingly being demanded by consumers and some clinicians. This occurs locally at Sir Charles Gairdner Hospital.

Initiative 11: The Cancer Network will audit current services and develop a plan ensuring patients have access to a range of supports such as allied health, psychosocial, and complementary supportive care. Cancer Nurse Coordinators have a referral role to clinical psychology and other psychosocial support services, liaising closely with the Cancer Helpline and other non-government sources of psychosocial support.

Initiative 12: Increase the number of and access to clinical psychologists and counselling psychologists for public patients. Increase public, specialist and GP awareness of these systems.

Initiative 13: Each Tumour Collaborative is to have links to a specialist clinical psychology service. The Breast Cancer Clinical Psychology Service could be expanded with additional resources to include all cancer patients.

Initiative 14: All cancer nurses and other cancer care professionals will have access to training in counselling skills, professional supervision, and other advanced cancer care skills supported by the State Cancer Network Secretariat and Area Health Services.

Initiative 15: Assessment of a patient-held record and/or electronic record will be undertaken by the State Cancer Network Secretariat over the next three years.

Initiative 16: A Directory of Cancer Services is developed and published by the State Cancer Network Secretariat within 12 months.

Initiative 17: A plan to increase access to domiciliary services will be implemented through consultation with appropriate community service providers by the State Cancer Network Secretariat within 12 months.

Initiative 18: The Cancer Network and Cancer Nurse Coordinators will work with the Aboriginal Medical Service (AMS) to improve knowledge of cancer and support available by AMS health workers.

4.6 Clinical trials and cancer data management

Cancer Clinical Trials

Cancer clinical trials focus on developing new strategies for the prevention, detection, treatment, and overall improvement of the care and quality of life of people with cancer or people at high risk for developing cancer. There is evidence that patients who enter clinical trials have better survival and quality of life outcomes compared to patients who do not participate in trials. Therefore, for Western Australian patients there is the potential for a direct personal benefit from taking part in a clinical trial, and providers of cancer services should have systems and infrastructure that maximise the ability of clinicians to offer patients the opportunity to participate in trials.

The involvement of clinicians in clinical trials has a positive overall impact on treatment standards and approaches in the hospital or clinic where they practice. These effects include:

- An increased utilisation of evidence-based medicine.
- A greater tendency to utilise a multidisciplinary team approach to solving cancer treatment problems.
- A greater propensity to adopt leading-edge treatment approaches.

Despite these benefits, it is estimated that around 5% of adult cancer patients enter a clinical trial in Australia. No overall figures are available for Western Australia, but it is expected that the situation is in line with the national average. A survey of breast cancer patients in WA showed 2% were treated as part of a clinical trial. This is in marked contrast to paediatric oncology practice where most centres, including Princess Margaret Hospital, enter more than 80% of patients into trials. Provision of specific funding and infrastructure support for clinical trials has resulted in higher participation rates in Victoria (through the Victorian Co-operative Oncology Group Clinical Trials Management Scheme, VCOG) and in NSW (through Cancer Trials NSW coordinated through the NSW Cancer Council). The NSW Cancer Institute has also announced substantial new funding for cancer clinical trials in NSW. In Victoria, trial support through VCOG has resulted in 8% of

³ VCOG 2005

breast cancer patients being treated on a clinical trial, four times the WA rate.³ Both VCOG and Cancer Council NSW preferentially support cancer trials run by national cooperative groups and individual investigator-initiated trials (See Appendix 6).

The difficulties and barriers to accrual of cancer patients into clinical trials in WA include:

- Inadequate coordination of cancer clinical trials between different institutions.
- Inadequate access to a common source of professional assistance and education in the development and management of cancer clinical trials.
- Inadequate funding for research support.
- Inadequate public awareness of clinical trials.

Currently there is no formal centralised resource in WA that interested clinicians can use for guidance and education on cancer clinical trial management and development. This has several impacts:

- If a clinician or an institution wishes to become involved in a cancer clinical trial they must develop the systems and process themselves. This may prove to be too burdensome and hence they decide not to participate in clinical trials.
- Often more than one institution in Perth is involved in the same clinical trial yet no system exists to discuss and solve common issues associated with the conduct of specific trials, for example, pathology sampling, ethics committee issues etc. A number of tasks associated with 'opening' a clinical trial are duplicated at each site. Thus there is significant and unnecessary resource duplication.
- Much of the knowledge gained by the nurse researchers and data managers is done on-site with no reference to a formal education program or continuing education framework. This results in different approaches and a lack of access to peer group support.
- There is ineffective dissemination and coordination of relevant clinical trials information and initiatives that originate from both national and local sources.

Each facility wishing to participate in cancer clinical trials must have the resources to enrol patients and to ensure compliance with approved protocols. This requires the services of a skilled research nurse and/or data manager who works in collaboration with the clinicians at the institution. There are also significant infrastructure costs related to office space, computing facilities and administrative overheads. Many of the facilities in WA do not have identified funding for research support and this restricts their capacity to become involved in cancer clinical trials.

While there is some funding available through industry sponsored chemotherapy trials, in many instances the funding provided does not adequately cover the costs associated with all aspects of conducting clinical trials. Funding from national or international academic groups is usually much less. In addition, there are very few funding sources available to enable clinical trials to be undertaken in prevention, detection, surgery, radiation therapy or quality of life issues for people with cancer or people at high risk of developing cancer.

There is a lack of consistent education provided to the public regarding the benefits and availability of clinical trials. It is accepted both nationally and internationally that appropriate education of the public regarding clinical trials is critical to increasing participation in trials. Many people do not understand the clinical trial process and are not aware that there is a strict scientific and ethical protocol that must be adhered to. This lack of knowledge about how trials are conducted results in patients not asking about their suitability for clinical trials, or being

reluctant to participate. The Cancer Council WA (TCCWA) has had some experience and success in providing public education in this area⁴.

However, there are reasons to expect that a more coordinated approach to cancer clinical trials would lead to meaningful gains in WA:

- The number of cancer patients and treatment units is sufficient in aggregate but not so large as to make coordination of trials difficult.
- The success of the WA Institute of Medical Research (WAIMR) in developing and coordinating basic research across the University of WA (UWA) and the teaching hospitals has shown what can be achieved in this area of research, and the lessons learned could be applied to cancer trials.
- There are high-class laboratories researching aspects of cancer biology, cancer genetics and cancer immunology in WA that will enable clinical trials to link to important translational research questions.
- The setting up of the Western Australian Research Tissue Network (WARTN) means that clinical trial data can be matched with tissue samples to generate and test scientific hypotheses in a way that is unique in Australia. Funding of this service is essential to continue this valuable service in WA.
- The potential linking of clinical trial data, WARTN samples, and the highly developed WA population health and outcomes databases will provide a resource of international importance.
- The CCWA is highly experienced in public education and awareness programs, and has particularly high public visibility in WA. The CCWA strongly supports cancer clinical trials and is funding The Cancer Council Chair in Clinical Cancer Research.

TCCWA in conjunction with WAIMR has commenced the establishment of a clinical trials unit, Cancer Trials WA, and this forms the basis of plans to advance this area.

Cancer Data Collection and Use

This topic should be considered in two parts. Firstly, the collection of data on all cases of cancer that is used primarily on a population basis ('Cancer Registry') and secondly, the use of data in the management of individual patients. This second type of data can subsequently be analysed in the aggregate to examine adherence to treatment guidelines, audit outcomes of treatment, and investigate variations of practice between individual treatment centres.

