Senate Community Affairs Committee

Inquiry into Services and Treatment Options for Persons with Cancer

Submission prepared March 2005 by Department of Health Western Australia

The Department of Health Western Australia is pleased to offer input into this senate inquiry into cancer services. Whilst the standard of care for cancer patients in Western Australia is very high and outcomes are some of the best in the world, it is recognised that there are inequalities in care both geographically and socio-economically, as well as some related to tumor site.

The Health Reform Committee (HRC) chaired by Professor Michael Reid examined cancer service delivery in Western Australia. This review was conducted by Professor James Bishop and resulted in the report Review of Cancer Services for the Health Review Committee of Western Australia in October 2003. The Health Reform Implementation Taskforce (HRIT) was established to implement the recommendations of the HRC. Dr Neale Fong is the Executive Chairman of HRIT and the Acting Director General of Health, Western Australia.

To implement the cancer service recommendations and achieve best possible patient outcomes, Western Australia has established a taskforce to develop a comprehensive and integrated network of cancer services. The Western Australian Cancer Services Taskforce (WACST) has been convened by the Acting Director General of Health WA to formulate a comprehensive state-wide framework for cancer services ensuring an integrated approach to cancer care and service delivery. The taskforce consisting of clinical experts in cancer care and community representatives, was established in January 2005 and is due for completion by June 2005.

This submission will address the terms of reference in the inquiry that relate to the key areas being undertaken by the WACST in the development of a statewide framework for improving cancer services.

WACST members appointed by the Executive Chairman, HRIT are as follows:

Professor Christobel Saunders (Chair) – Prof 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 WACOG, Prof Clinical Cancer Research, SCGH, UWA
Dr Marianne Phillips – Consultant Paediatric & Adolescent Oncologist, PMH
Associate Professor Cameron Platell – Surgeon, Department of General Surgery, FH

Ms Violet Platt – Clinical Nurse Manager Medical Oncology, SCGH
Ms Susan Rooney – CEO Cancer Council WA
Dr Margaret Stevens – Executive Director Division of Population Health
Ms Liza Houghton – HRIT Senior Project Officer

The requirement for state wide cancer planning in Western Australia was driven by:

- increasing cancer incidence;
- increasing costs of drugs, equipment, facilities for and personnel needed to manage cancer;
- increasing complexity and number of interventions required to achieve world's best practice cancer care;
- relatively small number of cancer cases occurring in Western Australia making the development of the necessary sub-specialization a challenge;
- remote nature of some communities in Western Australia; and
- inequities of cancer care eg rural/metro leading to poorer outcomes for these patients
- perceived lack of structure and networked services
- sub standard communication and coordination of patients through a maze of services
- long waiting times for radiation therapy
- increasing numbers of clinical trials with limited funding
- national shortage of qualified health professionals in cancer care expected to get worse as baby boomers approach retirement

The taskforce will incorporate the following areas into an overall cancer services framework:

1. Prevention
2. Early detection
3. Diagnosis and referral systems
4. Treatment (including Chemotherapy, Surgery and Radiotherapy)
5. Cancer research
6. Education, training and workforce development
7. Patient information and genetic counselling
8. Palliative care
9. Rural and remote care
10. Private hospital/service interface

Cancer Australia
We support 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 implement the recommendations in the National Service Improvement Framework for Cancer.

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Summary

This submission will address the terms of reference in the inquiry that relate to the work being undertaken by the WACST in the development of a statewide framework for improving cancer services. The key recommendations are noted below. The main submission primarily covers Part A of the inquiry. Part B is not covered by this submission other than the WACST believes that there is a role for less conventional and complementary therapies as long as they are part of an evidence-based approach to care.

Key Recommendations:

Part A. 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 tumor networks are a critical part of best practice cancer care. Multidisciplinary tumor 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 co-ordinator 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 tumor 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 tumor network and location ie. 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. WACST also believes that the Commonwealth would benefit from providing an Australia wide training program for these care co-ordinators, 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 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 standard assessment and referral processes 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 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.
- 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).