All cancer diagnoses (other than non-melanoma skin cancer) in WA are required to be notified to the State Cancer Registry. This is predominantly done through pathology services that diagnose a malignancy on a biopsy or surgical specimen or via radiation oncology. By cross-reference to death records, overall survival rates of cancer patients can be determined and variations related to patient demographics ascertained. For example, recent analyses have indicated that survival rates are worse for country patients in WA (See Appendix 8). However, the State Cancer Registry does not collect information on staging of cancer at diagnosis making it difficult to determine if a survival difference is related to country patients presenting with later-stage disease. If this was the case, it would suggest that improvements could be gained by improving community education, access to screening services, and primary care whereas if the stage at presentation

⁴ Katris P, Slevin T, Comfort J. *Going public with clinical trials*. Applied Clinical Trials 2001;10: 66-68

were similar it would suggest improvements could be gained by providing better access to treatment services. A staging feasibility study funded by the National Cancer Control Initiative (NCCI) in 2003 found that staging information could be collected by the State Cancer Registry at a very modest cost.

Hospital-based cancer registries are more detailed data collections that include stage at diagnosis and some information on treatment given. Such registries exist at major tertiary hospitals. However, the existing hospital-based registries were set up predominantly by clinicians interested in certain types of cancer, and primarily used for individual research and audit purposes. No existing hospital-based registries collect data on all types of cancer and different information is collected on the same type of cancer at different hospitals. As these registries were set up independently, there is no common database software or information technology requirement, making it difficult or impossible to combine the existing registries together.

It is recognised that patients treated in the private sector are a significant part of the overall cancer treatment in WA. Apart from statutory requirements to report diagnoses to the State Cancer Registry, there is no incentive to compel private practitioners and private hospitals to contribute data on cancer patients. National developments in accreditation and audit make it likely that major private sector service providers would be willing to enter into an agreement with a public sector hospital registry. Where state public hospital patients are treated in the private sector or by public/private partnerships, it should be a requirement that the private provider give the same data as is collected in the public sector.

To implement coordinated multidisciplinary cancer care it is imperative that a single common medical record and treatment record be used for cancer patients at all sites where they are treated. Currently there are multiple different, predominantly paper-based medical records and some use of electronic data recording mainly in radiation oncology (See Appendix 7). There is no uniform recording of important data like treatment-related toxicity and direct outcomes of treatment. Systems used for patient bookings and attendance records do not directly communicate with electronic results for laboratory and radiology services. While electronic access to pathology results and diagnostic imaging is possible between major metropolitan hospitals, electronic access to pathology and radiology tests done in metropolitan hospitals is not easily available by practitioners in regional and rural centres, making coordination of care more difficult.

Initiative 19: The Director of the Cancer Network develops a strategy for increasing participation in clinical trials in collaboration with the Western Australian Institute of Medical Research and the Cancer Council WA.

Initiative 20: The Director of the Cancer Network will support facilitation of regulatory affairs, biostatistical support and data management. Other roles such as management of hospital based data managers, improving pharmacy services to support trials and supporting pathology and radiology input into trials, is to be explored.

Initiative 21: The State Cancer Network Secretariat be responsible for documenting and improving patient participation in cancer clinical trials in WA and establishing and maintaining a central register of cancer clinical trials and clinical audits and resulting changes to practice.

Initiative 22: The process of the ethics committee review of clinical trials be examined and streamlined to reduce duplication and delay in protocol activation.

Initiative 23: The State Cancer Network Secretariat undertakes an inventory of all existing individual/institutional cancer registries.

Initiative 24: A single unified hospital based electronic system, established and run by the State Cancer Network Secretariat, for recording clinical data, treatments and outcomes, be used by all providers of cancer services. Data collected must comply with the national clinical cancer minimum dataset of the NCCI and any contractual agreements whereby public patients are treated in the private sector must require the same data to be collected. This State Clinical Cancer registry will be linked to a cancer bio-specimen database and would be required to participate in data exchange and reconciliation processes with the State (Population-Based) Cancer Registry.

Initiative 25: Data in the State (Population-Based) Cancer Registry will be available by remote access to facilitate care of patients in regional and rural areas.

Initiative 26: The State (Population-Based) Cancer Registry will be funded to collect staged cancer data for all major cancers.

4.7 Rural Cancer Services

It is recognised that patients from rural and remote areas, and especially patients treated in rural and remote areas of WA, have a range of poorer outcomes in cancer, including mortality, morbidity, access and completion of appropriate treatments and access to information. Other aspects of care such as multidisciplinary care, patient support, and access to psychosocial intervention are also less than optimal for those living outside metropolitan Perth.

Specific gaps identified include:

- Poor quality and quantity of information on burden of cancer in rural areas.
- Fragmentation and lack of coordination of services.
- Workforce shortages:
 - Most cancer specialists are based in Perth and staffing is below recommended national levels in most areas.
 - Shortage of rural doctors and nurses (with a high turnover of all, in particular rural GPs). Nurses in rural areas are recognised as pivotal for support, delivery of service and palliative care.
- Patient access to transport and accommodation support including in some instances PATS for repeated and prolonged treatments.
- Outcomes are poor (See Appendix 8).
- Multidisciplinary care - lack of access to specialist surgeons in some cases and other aspects of multidisciplinary care including nursing and psychosocial care.

Models of Regional and Rural Cancer Care

The model suitable to different areas of WA will need to vary according to site and present services. In addition, the models will need to be flexible and sensitive to other health services in the area. Four current models of how specialist public cancer services are delivered in rural WA include:

1. "Fly in fly out" medical oncologists consulting and treating public patients in a private facility with full rebate and some links to other local services such as surgery (Bunbury);
2. "Fly in fly out" medical oncology service seeing and treating patients in a public hospital without local multidisciplinary care (Kalgoorlie);
3. "Fly in fly out" medical oncology service seeing patients in a public hospital with treatment by nurses in a public hospital (Geraldton); and
4. Local medical oncologist seeing and treating patients in a regional hospital with inadequate links to metropolitan services (Albany).

Although the latter system offers patients some excellent facilities, a number of shortcomings are identified. The region of Albany has a population of 60,000 with one specialist physician dedicating 20% of his time for cancer but has no backup or leave relief. There are currently three chemotherapy nurses and two general surgeons for a small part of their time. There is no audit or data collection and no research, so outcomes are unknown. The only specialist nurse is a part-time breast nurse (this position has Federal funding until 2007).

Notwithstanding variations, some principles and standards can be laid down which will act as a basis for rural services. The agreed standard is that highly specialised cancer services are provided at a limited number of sites to ensure that expertise is maintained and outcomes are optimal. Cancer Centres are proposed at tertiary sites with Cancer Units at some hospital facilities, and Outreach Programs to other regional and rural locations. All services will be accredited by the Director of the Cancer Network's Office and national standards. Further details of the standards are provided in Appendix 9 and can be summarised as follows:

- A Cancer Centre is a facility that provides all oncology treatments for patients with more common cancers as well as managing patients with rare or more complex cancers. Clinician specialisation in cancer sites is evident, as well as a coordinated comprehensive multidisciplinary approach, and evidence of clinical research and teaching.
- A Cancer Unit is a specialist unit within a hospital facility, usually a secondary hospital or Regional Resource Centre. Cancer Units are able to manage the more common cancers. They do not have the resources, volume of patients or specialisation to optimally manage more complex or rare cancer cases, these cases are referred to a Cancer Centre. Each Cancer Unit has formalised links to a Cancer Centre, Cancer Nurse Coordinators, support, clinical audit and Tumour Collaboratives.
- A Cancer Outreach Program is to be utilised in geographically remote areas where there is no Cancer Centre or Cancer Unit. Specialist cancer services will be provided by the Cancer Centre, with local health providers having formal links with a specified Cancer Centre and the relevant Cancer Nurse Coordinators. Each service will have a lead clinician (often a nurse) and with protocols which guide the limits of service.
- For more remote and/or smaller communities, provision of services by telemedicine links are important and it is urgent that the State and Federal Governments address issues that could inhibit this process such as Medicare billing, medico-legal protection and cross-state border registration.

Other initiatives, that will facilitate the provision of cancer services in rural and regional WA include:

- Establishment of Tumour Collaboratives to provide formal multidisciplinary links/support across metropolitan/rural and remote regions.
- Introduction of Cancer Nurse Coordinators across rural areas. This needs to be done in a manner sensitive to local priorities and resources, and a process of establishing this needs to be initiated immediately.
- The Cancer Council WA is increasing patient support activity and will subsidise psychosocial support in the country although this is not as widely used as may be needed. Further support by the Area Health Services is vital, in particular provision of local psychology and other support services and improved training of existing clinical staff in recognition and management of psychosocial distress.
- Review of workforce issues:
 - Mentoring regional cancer services.
 - Training/education of cancer specialists with a rural interest and up-skilling regional generalists.
- Recent State Government commitments include funding doctors in country hospitals who have a particular interest in cancer, to act as lead cancer clinicians, provide outpatient services and educate GPs in dealing with cancer care. Improvements in communication are expected through the Tumour Collaboratives and tertiary cancer services. The Federal Government has committed to a mentoring program, linking metropolitan teaching hospitals to regional centres and promoting multidisciplinary care.
- The Director of the Cancer Network works with the WA Country Health Service and South West Area Health Service to determine if travel and accommodation support can be improved or better tailored to suit country cancer patients.
- Information technology support for the country, e.g. video-conferencing linked in to Tumour Collaboratives and Cancer Units, as well as for remote areas. The introduction of the Picture Archiving Compression System (PACS) in rural areas is an urgent priority. Pathology results equally need to be easily accessible by computer.

Initiative 27: Cancer Units be developed in some regional centres with formalised links to a Cancer Centre, Cancer Care Coordinators, audit and Tumour Collaboratives. A lead clinician at each local site will be identified to run the Unit, supported from identified funds.

Initiative 28: All services undergo accreditation processes as developed by national standards and the Director of the Cancer Network.

Initiative 29: The clinical staff delivering cancer services undergo credentialing as developed by national standards and the Director of the Cancer Network.

Initiative 30: Other regions, in conjunction with the Rural Medical Service, develop Cancer Outreach programs, each with a lead clinician and providers having formal links with a specified Cancer Centre and the relevant Cancer Care Coordinators.

Initiative 31: Rural Cancer Care Coordinators are set up immediately, reporting to Area Health Services and the State Cancer Network Secretariat.

Initiative 32: The Director of the Cancer Network works with the WA Country Health Service and South West Area Health Service to determine if travel and accommodation support can be improved or better tailored to suit country cancer patients.

4.8 Prevention and Screening

While the treatment and care of people with cancer is an essential medical responsibility, the major opportunity for reducing the incidence and mortality from cancer is through prevention and early detection. Our knowledge of the risk factors for cancer is such that it would be possible to reduce the burden of cancer by 50% if the appropriate policies were implemented.⁵ Prevention and early detection can be population-based or directed to the individual.

Population-based programs

Western Australia has the following population-based programs that aim to reduce the incidence of and mortality from cancer:

- Sun protection.
- Programs that target the risk factors for chronic disease such as, good nutrition, physical activity, weight maintenance, alcohol control, smoking cessation.
- Screening mammography.
- Cervical screening.
- Familial cancer prevention.

A national population-based colorectal cancer screening program is planned to be implemented by 2008. These programs are evidence-based, generally have been tested as effective in a Randomised Controlled Trial and are run on a national or statewide basis.

Individual cancer prevention

Many people receive personal advice about reducing their cancer risk, for example to stop smoking, or accept interventions that detect malignancy early, for example, testicular examination for teratoma, breast self-examination, excision-biopsy of skin lesions, PSA testing for prostate cancer.

Status of and recommendations regarding WA's population-based prevention programs

Sun protection

Historically, sun protection programs have been funded and run by The Cancer Council WA, supported by specific grants from Healthway. The State Government has promised to provide \$1.2 million over four years commencing in 2005 to The Cancer Council WA to enable them to expand the program. A routine application for funding for 2005-2007 has also been made to Healthway. Skin cancer prevention is included in the National Cancer Prevention policy of The Cancer Council Australia. There is no state-based policy or plan. The Cancer Council WA has a strategic plan for skin cancer prevention in WA.

⁵ Colditz G et al. Harvard Report on Cancer Prevention, Volume 5. Fulfilling the potential for cancer prevention: policy approaches. Cancer Causes and Control 2002; 13: 199-212

Chronic disease risk factor reduction

There are ongoing prevention programs in various risk factor areas including smoking cessation, alcohol control, nutrition and physical activity.

The gains have been patchy with the prevalence of obesity rising; alcohol consumption in WA the second highest per head of population in Australia; and the prevalence of smoking falling and the incidence of lung cancer in men also falling. A key reason for this is the lack of consistent or effective levels of funding. Tobacco has had substantial funding over the past 25 years. The lack of funding and attention attributed to obesity and alcohol consumption in the past 25 years, compared with tobacco control, may account for the discrepancy.

It is important to note that the risk factors for cancer are common to other medical conditions. There is a significant body of evidence for effective prevention strategies. The WACST strongly supports existing and planned state and national cancer prevention strategies (including the National Cancer Prevention Strategy, the National Chronic Disease Strategy in development, the National Tobacco Strategy etc.) and recommends a State Chronic Disease Prevention Strategy.

The State Government has made an electoral commitment to increase the funding in these program areas to \$10 million per year, and to move the administration of the education programs to the non-government sector. There are a plethora of plans at the national level, and currently a State Chronic Disease Framework, including prevention, is being developed by the DOH.

BreastScreen WA

BreastScreen WA screens well women with the aim of detecting early cancer changes, thereby improving likelihood of successful treatment. It is a national program with national policies and is funded jointly by the Commonwealth and States through the Public Health Outcome Funding Agreement.

BreastScreen WA operates from a central administration unit within the DOH. The service has seven permanent clinics in the metropolitan area and four mobile vans to service the rural and outer metropolitan areas. BreastScreen WA targets women aged 50-69 years of age and aims to re-screen women every 24 months. Current screening participation of the target group is 58% and BreastScreen WA is unable to increase screening within the existing clinic capacity. BreastScreen WA has achieved a four-year accreditation status, the highest accreditation level possible.

Cervical Cancer Prevention Program

The WA Cervical Cancer Prevention Program (WACCPP) is a joint Commonwealth/State initiative funded under the Public Health Outcome Funding Agreement. The WACCPP has two components - the Cervical Cytology Registry (CCR) and the recruitment component. The CCR provides a back-up reminder system for women who have ever had a Pap Smear; the recruitment program aims to increase the participation of women in cervical cancer prevention. The provision of data to the CCR is underpinned by legislation.

In Western Australia, 60% of the target population were screened during the period starting 1 January 2003 to 31 December 2004 (the national average is approximately 61%). The National Health and Medical Research Council (NHMRC) *Guidelines for the Management of Asymptomatic Women with Screen Detected Abnormalities*, will change the way early cervical lesions due to Human Papillomavirus (HPV) are managed, with consequential changes to the operations of the CCR.