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

i) The efficacy of a multidisciplinary approach to cancer treatment:

Multi-disciplinary care includes surgical oncology disciplines, radiation oncology, medical oncology, other medical specialities (including GPs), oncology nurses, radiation therapists, 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 plan. The approach requires clinical consensus on treatment through multidisciplinary team meetings or previously agreed 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.

Multidisciplinary tumor networks will be established in Western Australia:

- To achieve best practice and excellent outcomes for all patients diagnosed with cancer
- To develop benchmark outcomes for the various groups and monitor achievement of these throughout the state
- To establish the resources needed to achieve these outcomes and lobby for their provision
- To ensure minimum standards by all providers – both personnel and institutions – are maintained. (Formal accreditation and credentialing as being developed by the national Cancer Strategies Group may be part of the future plans of the networks in conjunction with the Director of Cancer Services).
- To measure agreed outcomes for all patients eg. mortality, morbidity
- To act as a communication forum and facilitate multidisciplinary care
- To develop management guidelines for each tumour and audit adherence to these
- To act as an education focus
- To network across all sites (metro and rural) in the public sector treating cancer patients and be applicable across disciplines
- To address special needs for patients from rural areas and for rural practitioners

Multidisciplinary tumor 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 co-ordinator to assist patients and/or their primary care givers:

The care coordinator's involvement in the patient process ensures that the patient has a one-on-one relationship, facilitated navigation of the system, and a central point for information and support. It provides a direct link into the tumor network and all of the benefits that can be achieved through a multidisciplinary care model.

Availability of a "care coordinator" is seen to be important in supporting people through treatment.

- Many patients experience confusion and lack of information during their negotiation through cancer care 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.
- Inequities in access to support and information services.[1]

In Western Australia Cancer Care Coordinators (CCC) are being appointed to:

- be a readily accessible contact point for patients and health care providers
- provide information on multiple occasions and at appropriate times
- provide emotional support
- provide practical support and information
- assist the patient navigate the health care system
- facilitate referrals to other services as required

The CCC will use documented protocols, guidelines and templates to provide coordinated and continuous care:

- Protocols relate to patient care: what services are available, what they provide and how to access them
- Guidelines are models of practice that assist CCC activities or decision making
- Templates provide consistency of information in communications (both paper and electronic)

It is anticipated that the model of cancer care coordination will be adapted to suit the needs of the patient group depending on the tumor network and location ie. 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.

Recent state government commitments include funding for Cancer Care Coordinators to provide integrated treatment programs for cancer patient. WACST believes that the Commonwealth would benefit from providing an Australia wide training program for these care co-ordinators, by patients moving through the cancer system in a more efficient manner.

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[1] Clinical Oncological Society of Australia (COSA), The Cancer Council Australia (TCCA), and National Cancer Control Initiative (NCCI), 2003 Optimising Cancer Care in Australia

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

Consumers believe that clinicians are not sufficiently aware of psychosocial aspects of 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 standard assessment and referral processes to ensure needs are being met. There is the lack of coordinated, integrated access to psychosocial services across the public and private sector.

Some of the current concerns include:

- There is a recognised under-provision of psychosocial support services including liaison psychiatry in the public sector.
- 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 (eg breast) have good support services but this is not the case across all tumour groups.
- There is limited documentation of available services.