Familial Cancer Prevention

There is a genetic basis for 5 to 10% of ovarian, breast and colorectal cancers. Detection of potentially affected individuals and the subsequent screening of family members depend on the treating clinician recognising high risk individuals, or pathology testing in the case of bowel cancer. A statewide service exists with participation of the DOH Genomics program, the Familial Cancer Program at KEMH, the ovarian high-risk clinic at KEMH and a breast cancer high-risk clinic at RPH. Genetic Services WA offers counselling, education, genetic testing and advice on surveillance or prophylaxis.

Colorectal cancer screening

There is Level 1 evidence for the effectiveness of screening using faecal occult blood test to reduce mortality from colorectal cancer (CRC). Investigation of an abnormal screen is by colonoscopy. Randomised Control Trials have shown a reduction in mortality of up to 30 per cent in a screened population.

There are three nationally funded pilot programs in Queensland, Victoria, and South Australia to determine the parameters of a national program in Australia. A statement has been made by the Federal Minister for Health and Ageing that the national program will be implemented by 2008. The State Government has committed to provide \$700,000 per year for four years for CRC screening in WA.

WA must be prepared for the negotiations with the Federal Government's Department of Health and Ageing that will precede a national program by understanding the impact of a national program on the State's resources. WA must also be prepared for the implementation of the national program, which will depend to some extent on the configuration of the program.

At a minimum, we need to:

- Ensure adequate workforce and facilities for colonoscopy.
- Ensure adequate workforce and facilities for histopathology.
- Provide community and health professional education and support.

When the colorectal cancer screening program is established in WA it is recommended that an Office of Cancer Screening be established within the WA Cancer Network. This would include the BreastScreen WA and Cervical Cancer Prevention programs. The establishment of this office would aim to maximise utilisation of resources and equity of access statewide.

The major area in which work is required is to provide objective and easily understood advice to men and their families on the implications of screening for prostate cancer by prostate specific antigen (PSA).

Prostate cancer

Prostate specific antigens are produced by the prostate gland, but raised levels in the blood are not specific to prostate cancer. There is as yet no randomised control trial evidence that screening using prostate specific antigen (PSA) reduces the mortality in the screened cohort. Interventions for prostate cancer by radiotherapy or surgery have a measurable morbidity from incontinence and impotence. If screening detects cancers which would have been indolent, and so are not a threat to survival, the screening may cause morbidity without any health gain. However, PSA is used extensively by clinicians as a de-facto screening tool, often with little patient education and discussion as to the implications of a positive test.

Initiative 33: The State Cancer Network acknowledges the importance of skin cancer prevention and endorses efforts by The Cancer Council WA to bring skin cancer prevention opportunities to fruition in WA.

Initiative 34: A (non-cancer specific) State Chronic Disease Prevention Strategy is developed to coordinate the individual risk factor reduction strategies and to link prevention, screening and management.

Initiative 35: The BreastScreen WA program expand to maintain a high level of participation in the face of the rapidly aging population. In the next five years BreastScreen WA consider:

- relocating and establishing new facilities to meet the demand
- converting to digital mammographic technology to address manpower and film storage problems
- improving the attraction and retention of diagnostic radiographers.

Initiative 36: Planning for a Colorectal Cancer Screening program is established immediately to prepare the State for the national program.

Initiative 37: When the proposed Colorectal Cancer Screening program is initiated, consideration is given to co-locating it within an Office of Cancer Screening, along with the BreastScreen WA and WA Cervical Cancer Prevention programs.

Initiative 38: The WA Cervical Cancer Prevention recruitment program is strengthened to increase the cervical screening participation of women in WA.

Initiative 39: The Familial Cancer Program is strengthened to:

- Improve the recognition of the importance of family history in establishing risk within current and planned population screening programs for breast and colorectal cancer; and
- Develop protocols within current and planned population screening programs to identify and refer high-risk patients to specialist services.

Initiative 40: GPs and consumers have access to objective material on the implications of a Prostate Specific Antigen (PSA) test, and support in decision-making.

4.9 Workforce planning

Coordinated cancer care includes all aspects of the patient's experience from diagnosis, through treatment provided by many disciplines in inpatient and outpatient settings, to follow up and rehabilitation. The multidisciplinary workforce needs to be considered in relation to all stages of this care process and in all settings. The importance of providing multidisciplinary care in all cases of cancer care underpins the key principles for the cancer workforce.

Key principles for the cancer workforce include:

- Cancer work should be located at a concentrated number of locations such as major tertiary sites and a limited number of additional accredited Cancer Units.
- Guidelines and standards including those for Cancer Nurse Coordinators and multidisciplinary teams must be available at any site of cancer care and accreditation based on these standards.
- Flexibility for the workforce is required to attract and retain skilled health professionals.
- Multidisciplinary care includes diagnostic specialists, surgical oncology disciplines, radiation oncology, medical oncology, other medical specialities (including GPs), oncology nurses, radiation therapists, medical physicists, psychologists and allied health professionals. A multidisciplinary approach involves the team of clinicians agreeing on a precise diagnosis and staging of the disease, the best treatment option for the patient, and development of a treatment and follow up care plan. The approach requires clinical consensus on diagnosis and treatment through multidisciplinary team meetings or previously agreed care protocols when the diagnosis, treatment and outcome for the condition are relatively uniform from case to case. The patient is part of the team and receives information about options in order to make an informed decision about treatment.
- Accreditation of multidisciplinary teams is recommended through the Tumour Collaboratives to ensure standards of care are consistent across the State.

The cancer workforce is differentiated into a number of vital groups, which are discussed separately.

Diagnostic Services

Pathology workforce

The Australian Medical Workforce Advisory Committee's (AMWAC) review of Pathology Workforce has recommended that an additional 100 training positions per year are created nationally. In the field of cancer pathology there has been an exponential increase in workload, caused by newer and better technologies. The AMWAC report highlights some new developments in pathology that are impacting upon workforce issues for cancer pathology:

- Increased numbers of specimens generated by screening programs.
- The need to correlate cytology and histology, for example, quality assurance needs of practice for the cervical cancer audit process.
- Increased need for pathologists with specialist expertise.

Radiology workforce

Diagnostic radiology services for cancer (including Nuclear Medicine) have increased in complexity and specialisation. Although there is probably adequate workforce within the private sector, in the public sector there is a shortage of radiologists and radiographers as recognised by AMWAC and Royal Australian and New Zealand College of Radiology (RANZCR). Rapid advances in technology and hardware have also created a lack of adequate imaging infrastructure in most public hospitals. Finally, rural services are particularly vulnerable to increasing specialisation. It is suggested that recommendations for staffing in AMWAC be considered.

Surgical Services

The surgical workforce is often divided in their clinical workload between malignant and non-malignant cases. Therefore, consideration of the 'other' work that surgeons are doing is vital in planning the surgical service delivery across a number of sites. If the work of surgeons is concentrated at a limited number of sites there may actually be an adequate number to meet the need.

Surgeons are mostly specialised to concentrate on a particular cancer group and for some cancers a large proportion of the patients require surgery, for example over 90 per cent of breast cancers are resected. It is vital that complex cancers are managed by specialist surgeons accredited for that function and evidence exists to demonstrate superior outcomes including survival when this occurs.

Medical and Haematological Oncology

In April 2001 the AMWAC released *The Specialist Medical and Haematological Oncology Workforce in Australia: Supply, Requirements and Projections*. The process behind this workforce planning report involved extensive participation of the Medical Oncology Group of Australia (MOG) and the Haematological Society of Australia and New Zealand (HSANZ). The main objective of the working party charged with the production of the document was to promote an optimal supply and appropriate distribution of medical and haematological oncology services across Australia with a view to ensuring that future supply best matches need.

The working party concluded that several changes are likely to significantly influence requirements for medical and haematological oncologists in the next 10 years including:

- Increasing use of adjuvant chemotherapy in women with breast cancer.
- Full disclosure of information about all cancer patients at all stages, as evidenced by statements in all NHMRC clinical practice guidelines.
- Use of chemotherapy in colorectal cancer.
- Use of chemotherapy in palliative treatment of metastatic non-small cell lung cancer.
- Increasing use of combined modality therapies for cancers of the cervix, bladder, head and neck.
- Increasing survival of patients with advanced malignancy.
- Increasing use of complex chemotherapy regimes.
- Increasing opportunities for patients to participate in clinical trials.

During the past five years prior to the release of the report, the number of Medicare services provided by medical and haematological oncologists had increased by 32.9%, with a compound average increase of 7.4%. Based on the benchmark of the American Cancer Society of 1.8 oncologists per 100,000 persons, there is national undersupply of oncologists. In 2001, data from MOG and Haematological Society of Australia and New Zealand (HSANZ) indicated that there were 1.4 medical and haematological oncologists per 100,000 population. This estimate takes into account the average total work time (61.4%) that haematological oncologists spend working in oncology. By sub-specialty in Australia, there were 0.9 medical oncologists per 100,000 persons. Across geographic regions in Australia there were 2.0 Full Time Equivalents (FTE) medical and haematological oncologists per 100,000 persons in capital cities, 1.4 in urban areas, 0.8 in large rural centres and 0.2 in other rural and remote areas.

The relatively well-supplied States/Territories, as indicated by population share, were NSW, VIC, SA and ACT. The NT, QLD and WA were highlighted as being relatively poorly supplied. WA is reported as having 1.2/100,000. Given the population numbers residing in South-Western WA it is clear that there is a shortage of medical/haematological oncologists according to the AMWAC figures. Bunbury is the only South West location with visiting services according to the benchmark figures presented in the report.

Radiation Oncology

In the Radiation Oncology Jurisdictional Implementation Group (ROJIG) Final Report it is stated: "The radiotherapy workforce is made up of a broad range of health professionals; the major groups are radiation therapists, medical physicists, and radiation oncologists. These groups have been affected by national and international workforce shortages. It is acknowledged that a comprehensive suite of short, medium and long-term strategies is required for each of these professional groups if Australia is to be able to meet its objectives for increased radiation oncology treatment."⁶ WA has some strategies in place and has invested in a range of initiatives to promote retention and recruitment to these professions.

The Royal Australian and New Zealand College of Radiology (RANZCR) has recommended 250 new cases a year as the acceptable workload for a radiation oncologist, but there is no current funding to implement the RANZCR recommended staffing level.

The Australian Institute of Radiography has recommended 1.06 radiation therapists per operating hour as a minimum-staffing standard. The shortage of this workforce in WA has been resolved by implementing a number of initiatives including short, medium and long-term contracts to overseas radiation therapists, DOH scholarships for WA students to train in South Australia and some dedicated Professional Development Year (PDY) positions to facilitate new graduates obtaining their professional accreditation. A long-term initiative for training radiation therapists within WA and in conjunction with Monash University in Melbourne has proved very successful with students rotating between the public and private facilities for their clinical practice while doing all their didactic work via distance learning.

An accepted figure for Medical Physicists is 1.7 per linear accelerator. The difficulty in WA is retaining senior medical physicists due to many factors including workload, overseas salaries and research opportunities in fully staffed centers interstate and overseas. A key factor in recruitment is the access to research, teaching and new technologies.

⁶ Department of Health and Ageing, September 2003, Radiation Oncology Jurisdictional Implementation Group (ROJIG) Final Report, page 30

A new formal training program is being developed by the profession and it is important that this is supported in WA to address the workforce issues in the future. WA has implemented a recruitment and retention allowance for senior qualified medical physicists in recognition of the importance of this important profession in the radiation oncology team.

The current long waiting lists for radiotherapy are being addressed by working extended hours, with further reduction expected with stage one of the Cancer Centre development.

Nursing

There is an overall shortage of nursing workforce, and in particular a shortage of oncology trained nurses. The access to education and training for nurses needs to be reviewed and considered in order to encourage nurses to pursue higher education and specialist qualifications.

As previously mentioned in Section 4.5, it is anticipated that the model of Cancer Nurse Coordination will be adapted to suit the needs of the patient group depending on the Tumour Collaboratives and location, i.e. metro/rural. Nurse Practitioners could be the effective model for rural areas and a national strategy to recruit and support a rural workforce of Nurse Practitioners would contribute towards addressing inequalities of health care in the rural sector.

Psychologists

There is no foreseeable shortage of psychologists in WA. According to the Psychologists Registration Board of WA there are 560 registered clinical psychologists in WA, plus 65 registered counselling psychologists in WA. This is a more than adequate supply for a statewide cancer service. What is lacking is appropriate dedicated positions. As of April 2005, 1.2 FTE clinical psychologists are dedicated to breast cancer at RPH as part of a statewide service. The Cancer Council WA employs 1 FTE psychotherapist and 0.7 FTE counselling psychologist dedicated to cancer counselling. Clinical psychology services are accessible at all teaching hospitals but an unpublished report of the WA Clinical Oncology Group Psychosocial Advisory Committee indicates that access is far from ideal.

Published guidelines on best practice psychosocial care for adults with cancer in Australia suggest that up to 25% of cancer patients in the first year after initial diagnosis experience levels of distress that warrant assessment and intervention. Analysis of the cost-effectiveness of introducing short-term cognitive behavioural therapy and longer-term supportive psychotherapy suggests that this would produce an important reduction in psychosocial disability at moderate cost.

Initiative 41: The Director of the Cancer Network identify gaps in workforce in relation to national benchmarks, and include a workforce plan as part of the Statewide Strategic Cancer Plan.

Initiative 42: The State Cancer Network supports and provides a structure for workforce planning, career path and recruitment, including training programs and ongoing education for all health care professionals.

Initiative 43: Review of access to allied health, other supportive care services, and complimentary therapies is undertaken by the State Cancer Network Secretariat to ensure appropriate screening of patients and referral to services.

Initiative 44: A structure of accreditation of individual health care professionals and multidisciplinary teams be developed and monitored through the Director of the Cancer Network.

Initiative 45: Review multidisciplinary workforce issues in the development of rural cancer services.