In Western Australia the plan is to:

- increase available psychologists/counsellors and access to these for patients
- increase public, specialist and GP awareness of these systems
- ensure each Tumour Network will have an attached specialist psychology service
- facilitate Cancer Care Co-coordinators for each tumour network to take on a referral role and liaise closely with psychosocial support services
- provide all cancer nurses with access to training in counselling skills
- expand the directory of services

There is a lack of provision and access of psychosocial services in the public sector. WACST recommends 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:

Some of the current concerns about rural cancer services in Western Australia include:

- Cancer services outside the metropolitan area have some components of care but these may be variable, fragmented, and poorly coordinated or incomplete.
- The volume of patients seen in outreach clinics is variable without clear linkage between the needs and the depth of service provided.
- Local services and staff may be supported by metropolitan cancer centres for training, in-service, and in providing a depth of service or breadth of expertise.
- Is fragmented in both tertiary and secondary level hospitals, which may predispose to inconsistent results with patients often moving between multiple sites, diagnostic and treatment, in public and private, with poor coordination.
- There appears to be opportunities to develop tumour specific teams, concentration of expertise further in both high and low volume cancers.
- There are opportunities to develop tumor specific guidelines in order to provide consistent standards of treatment regardless of where treatment is provided.[2]
- The sub-specialization cancer expertise is limited in the state so that integration of effort in the teaching hospitals appears necessary.
- Rural services are provided by short term visiting practitioners using different funding models. These models have been developed by individual practitioners, outside any agreed statewide strategic plan.[3]

Western Australia plans to proceed with the following:

- Develop a model for the provision of cancer services outside the metropolitan area that considers the size of the population, disease incidence, level of complexity, specialisation and availability of service providers.
- Introduce 10 Cancer Care Coordinators across rural areas
- Review workforce issues
    a. Mentoring regional cancer services
    b. Training/education of cancer specialists
- Review of patient transport scheme to identify usage and improvements

Recent state government commitments include funding specialised cancer doctors in country hospitals to provide outpatient services and educate GPs in dealing with cancer care as well as improving access to specialised cancer services for rural patients. The Federal Government's commitment to a mentoring program, linking metropolitan teaching hospitals to regional centres and promoting multidisciplinary care, is commended. WACST recommends a national approach to addressing the inequities in rural and remote areas.

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[2] Hebert-Croteau N, Brisson J, Latreille J, Rivard M, Abdelaziz N, Martin G. Compliance with consensus recommendations for systemic therapy is associated with improved survival of women with node-negative breast cancer. J Clin Oncol. 2004 Sep 15;22(18):3685-93. Epub 2004 Aug 02.

[3] Bishop, J. 2003 Review of Cancer Services Western Australia: for the Health Reform Committee of Western Australia, October

Indigenous Australians provide another area for consideration in the provision of cancer services in Western Australia. It is recommended that the Aboriginal Health Care Workers are further supported in their role to strengthen their capacity to provide access to services and treatments for Indigenous Australians. The specific needs related to ATSI patients with cancer are also 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 most significant barrier for Western Australia's provision of best practice cancer services is the current lack of a coordinated integrated network of services across. Multidisciplinary tumour networks, cancer care coordinators, provision of psychosocial supports and rural cancer services are some of the strategies discussed, that the WACST propose to implement to address this barrier. Additional strategies to be implemented by WACST include:

Cancer Services Structure

A new structure is proposed for cancer services in the state to ensure leadership of the cancer control efforts. Reporting relationships will include direct reporting to the Director General of Health and close working relationship with the Chief Executives of Area Health Services to determine the cancer service provision for each population.

Director of Cancer Services

A Director of Cancer Services will be appointed to lead the statewide Office of Cancer Services for the purposes of developing and implementing the clinical vision and strategic reform of all cancer services throughout the State.

Under the leadership of the Director of Cancer Services the Cancer Services Executive Group will have responsibility to:

- provide strategic direction and prioritisation of issues for the cancer services system of Western Australia,
- identify and address system level problem areas
- monitor system performance including the effective use of resources to support the full continuum of cancer services.
- contribute to the development of State cancer policy

The committee will consist of the Director of Cancer Services, Chair of the West Australian Clinical Oncology Group, various cancer services experts, Area Health representatives, a representative of the Cancer Council of Western Australia, and a consumer representative.

Recent state government commitments include funding for the establishment of an office of a statewide Director of Cancer Services, which will ensure this vital strategy is implemented. 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.