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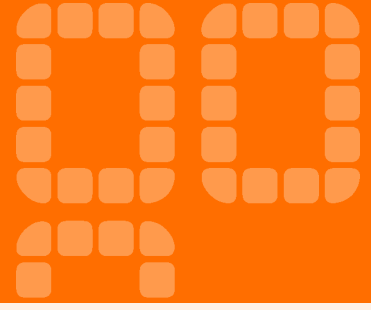
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Appendix 1: Cancer Care Senate Inquiry March 2005

Key Recommendations from the WA Cancer Services Taskforce (WACST):

The delivery of services and options for treatment for persons diagnosed with cancer:

i) The efficacy of a multidisciplinary approach to cancer treatment

WACST believes that multidisciplinary tumour networks are a critical part of best practice cancer care. Multidisciplinary tumour networks are expected to become a resource for all aspects of care from diagnosis to treatment, define minimum standards of care, and improve survival and other defined outcomes for specified tumours. Each network needs funding to enable the large task of developing tumour site-specific guidelines with clinical indicators in a manner that will be easily accessible to other health care professionals across the state. To ensure that this is a priority and a national coordinated approach, it is suggested that the Commonwealth fund the facilitation of the establishment of these networks.

ii) The role and desirability of a case manager/case coordinator to assist patients and/or their primary care givers

The Care Coordinator's involvement in the patient process will ensure that the patient has a one-on-one relationship, facilitated navigation of the system, and a central point for information and support. It will provide a direct link into the tumour network and all of the benefits that can be achieved through a multidisciplinary care model. It is anticipated that the model of cancer care coordination will be adapted to suit the needs of the patient group depending on the Tumour Collaborative and location, i.e. metropolitan/rural. Nurse Practitioners could be the effective model for rural areas and a national strategy to recruit and support a rural workforce of Nurse Practitioners would contribute towards addressing inequalities of health care in the rural sector. WACST also believes that the Commonwealth would benefit from providing an Australia wide training program for these Care Coordinators, by patients moving through the cancer system in a more efficient manner.

iii) Differing models and best practice for addressing psychosocial factors in patient care

The provision of multidisciplinary care and care coordination requires the psychosocial care needs of cancer patients to be addressed. There is a need for the implementation of national standards and guidelines to ensure consistent standards of care. The approach needs to include a standard assessment and referral process to ensure needs are being met. There is a lack of provision and access of psychosocial services in the public sector. It is recommended that the Commonwealth facilitate the coordination of developing these standards, and ensure funding for cancer care includes adequate provision for the psychosocial needs of cancer patients.

iv) Differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians

WACST recommends a national approach to addressing the inequities in rural and remote areas. The specific needs related to ATSI patients with cancer are being looked at by the Cancer Oncological Society of Australia (COSA) and The Cancer Council Australia (TCCA), and other needs will be addressed by improving access to and outcomes of regional cancer care.

v) Current barriers to the implementation of best practice in the above fields

The barriers for Western Australia's provision of best practice cancer services include the current lack of a coordinated integrated network of services. There is a lack of clinical and managerial leadership, cancer workforce, resources, access to some cancer medications as well as constraints of geography and access to coordinated multidisciplinary care. WACST is addressing these needs by identifying specific initiatives to address these areas for Western Australia, and sees the Commonwealth Government contributing in facilitating a common national approach.

Due to the remote nature of many of Western Australia's communities and the current inequalities in the provision of cancer services, it is recommended by WACST that further resources are required for Western Australia to fully implement all of the strategies discussed in this submission. These include:

- Implementation of the Colorectal Cancer Screening program;
- Funding to increase access to radiotherapy for all cancer patients;
- Medicare numbers for multidisciplinary clinics and psychosocial care to increase participation and access for patients;
- Funding for education at tertiary hospitals to upskill workforce especially nurses;
- Doctor recruitment and retention;
- National credentialing and accreditation implementation of recommendations from Cancer Strategies Group; and
- Implementation of recommendations (once finalised) from the cancer funding reform working group work, being conducted by the Centre for Health Economics Research and Evaluation (CHERE).

Appendix 2: Western Australian Cancer Network Structure

Director of the Cancer Network

The Director leads implementation of the Framework, and development and implementation of Statewide Strategic Cancer Plan. The Director will have management responsibility for staff and resources of the WA Cancer Network Secretariat. The Director will report to Executive Director, Health Policy and Clinical Reform.

Western Australian Cancer Network Secretariat

The Secretariat will consist of an office manager, project officers for policy development, audit, development of a hospital-based cancer registry, credentialing, accreditation, oversight of Cancer Nurse Coordinators, and administration of Tumour Collaboratives. Secretariat staff will report to the Director of the Cancer Network.

Cancer Network Advisory Group

This Group advises the Director of the Cancer Network and will comprise senior management representatives from Area Health Services, key clinicians from Tumour Collaboratives, NGO's, private sector and co-opted members for specific tasks.

Tumour Collaboratives

These Collaboratives are multidisciplinary teams who provide cancer care to a specific cancer group. They will define standards of care, aim to improve survival and other defined outcomes for specific tumours, and act as a resource for all aspects of care from diagnosis to treatment. Members of the Tumour Collaboratives will report through Area Health Services and be supported through the WA Cancer Network Secretariat.

Cancer Nurse Coordinators

The Cancer Nurse Coordinators' involvement in the patient process will ensure that the patient has a one-on-one relationship, facilitated navigation of the system, and a central point for information and support. It will provide a direct link into the Tumour Collaboratives and all of the benefits that can be achieved through a multidisciplinary care model. It is anticipated that the model of cancer care coordination will be adapted to suit the needs of the patient group depending on the Tumour Collaboratives and location, i.e. metro/rural. Cancer Nurse Coordinators will report through Area Health Services and be supported for professional development through the WA Cancer Network Secretariat.

Appendix 3: Models of Cancer Centres

Four models of a Cancer Centre in WA have been described by the WACST with the fourth model being the preferred option.

Model 1

- Single ambulatory care facility at SCGH
- Inpatient care at all tertiary sites

Advantages:

- Facilitates tumour sub-specialisation

Disadvantages:

- Not patient-focussed - for most patients with common malignancies this model will reduce ease of access
- Inconvenient for staff (travel) - while staff can travel between sites when necessary this is less efficient and should be minimised when possible
- Disrupts continuity of care - inpatient and outpatient care are at separate sites and ensuring continuity of care is more difficult
- Major resource requirements to develop outpatient resources - accurate estimates not available but the single Cancer Centre model would be 2 - 3 times the size of the current facility

Model 2

- Single ambulatory care facility
- Single inpatient facility, i.e. 'Cancer Hospital'

Advantages:

- More efficient use of staff
- Improves continuity of care

Disadvantages:

- Enormous resource requirements
- Relocation of clinicians will disrupt non-cancer services

Model 3

- Ambulatory and inpatient facilities at all tertiary hospitals
- Super-speciality units at a single designated 'Cancer Hospital'
- Oversight by central cancer coordinating centre

Advantages:

- Patient focussed, not centre focussed
- Better access for patients
- More efficient use of staff
- Less disruptive to non cancer services

Disadvantages:

- Super-speciality relocation may disrupt other services

Model 4

- Ambulatory and inpatient facilities at all tertiary hospitals
- Rationalisation/designation of super-speciality units (at sites where expertise exists)
- Oversight by central cancer coordinating centre

Advantages:

- Patient focussed, not centre focussed
- Better access for patients
- More efficient use of staff
- Less disruptive to non-cancer services
- No disruption of non-cancer services provided by members of the multidisciplinary team
e.g. surgical services

Disadvantages:

- All cancer services are not provided in one centre.

Appendix 4: Definitions - Oncology Services as defined by the WA Health Clinical Service Framework 2005 - 2015

Level 1

- Care is carried out by GPs (potentially visiting) with or without the assistance of RNs depending on the type of patient care needed.

Level 2

As for level 1 plus:

- Inpatient and outpatient care.
- Visiting GP.
- 24-hour cover by RN.

Level 3

As for level 2 plus:

- GP inpatient care.
- 24-hour cover by RN.
- Outpatient care by visiting general physician and possibly oncologist.

Level 4

As for level 3 plus:

- Inpatient care by resident general physician.
- Outpatient consultation by visiting oncologist.
- Links with radiotherapy, palliative care and pain management services.
- Specialist RN.