Cancer Centres

The agreed principle is that highly specialised cancer services are provided at a limited number of sites to ensure that expertise is maintained. Cancer Care Centres are proposed at all tertiary sites with cancer units at some hospital facilities and outreach clinics to other regional and rural locations. The WACST defines the following facilities.

A <u>cancer centre</u> 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 or district hospital. 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 unit has formalised links through to a cancer centre and tumour network.

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 care co-ordinators.

For more remote and/or smaller communities, provision of services by telemedicine links are important and it is urgent that the Government addresses issues that could inhibit this process such as Medicare billing, medico legal protection and cross-state border registration.

Data management

Evaluation of practice and outcomes requires accurate and timely data, which measures the performance of the system and groups within the system. To produce key outcome measures, data collection and analysis must be complete, relevant, timely and available to clinicians and health professionals with key measures also available to the public. Current problems exist preventing adequate monitoring of patient outcomes in Western Australia.

Current systems are fragmented at each site; there is no comprehensive linked statewide system that provides:
- minimum data
- data on all cancer patients
- support for private hospitals to encourage their contribution
- for staging data to be entered
- facilitation of the analysis of outcomes

Western Australia is aiming to implement the following:
- Clinical treatment guidelines
- Register of clinical trials
- Clinical trials office to provide central statewide coordination
- Minimum datasets using the national minimum data set ratified by AHMAC and advocated by the NCCI.

The aim will be to ensure cancer services have evidence of their patterns of care and survival by stage and other key indicators, and will be able to monitor quality of care. WACST also refer the committee to a separate submission to this inquiry by Dr Timothy Threlfall calling for the routine collection of cancer staging data for cancers treated in Australian centres.

Strengthening Cancer Care

We commend the initiatives committed to in the Coalition’s pre-election document Strengthening Cancer Care. Cancer care provision will be improved through initiatives announced in the policy, such as:

- Increase access to trained cancer care professionals
- Cancer workforce training and distribution
- Mentoring regional health services
- Strengthening palliative care services
- Building Cancer Support Groups
- Cancer Australia

Whilst we support the above we feel 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
- Funding for education at tertiary hospitals to upskill workforce especially nurses
- Doctor recruitment and retention
- Medicare numbers for multidisciplinary clinics and psychosocial care to increase participation and access for patients. Expand MBS to include all specialists involved including medical, surgical and radiation oncologists, pathologists and radiologists. Build cancer accreditation into the Medicare schedule. Cancer Australia could liaise between clinician and consumer groups and the Department of Health and Ageing to explore other options for tailoring Medicare to better support multidisciplinary care.
- National credentialing and accreditation implementation of recommendations from Cancer Strategies Group. There is a critical need for a national cancer accreditation and credentialing system. Funding is required to enable guideline implementation and the use of a regulatory framework that measures outcomes and adherence to best practice models and approaches.
- 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), involving:
    - the continuum of cancer care service delivery and funding arrangements for public and private sectors;
    - how funding arrangements influence the equitable delivery of best practice services; and
    - possible recommendations for funding reform.

References

Australian Institute of Health and Welfare, 2001 Cancer in Australia

Bishop, J. 2003 Review of Cancer Services Western Australia: for the Health Reform Committee of Western Australia, October

Clinical Oncological Society of Australia (COSA), The Cancer Council Australia (TCCA), and National Cancer Control Initiative (NCCI), 2003 Optimising Cancer Care in Australia

Coalition’s pre-election document, Strengthening Cancer Care 2004

Hebert-Croteau N, Brisson J, Latreille J, Rivard M, Abdelaziz N, Martin G. Compliance with consensus recommendations for systemic therapy is associated with improved survival of women with node-negative breast cancer. J Clin Oncol. 2004 Sep 15;22(18):3685-93. Epub 2004 Aug 02.

National Priority Action Council, 2004 National Service Improvement Framework for Cancer, July