Level 5

As for level 4 plus:

- Inpatient care by resident oncologist.
- Registrar/RMO.
- Regional referral role.
- Access to specialist Senior Registered Nurse.
- Some undergraduate teaching and possibly some research role.
- Multidisciplinary management of patients including case conferences.
- Links with palliative care services and may have pain management clinic.
- Emergency care available.

Level 6

As for level 5 plus:

- Full range of oncology services, with oncology department and emergency services.
- Statewide referral role.
- Undergraduate and postgraduate teaching role.
- Research role.
- Access to specialist Senior Registered Nurse.
- Multidisciplinary management of patients including case conferences.

Appendix 5: Proposed Models for Cancer Nurse Coordinators in Western Australia

Current proposed funding allows for 20 new positions of Cancer Nurse Coordinators (CNC) to be established including a team leader based at the WA Cancer Network Secretariat.

This is in addition to nurses currently fulfilling some of this role, for example, rural breast nurses, specialist breast nurses in four metropolitan public hospitals and one private hospital, specialist haematology nurses and others.

Due to the difference in volume of cases there will be differences between rural and metro models for CNC:

Rural:

- Accessed by all cancer patients.
- Has a program of professional development for the CNC based on the four most common cancers in that health service.

Metropolitan:

- Speciality-based, i.e. breast, colorectal, lung, etc.
- Is a member of the multidisciplinary team.

Number and FTE of CNC to be based on the incidence of cancer and cumulative caseload, with the latter taking into account the proposed number of planned patient interventions. In essence, a community-based model - consider the role of Child Health Nurse as an analogy for operating.

Key components of the role:

- A readily accessible contact point for all (patients and health care providers).
- Provides information on multiple occasions and at appropriate times.
- Provides emotional support.
- Provides practical support and information.
- Helps with navigating the health care system (making appointments, explaining procedures, etc.).
- Referral to other services such as Palliative Care, Silver Chain, community support services, etc.
- There can be any number of patient-initiated contacts.
- The CNC have discretion to initiate any number of patient contacts.
- Use of a validated tool to screen for psychosocial distress (e.g. GHQ12), administered at diagnosis and on discharge from care.

- Uses documented protocols, guidelines and templates (developed by WA Cancer Network Secretariat):
 - Protocols relate to patient care: what services are available, what they provide and how to access them.
 - Guidelines are models of practice that assist CNC activities or decision-making.
 - Templates provide consistency of information in communications (both paper and electronic).

GP communication is a vital component of the role. Mechanisms to facilitate it include the use of guidelines and templates. Consideration of other strategies such as patient-held records, secure electronic transfer of information (Medical Director, DocFax, etc.), include GPs in multidisciplinary team meetings and communications, and at times arrange visiting rights if patient long-term/multiple hospitalisation, also to include GPs in promotion strategies.

Management, Support & Funding:

- The Lead Nurse of the Cancer Network will manage and provide professional support for the CNC positions.
- The Lead Nurse will provide service reports to health service divisions to promote local support, especially of rural CNC.
- Location of rural CNC should be considered with respect to the type of service, reporting responsibility and funding source.
- CNC will receive regular clinical supervision for professional debriefing, provided by an independent appropriately qualified clinical psychologist.
- CNC will have access to mentoring and specialist expertise as needed, arranged and/or provided by the Lead Nurse or the Area Health Service.
- There will be an ongoing program of professional development.

Qualifications & Training:

In recognition of the shortage of appropriately qualified RNs, particularly in rural areas, appropriate training will be provided.

- Speciality courses as available (e.g. breast and prostate).
- A program of clinical placements (e.g. assessment and diagnostic procedures, chemotherapy units, radiation oncology, theatre, etc.).
- Required reading and learning objectives.

Level of expertise of the CNC incumbent should be considered when determining salary.

Integration of Role:

Planning (in each area or institution):

- Recruit Lead Nurse Service.
- Map pathways of care (contract project officer role).
- Identify key stakeholders and recruit ownership of the role through the formation of a Network Advisory Group. Members will have a key role in providing peer and professional support (knowledge, referral, etc.).

- Make the components of the role to each area flexible, particularly in rural regions, for example:
 - it may be job-shared, based on type of cancer or gender;
 - there may be existing skills that can be utilised (e.g. a urology nurse position); and
 - the administration or MDM coordination may be separate.

Promotional strategies, to include:

- GPs - doctors, Divisions, practice nurses and managers.
- Hospital staff.
- Community agencies (Palliative Care, Silver Chain, etc.).
- Non-government organisations providing support services.

Appendix 6: Clinical Trials

Trial Ranking for Support from Victorian Clinical Oncology Group (VCOG)

Trial Priority Rank	Trial Rank Description
4	Investigator-initiated trials auspiced by recognised national or international clinical trials groups and open to all participating centres of the group, e.g. VCOG, ANZ BCTG, AGITG, TROG, IBCSG, ECOG
3	Investigator-initiated trials auspiced by recognised national or international clinical trials groups, but only open at selected centres
2	Investigator-initiated trials involving one or two centres - ad hoc collaborative groups (non-collaborative group trials)
1	Management Surveys/Quality of Life Surveys/Supportive Care Studies - initiated by VCOG or National groups and conducted under the auspice of the Cancer Council or national cancer organisation, e.g. NCCI, NBCC
0	Industry-initiated trials funded for data management and Industry - initiated trials nil-funded for data management

Appendix 7: Clinical Data

The VARiS information system that comes with the new linear accelerators planned at SCGH has a Medical Oncology package that links into the VARiS database. The following will be possible later this year:

- Demographic download from TOPAS (or whatever system replaces it) - verbal permission from Info Health received already. Testing to commence early in the new financial year when software is fully in place.
- Scheduling modules for both Medical and Radiation Oncology that access the same database flagging conflicts and enabling those with rights to see the schedules of both departments but only having rights to change their own appointments. This should greatly improve the combined modality protocols.
- Dictation done in either department can be viewed as a single health records document for each patient making continuity of care.
- ICD codes for Australia are built into the system and staging information can be also entered at various dates e.g. at diagnosis, at first consultation, at follow up. This information can be accessed through drop down menus or when running reports (i.e. history is kept not over ridden with new entries).
- Billing and workload measurements can also be done using the reports feature as required.
- A multidisciplinary assessment module will be available in 2006 which will enable nursing, radiation therapist and allied health records to be entered at the point of care and available to all health care professionals involved in the patients care at SCGH to see this information in a timely manner. For example, dietician assessment and recommendations can be supported by the nurses and radiation therapists when they can access this information electronically.
- Theoretically all laboratory, pathology and imaging results from SCGH can be downloaded electronically into the system however this discussion has yet to take place with the various departments. External laboratory, pathology and imaging reports can also be scanned into the system similar to a fax.
- Images for radiation therapy planning and treatment are already available in the system, the ability to view these in other departments is a software licensing expense.
- Discussion with Dr Tim Threlfell from the WA Cancer Registry (WACR) have already commenced to have information regarding treatment into the WACR so that data can reflect treatment modalities in the future, for example, % of patients with breast cancer that are treated with radiation therapy. A test of sending data electronically to them will happen once the data dictionary is the same in both information systems - we are both currently working on this.

(Information from Rhonda Coleman, Radiation Oncology, SCGH)

Appendix 8: References on Rural Inequalities

Hall, S. and Holman, C. 2003, *Inequalities in Breast Cancer Reconstructive Surgery According to Social and Locational Status in Western Australia*, EJSO Vol 29, pp.519-525, Perth WA

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Hall, S., Holman, C., Wisniewski, S. and Semmens, J. 2005, *Prostate cancer: socio-economic, geographical and private-health insurance effects on care and survival*, BJU International Vol 95, pp.51-58, Perth WA

Ingram, D., McEvoy, S., Byrne, M., Fritschi, L. Joseph, D. and Jamrozik, K. 2005, *Surgical Caseload and outcomes for women with invasive breast cancer treated in Western Australia*, The Breast Vol 14, pp. 11-17, Perth WA

Spilsbury, K., Semmens, J., Saunders, C., Hall, S. and Holman, C. 2005, *Subsequent Surgery after Initial Breast Conserving Surgery: A Population Based Study* Perth WA (unpublished)

Spilsbury, K., Semmens, J., Saunders, C. and Holman, C. 2005, *Long Term Survival Outcomes Following Breast Cancer Surgery in Western Australia; Survival following breast cancer surgery*, Perth WA (unpublished)

Appendix 9: Proposed Models for Cancer Units Outside the Metropolitan Area

The aim of the Regional Cancer Unit would be to provide safe, high-standard treatment of equivalent standard to a Cancer Centre with adequate support (nursing, medical, allied health, etc.). Regional/rural Cancer Units should have established protocols for:

- Cytotoxic administration by trained staff including method of administration, monitoring of blood parameters, antiemetics and management of other side effects.
- Protocols for management of extravasation.
- Protocol for management of cytotoxic spillage.
- Protocols for common cytotoxic regimes.

The Director of such a unit would preferably be a physician who has proven experience in the management of cytotoxic chemotherapy (if there is a physician locally available) or alternatively, where this is not possible, there would be a regular visiting service by a cancer specialist from a Cancer Centre. In some situations, if none of these are possible, or as a support to a visiting cancer physician, an appropriately trained nurse would be the director of the unit.

The Cancer Unit should have close liaison with all Cancer Centres in Perth. This would include telephone support, easy access for direct referrals and assessment, one or two yearly visits by a cancer specialist, availability of linking via video conferencing, leave coverage for where the director is a resident physician, involvement in clinical trials where possible, support for collection of data, and other quality assurance research.

The nursing staff of such Regional Cancer Units should have appropriate cytotoxic education and experience and be supported by the Statewide Cancer Network Secretariat to attend and complete training sessions. Cancer specialist nurses should be available to assist with patient information and other patient supports.

Limited surgery for cancer patients can be done at a Regional Cancer Unit where the quantities are sufficient to ensure accredited practice as determined by Tumour Collaboratives and the Director of the Cancer Network.

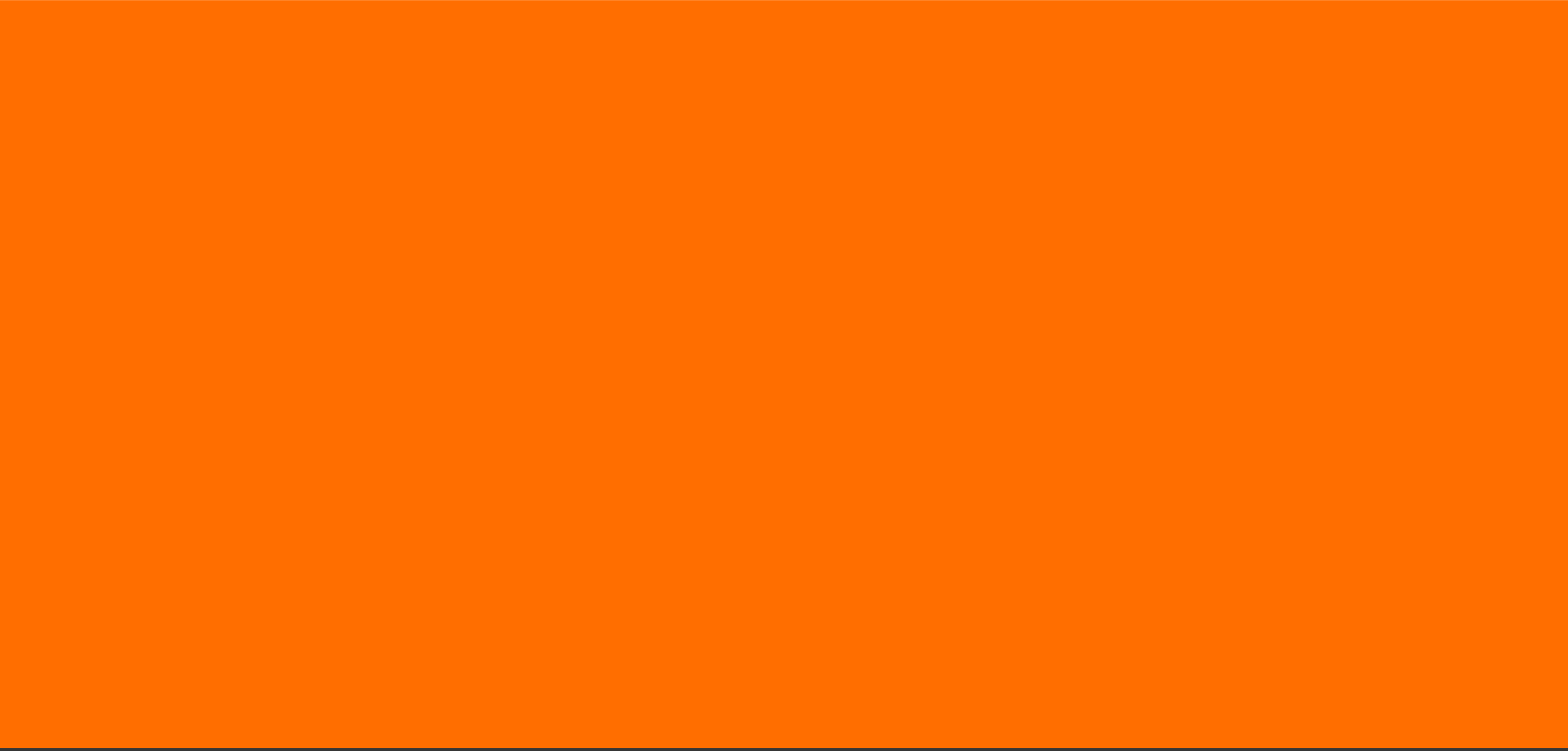
Cancer Units need to have close liaison with a palliative care service (e.g. in Albany's case; Albany Hospice, which is a private hospice facility attached to the hospital, and the oncology nurses provide a cannulation service for patients requiring blood transfusions and palliative chemotherapy, and administer the chemotherapy in the Hospice).

Regional Cancer Units need to be accredited and include audits of clinical practice, participation in clinical research, multidisciplinary meetings, liaise with Tumour Collaboratives, and adhere to protocols and guidelines as part of the cancer service provided.

Model for Cancer Outreach Services or for Smaller District Hospitals

Some of these hospitals will have nurses who have had oncology/cytotoxic experience. It is possible the local doctor may have also had this type of experience. Where they have suitably trained cancer nursing staff, appropriate protocols for chemotherapy administration and management of extravasation and spillage, and the local general practitioner has some experience, it would be reasonable for some of the more common cytotoxic regimes be given to these district hospitals. This would only be in close liaison with a Cancer Centre or Cancer Unit and at an accredited facility.

Limited surgery for cancer patients can be done at smaller district hospitals where the quantities are sufficient to ensure accredited practice as determined by Tumour Collaboratives and the Director of the Cancer Network.





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